#### http://researchcommons.waikato.ac.nz/

#### Research Commons at the University of Waikato

#### **Copyright Statement:**

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand).

The thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognise the author's right
  to be identified as the author of the thesis, and due acknowledgement will be
  made to the author where appropriate.
- You will obtain the author's permission before publishing any material from the thesis.

# A Mobile Augmented Memory Aid for People with Traumatic Brain Injury

A thesis

submitted in partial fulfillment of the requirements for the degree

of

**Doctor of Philosophy** 

in

**Computer Science** 

at

The University of Waikato

by

**Su-Ping Carole Chang** 



Department of Computer Science
Hamilton, New Zealand
January, 2017

© 2017 Su-Ping Carole Chang

Dedicated to My Parents

# **Abstract**

Traumatic Brain Injury (TBI) occurs when an external mechanical force traumatically injures the brain. The 2010/2011 population-based study shows that the total incidence of TBI in New Zealand has increased to 790 per 100,000 population. Memory impairment is the most common symptom and affects most TBI survivors. Memory impairments resulting from TBI take many forms depending on the nature of the injury. Existing work to use technology to help with memory problems focuses predominantly on capturing all information digitally to enable 'replaying' of memories. Other software applications (like calendar that reminders) are designed to assist the average people tracking their schedules. Both are inadequate for supporting TBI survivors.

The aim of this research is to build an augmented autobiographical memory system for a mobile device for supporting TBI survivors with their memory problems. I address the lack of information about TBI survivors' use of digital aids through user studies and interviews.

This research includes three studies. The first study is the interview user study, which aims to investigate TBI survivors' use of their own memory aids/strategies to cope with difficulties caused by memory impairments. The results contribute to develop the conceptual design of the prototype.

The second study is the interface user study, which aims to examine the usability of the conceptual design. Findings from this study provide the data and feedback for structuring the implementation of the MyMemory prototype on a mobile device. MyMemory is an augmented autobiographical memory aid specialized for TBI survivors with memory impairments. According to the results from the interface user study, we develop the implementation of the MyMemory prototype.

The third study aims to evaluate the effectiveness of MyMemory for improving autobiographical memory for people with TBI. This evaluation study is based on the ABAB case study used in psychology which can provide more accurate outcomes about the evaluation of MyMemory.

# Acknowledgements

Firstly, I would like to express my sincere gratitude to my two main supervisors, Annika Hinze and Judy Bowen for the continuous support of my research, for their patience, motivation, and immense knowledge. Their guidance helped me all the time in this of research as well as writing of this thesis. Many thanks also to Nicola Starkey, the second member of my supervisory panel, for guiding my research and helping me to develop my background in psychology.

Besides my supervisors, I would like to thank participants of my research, for their participation, suggestions and encouragement to improve my research from various perspectives. Without them this research would not be possible. Special thanks goes to Ella Scheepers and Marion Baird from *Think!* (the head injury society in Hamilton, NZ) for promoting this research and helping to recruit participants.

I also thank everyone who discussed my research with me, in the Computer Science department and at conferences. Past and present members of the ISDB (Information System & Databases, University of Waikato) group through the years provided constructive criticism and opportunities for discussion; thank you all. In particular I would like to thank Michael Rinck and Mumraiz Kasi: working with you guys has been a great experience.

I also want to extend my special thanks to Margaret Lyn Carlyon, for her comments and suggestions on writing this thesis.

My sincere thanks to all of my friends, especially to Celia Lai, Christine Yang, Janet Chang and Mitty Liu for believing in me and remaining positive through all of the ups and downs of my research.

Finally, I wish to express my heartfelt gratitude to my family. To my adorable parents; Ben and Amy who have the overwhelming love and

support. To my siblings; Cindy, Coco and Benson who help and encourage me. To my lovely dog; Maggie which walks with me every morning to clear my mind. I could not have done this without you all.

1 I	ntrodu	iction	1
1.1	Motiv	ration	2
1.2	Objec	tive and Hypothesis	3
1.3	Resea	arch Questions	4
	1.3.1	Question 1: What kind of memories do TBI survivors	
		remember or forget?	5
	1.3.2	Question 2: How can a mobile system help TBI sur-	
		vivors remember?	6
	1.3.3	Question 3: What kind of special requirements do TBI	
		survivors have for the design of an augmented mem-	
		ory aid?	7
	1.3.4	Question 4: What kind of information display will TBI	
		survivors accept?	7
	1.3.5	Question 5: Can memory training using a mobile sys-	
		tem make a difference for TBI survivors?	8
1.4	Struc	ture of this Thesis	8
2 E	Backgr	ound	11
2.1	Cogni	itive Psychology	11
	2.1.1	The Structure and Function of the Brain	12
	2.1.2	The Effects of Brain Damage on Cognition	15
2.2	Memo	ory	16
		Memory Process	16
		Three Store Model of Memory	18
		· ·	

	2.2.3 Sensory Memory	20
	2.2.4 Short-term Memory	22
	2.2.5 Long-term Memory	26
	2.2.6 Memory and TBI	32
2.3	Traumatic Brain Injury	33
	2.3.1 Epidemiological Literature	34
	2.3.2 Symptomatology	37
	2.3.3 Social Issues	40
	2.3.4 Treatment	41
2.4	Comparing TBI with Alzheimer's Disease	42
2.5	Discussion	43
	2.5.1 Memory Box Concept	44
	2.5.2 Memory Box Concept with TBI	45
	2.5.3 Memory Box Concept with AD	45
2.6	Summary	47
	elated Work	49
3.1	Research of Cognitive Psychology	49
	3.1.1 Digital Aids for TBI	50
3.2	Research of Computer Science	53
	3.2.1 Digital Aids for AD	53
	3.2.2 Digital Aids for TBI	58
	3.2.3 Digital Aids for Augmented Autobiographical Memory	61
	Discussion	66
3.4	Summary	67
4 I	nterview User Study	69
	Goal of the Study	70
	Method	70
	4.2.1 Recruitment	71
	4.2.2 Potential Participants	72
	4.2.3 Semi-structured Questionnaire	72

4.3	Procedure	74
4.4	Apparatus and Materials	75
4.5	Participants	76
	4.5.1 TBI-participants	76
	4.5.2 Caregiver-participants	79
4.6	Results	79
	4.6.1 Symptoms	79
	4.6.2 Particular Memory Problems	80
	4.6.3 Coping Strategies	83
	4.6.4 Factors of Memory	88
4.7	Extra User Study	90
4.8	Discussion	91
	4.8.1 Memory Impairments and other Symptoms and Issues	92
	4.8.2 Memory Strategies	93
	4.8.3 Technology Experience	94
	4.8.4 Factors of Memory	95
	4.8.5 Features of Application	98
4.9	Summary	99
	1 3 3	105
5.1		106
	5.1.1 Personas	106
	5.1.2 Scenarios	107
5.2	Concepts and Features of MyMemory	109
	5.2.1 Concepts of MyMemory	109
	5.2.2 Features of MyMemory	111
5.3	Paper Prototype of MyMemory	112
	5.3.1 Memory	114
	5.3.2 History	116
	5.3.3 Display	117
		118
5.4	Expert Walkthrough of MyMemory	119
	5.4.1 Using Activities to Describe Functions	120

	5.4.2 Pagination vs Long List for Adding Memory	120
	5.4.3 Pop-up Window for Confirmation	121
	5.4.4 Save Button in Adding Memory	121
	5.4.5 FlashCard Added as Training Option	121
5.5	Digital Paper Prototype of MyMemory	122
	5.5.1 Main Screen	122
	5.5.2 Adding Memory	122
	5.5.3 My Memories	125
	5.5.4 Training	127
	5.5.5 Settings	133
5.6	Summary	134
6 I	nterface User Study for the Conceptual Design of MyMemory	137
6.1	Goal of the Study	138
6.2	Method	138
	6.2.1 Recruitment	138
	6.2.2 Usability Test	140
	6.2.3 Tasks	140
6.3	Procedure	150
6.4	Apparatus and Materials	151
6.5	Participants	152
	6.5.1 TBI-participants Group	152
	6.5.2 Non-TBI-participants Group	152
6.6	Results	153
	6.6.1 MyMemory's Functions	153
	6.6.2 MyMemory's Information Display	159
	6.6.3 One-long Screen or Two-short Screen Design for Adding	
	Memory	160
	6.6.4 Sort By Time or By Event in My Memories	161
	6.6.5 MyMemory's Overall Performance	162
6.7	Discussion	165
	6.7.1 Time for Completion of Study	165
	6.7.2 Core Functions of MyMemory	166

	6.7.3 Feedback for MyMemory	167
6.8	Summary	168
7 I	mplementation of MyMemory	171
7.1	Architecture and Data Flow of MyMemory	171
7.2	Implementation	172
	7.2.1 Implementation Environment	173
	7.2.2 Memory Storage	174
	7.2.3 Display Event Data	176
	7.2.4 Selected Event Data	177
	7.2.5 Log and Record Report	177
7.3	User Interface	179
	7.3.1 Settings	179
	7.3.2 Main Screen	180
	7.3.3 Adding Memory	181
	7.3.4 Training Tools	185
7.4	Discussion	189
	7.4.1 Functions	189
	7.4.2 User Interface	189
7.5	Summary	190
8 E	Evaluating the Effectiveness of MyMemory	191
8.1	Goal of the Study	192
8.2	Method	192
	8.2.1 Recruitment	193
	8.2.2 Design	193
8.3	Procedure	194
8.4	Materials	198
	Participants	203
	8.5.1 TBI-participant	203
	8.5.2 Caregiver-participant	203
86	Analysis	206

	8.6.1	TBI-participant's smartphone experience	206
	8.6.2	TBI-participants Well-Being Index and Caregiver-partic	cipants
		Burden Inventory	210
	8.6.3	Memory Ability	215
	8.6.4	Autobiographical Memory	219
	8.6.5	MyMemory Evaluation	222
	8.6.6	MyMemory's Records	229
8.7	Discu	ssion	233
	8.7.1	TBI-participant's Improvements	233
	8.7.2	Caregiver-participant's Observations	235
	8.7.3	$\label{eq:myMemory} \mbox{MyMemory and TBI-participant's Memory Needs} \ \ . \ \ .$	237
	8.7.4	Limitation of the Study	241
8.8	Sumn	nary	241
9 5	Summa	ary and Conclusions	243
9.1	Answ	ers to the Research Questions	244
	9.1.1	What kind of memories do TBI survivors remember	
		or forget?	244
	9.1.2	How can a mobile system help TBI survivors remem-	
		ber?	245
	9.1.3	What kind of special requirements do TBI survivors	
		have for the design of an augmented memory aid? $\ .$	246
	9.1.4	What kind of information display will TBI survivors	
		accept?	246
	9.1.5	Can memory training using a mobile system make a	
		difference for TBI survivors?	247
9.2	Contr	ibutions	248
	9.2.1	Requirements for an augmented autobiographical mem	1-
		ory in TBI	248
	9.2.2	Analysis of related work for both Computer Science	
		and Psychology	248
	9.2.3	Special requirements for TBI survivors with memory	
		impairments	249

	9.2.4	Conceptual design for an augmented autobiographi-	
		cal memory system for TBI survivors $\ldots \ldots$	249
	9.2.5	Prototype implementation of the design $\ \ldots \ \ldots$	250
	9.2.6	An evaluation of the effectiveness of an augmented	
		autobiographical memory system in a user study $\ \ .$	250
9.3	Limit	ations	250
	9.3.1	Design Choices	250
	9.3.2	Implementation Choices	251
	9.3.3	Evaluation Choices	251
9.4	Futur	e work	252
	9.4.1	Following up on observations made in the evaluating	
		user study	252
	9.4.2	Conducting further user studies	253
	9.4.3	Support for iOS system or other wearable devices $$ .	253
9.5	Concl	usion	254
A N	Materia	al for Interview User Study	255
A.1	Appro	oval Letter	256
A.2	Poste	r in 2012	257
A.3	Poste	r in 2014	258
A.4	THIN	K! Newsletter	259
A.5	News		260
A.6	Partic	cipant Information Sheet	261
<b>A.</b> 7	Partic	cipant Consent Form	264
A.8	Interv	view Form	266
		al for Interface User Study	277
		oval Letter	278
		tion Email	279
		cipant Information Sheet	280
		arch Consent Form	281
B.5	Tasks	Form	282

C Material for Evaluating User Study of MyMemory	297
C.1 Approval Letter	299
C.2 Poster	300
C.3 Participant Information Sheet	301
C.4 Participant Consent Form – TBI	304
C.5 Participant Consent Form – Caregiver	305
C.6 Demographic Questionnaire – TBI	306
C.7 Demographic Questionnaire – Caregiver	308
C.8 Strategies of PDA/Smartphone Use Form	310
C.9 Assigned Task Sheet	314
C.10 WHO Well-Being Index (WHO-5)	315
C.11 Caregiver Burden Inventory (CBI)	316
C.12 Memory Functioning Scale – TBI	318
C.13 Memory Functioning Scale – Caregiver	320
C.14 Autobiographical Memory Questionnaire	322
C.15 MyMemory Evaluation Form	326
C.16 Memory Log Booklet Example	330
Publications and Contributions	331
Bibliography	333

2.1	The main sequential stages of the cognitive process. Reprinted	
	from An introduction to cognitive psychology: processes and dis-	
	orders (p. 2), by D. Groome, H. Dewart, A. Esgate, K. Gurney, R.	
	Kemp, and N. Towell, (1999), East Sussex, UK: Psychology Press.	
	Copyright 1999 by Psychology Press. Reprinted with permission	12
2.2	A side view of the human brain. Reprinted from An introduction to	
	cognitive psychology: processes and disorders (p. 9), by D. Groome,	
	H. Dewart, A. Esgate, K. Gurney, R. Kemp, and N. Towell, (1999),	
	East Sussex, UK: Psychology Press. Copyright 1999 by Psychology	
	Press. Reprinted with permission	14
2.3	Three Store Model of Memory. Reprinted from Cognitive Psychol-	
	ogy: applying the science of the mind (p. 137), by G. Robinson-	
	Riegler and B. Robinson-Riegler, (2007), USA: Pearson Education	
	Inc. Copyright 2007, by Pearson Education, Inc. Reprinted with	
	permission	19
2.4	Forgetting curve. Retrieved from http://peakmemory.me/2013/06/	
	$29/hermann-ebbing haus-and-the-forgetting-curve/.\ Copyright\ 2013$	
	by Peakmemory. Reprinted with permission	24
2.5	The example of digit span test. Reprinted from Memory. (p. 20),	
	by A. Baddeley, M. W. Eysenck and M. C. Anderson, (2009), USA:	
	Psychology Press. Copyright 2009, by Psychology Press. Reprinted	
	with permission	25
2.6	Taxonomy of Memory. Reprinted from Memory. (p. 10), by A. Bad-	
	deley, M. W. Eysenck and M. C. Anderson, (2009), USA: Psychology	
	Press. Copyright 2009, by Psychology Press. Reprinted with per-	
	mission	27

2.7	Memory box concept	44
2.8	Memory box concept for the memory impairments of TBI	46
2.9	Memory box concept for AD	46
3.1	Example of NeuroPage screen. Reprinted from Assistive Technology For Cognition (ATC), by Mark Harniss, Kurt Johnson, & Pat Brown, 2015, Retrieved from http://cognitivetech.washington.edu/presentations/summer_institute_04_files/textmostly/slide14.html. Copright 2015 by Assistive Technology For Cognition (ATC). Reprinted with permission.	y- 51
3.2	Person location/tracking using the location network. Reprinted from "Providing universal location services using a wireless E911 location network", by J. M. Zagami, S. A. Parl, J. J. Bussgang and K. D. Melillo, 1998, <i>IEEE Communications Magazine</i> , 36, p.70. Copyright 1998 by IEEE Communications Magazine. Reprinted with permission	56
3.3	Smart elder house. Reprinted from "mPCA–A mobile patient caregiving assistant for Alzheimer patients", by C. Giraldo, S. Helal, and W. Mann, 2002, First International Workshop on Ubiquitous Computing for Cognitive Aids (UbiCog'02). Copyright 2002 by First International Workshop on Ubiquitous Computing for Cognitive Aids (UbiCog'02). Reprinted with permission	57
3.4	Example screenshot of ExpiryDate. Apple Inc (2012). The pop up window. Retrieved from http://itunes.apple.com/tw/app/expirydate. Copyright 2012 by Apple Inc. Reprinted with permission	61
3.5	The photo of SenseCam. Reprinted from "SenseCam: A wearable camera that stimulates and rehabilitates autobiographical memory", by S. Hodges, E. Berry, and K. Wood, 19(7), 686. Copyright 2012 by Taylor and Francis. Reprinted with permission	62
3.6	The photo of SenseCam browser. Reprinted from "Automatically assisting human memory: A SenseCam browser", by A. R. Doherty, C. J. Moulin and A. F. Smeaton, 19(7), 789. Copyright 2012 by Taylor and Francis. Reprinted with permission	63

3.7	The Digital Parrot: Main view and all navigators. Reprinted from Augmenting Autobiographical Memory: An Approach Based on Cog-	
	nitive Psychology (p.105), by A. Schweer. Copyright 2011 by An-	
	drea Schweer. Reprinted with permission	64
2 0	Example screenshot of selection filtering. sReprinted from <i>Digital</i>	04
3.8		
	Parrot on Android. (p. 12 – 13), by J. Richmond. Copyright 2012 by	GE
	James Richmond. Reprinted with permission	65
4.1	Screenshot example of an on-line survey	73
4.2	Symptoms distribution	80
4.3	Memory problems distribution	82
4.4	Number of memory problems distribution	83
4.5	Left: example of writing notes on the hand (P2). Right: example	
	of writing notes on calendars: Weekly planner on the whiteboard,	
	Monthly planner on the paper-based calendar (P16)	87
4.6	Coping strategies distribution	88
4.7	Number of coping strategies distribution	89
4.8	An overview of symptoms reported by TBI patients with and without	
	reported memory problems	101
4.9	Example of handwriting and color coding notes on the tablet (P11).	102
4.10	Example of drawing the symbol related to the word (P13). $$	102
4.11	Example of color coding related to organize their memories (P6). $$ .	103
4.12	Example of sticky notes on Windows 7 (P9)	103
4.13	Screenshots of Rainlendar (Rainlendar, 2012) (P7)	104
4.14	Screenshots of P6's mobile device	104
5.1	Memory Box Concept for average people's memory	110
5.2	Memory Box Concept of TBI associated with the MyMemory. $\ \ . \ \ . \ \ .$	111
5.3	Features of MyMemory	112
5.4	MyMemory's structure of roles, tasks and elements	113
5.5	Paper prototype of MyMemory's main screen	113
5.6	Paper prototype for four screens of 'Memory'	115
5.7	Paper prototype of 'History'. Left: Overall stored event data list.	
	Right: The detail of single event data	116

5.8	Paper prototype of 'Display'. Left: 'Post-its' on the phone's home	
	screen. Middle: Text box on the 'Screensaver'. Right: Voice Records.	.117
5.9	Paper prototype of the 'Setting'	119
5.10	Digital paper prototype of MyMemory's main screen	123
5.11	Digital paper prototype for two-short screens design for 'Adding	
	Memory'	123
5.12	Digital paper prototype for one-long screen design for 'Adding Mem-	
	ory'	124
5.13	Digital paper prototype of 'My Memories'. Left: Overall recorded	
	event data list. Right: The detail of the single event data	126
5.14	Digital paper prototype of the primary producer of 'Training'. Left:	
	List overall recorded event data list. Right: Three things of 'Training'	.127
5.15	Digital paper prototype of the 'FlashCard Training'. Left: The flash-	
	card one. Right: The flashcard two.	128
5.16	Digital paper prototype of the 'FlashCard Training Records'	129
5.17	Digital paper prototype of 'Post-its'. Left: Questions on 'Post-its'.	
	Right: Answers on 'Post-its'	130
5.18	Digital paper prototype of the 'Screensaver' settings	131
5.19	Digital paper prototype of two screensaver designs. Left: Banner	
	design. Right: Text box design	131
5.20	Schematic drawing of the connection on 'Voice Recording' and Karotz	.132
5.21	Digital paper prototype of the 'Settings'	133
6.1	Paper copy of 'Adding Memory' for the first screen	141
6.2	Paper copy of 'Adding Memory' for the second screen	142
6.3	Paper copy of 'Adding Memory' for two types of design. Left: Two-	
	short screens design. Right: One-long screen design	143
6.4	Study environment	151
6.5	Average scores of each function with the standard deviation by TBI-	
	participants and Non-TBI-participants groups. Data is presented	
	as the mean of SEM. TBI-participants group $n=5$ and Non-TBI-	
	participants group n=4	154
6.6	Scores of MyMemory's function by TBI participants	155
6.7	Scores of MyMemory's function by Non-TBI participants	156
6.8	Example of the widget of Remember The Milk on the main screen.	158

6.9	Average scores of MyMemory's display items with the standard de-	
	viation by TBI-participants and Non-TBI-participants groups. Data	
	is presented as the mean of SEM. TBI-participants group $n=5$ and	
	Non-TBI-participants group $n=4$	160
6.10	Overall scores for the MyMemory by TBI-participants and Non-TBI-	
	participants groups. Data are presented as the mean od SEM. TBI-	
	participants group $n=5$ and Non-TBI-participants group $n=4$	163
7.1	Implemented parts of the conceptual design	172
7.2	UML diagram of MyMemory	175
7.3	ER diagram of the item table	176
7.4	Screenshot example of the log report	178
7.5	Screenshot example of the record report	178
7.6	Screenshot example of the setting	179
7.7	Screenshot example of the main screen	180
7.8	Screenshot example of event data	181
7.9	Screenshot example of 'Adding Memory'	182
7.10	Screenshot examples of the differences of the label colour. Left:	
	Colour coding with yellow. Right: Colour coding with blue and with	
	a photo attached	183
7.11	Screenshot example of the email and text message. Left: Example	
	of 'Adding Memory'. Middle: Example of the email. Right: Example	
	of the text message	184
7.12	Screenshot example of 'FlashCard'. From left to right: First ques-	
	tion card, First answer card, Second question card and Second an-	
	swer card	186
7.13	Screenshot example of 'Widget'	188
7.14	Screenshot example of 'Widget' on the home screen	188
8.1	Interview environment	194
8.2	Outline of MyMemory's evaluation study.	196
8.3	TBI-participants use of smartphones for remembering information	
	from the past. Frequency ratings were given from 0 (never) to $4$	
	(always)	209

8.4	TBI-participants use of smartphones for remembering to do things	
	in the future. Frequency ratings were given from $0$ (never) to $4$	
	(always)	210
8.5	TBI-participants' well-being index in each phase. Well-being index	
	ratings were given 0 (at no time) to 5 (all of the time). Well-being	
	index lists five questions and its maximum score is 25. $\dots$	211
8.6	Caregiver-participants' burden in each phase. Burden ratings were	
	given 0 (never) to 4 (nearly always). Caregiver-participants' burden	
	inventory consists of 24 questions, its maximum score is 96. $$	213
8.7	TBI-participants' memory functioning scale in each phase. Memory	
	function rating were given 0 (never) to 4 (always). This memory	
	function scale includes 13 questions, its maximum score is 52	215
8.8	Caregiver-participants' observed memory functioning scale for their	
	TBI relatives in each phase. Memory function ratings were given	
	from 0 (never) to 4 (always). This memory function scale includes	
	13 questions, its maximum score is 52	217
8.9	TBI-participants' autobiographical memory scores in each phase.	
	The autobiographical memory questionnaire lists 18 questions in	
	total and memory score ratings were given 1 (not at all) to 7 (as	
	much as any memory or as clearly as if it were happening right	
	now). Maximum score is 122	221
8.10	TBI-participants' event records, by three particular memory prob-	
	lems	231
A.1	Approval letter form	256
A.2	Poster in 2012	257
A.3	Poster in 2014	258
A.4	THINK!! Newsletter	259
A.5	News	260
A.6	Participant Information sheet	261
A.7	Participant Consent Form	264
A.8	Interview Form	266
B.1	Approval letter form	278
B.2	Invitation email	279

В.З	Participant Information sheet	280
B.4	Participant Consent Form	281
B.5	Tasks Form	282
C.1	Approval letter	299
C.2	Poster	300
C.3	Participant Information sheet	301
C.4	Participant Consent Form – TBI	304
C.5	Participant Consent Form – Caregiver	305
C.6	Demographic Questionnaire – TBI	306
C.7	Demographic Questionnaire – Caregiver	308
C.8	Strategies of PDA/Smartphone Use Form	310
C.9	Assigned Task Sheet	314
C.10	WHO Well-Being Index (WHO-5)	315
C.11	Caregiver Burden Inventory (CBI)	316
C.12	Memory Functioning Scale – TBI	318
C.13	Memory Functioning Scale – Caregiver	320
C.14	Autobiographical Memory Questionnaire	322
C.15	MyMemory Evaluation Form	326
C.16	Memory Log Booklet Example	330

# List of Tables

2.1	Recovery statistic and symptoms for TBI	38
2.2	Comparisons of AD and TBI	43
3.1	Digital aids for AD by types.	54
3.2	Digital aids recommended for improving TBI survivors' memory. $% \left( 1\right) =\left( 1\right) \left( 1\right$	59
4.1	TBI-participant demographics. *: The caregiver participated in the	
	study. F: Full-time jobs of 40hrs/week. P: Part-time job of 20hrs/week.	. 77
4.2	$Care giver-participant\ demographics.\ F: Full-time\ jobs\ of\ 40hrs/week.$	
	P: Part-time job of 20hrs/week	78
4.3	Summary of memory aids or strategies of TBI-participants used by	
	previous and current – 1	85
4.4	Summary of memory aids or strategies of TBI-participants used by	
	previous and current – 2	86
4.5	Factors affecting of TBI-participants' memory by post events and up	
	coming events	90
6.1	TBI-participants demographics. (F: Full-time jobs of 40hrs/week. P:	
	Part-time jobs of 20hrs/week.)	152
6.2	Non-TBI-participants demographics. (F: Full-time jobs of 40hrs/week.	
	P: Part-time jobs of 20hrs/week.)	153
6.3	Results of two interfaces of the 'Adding Memory' by TBI-participants	
	and Non-TBI-participants groups	161
6.4	Results of two sorting functions of 'My Memories' by TBI-participants	
	and Non-TBI-participants groups	162
7.1	Summary of the structure of an Android projects	173

### List of Tables

8.1	TBI-participants demographics – 1. (F: Full-time jobs of 40hrs/week.	
	P: Part-time jobs of 20hrs/week.)	204
8.2	TBI-participants demographics – 2	205
8.3	Caregiver-participants demographics. (F: Full-time jobs of 40hrs/wee	k.
	P: Part-time jobs of 20hrs/week.)	207
8.4	Summary of TBI-participants of the smartphone experience. $\ \ . \ \ .$	208
8.5	Results of TBI-participants' well-being index in each phase. Avg.:	
	Average. Comp.: Comparison	212
8.6	Results of Caregiver-participants' burden in each phase. Avg.: Av-	
	erage. Comp.: Comparison	214
8.7	Results of TBI-participants' memory functioning scale in each phase.	
	Avg.: Average. Comp.: Comparison.	216
8.8	Results of Caregiver-participants' observed memory functioning scale	)
	for their TBI relatives in each phase. Avg.: Average. Comp.: Com-	
	parison	218
8.9	Summary of TBI-participants' results of event and scores on Auto-	
	biographical memory questionnaire (AMQ)	220
8.10	Results of TBI-participants' autobiographical memory score in each	
	phase. Avg.: Average. Comp.: Comparison.	222
8.11	What do you think the way to add new event record, by starting	
	with 'Camera' and 'New Memory' in B1 and B2 phases. Feedback	
	ratings were given 0 (not as all helpful) to 4 (very helpful), – not	
	applicable	223
8.12	What do you think these features of Memory. Feedback ratings	
	were given 0 (not as all helpful) to 4 (very helpful), – not applicable.	224
8.13	What do you think about Memory training tools, 'FlashCard' and	
	'Widget' in B1 and B2 phases. Feedback ratings were given 0 (not	
	as all helpful) to 4 (very helpful), – not applicable	225
8.14	What do you think about the Assistant functions in B1 and B2 phases.	
	Feedback ratings were given 0 (not as all helpful) to 4 (very helpful), $$	
	– not applicable	226
8.15	Rate how much you agree or disagree with the six statements about	
	how MyMemory affects your memory and life in B1 and B2 phases.	
	Ratings were given from 0 (strongly disagree) to 4 (strongly agree).	228

### List of Tables

8.16	Number of event records by the participant and different categories	. 230
8.17	Number of uses grouped into the participant and function. $\ \ . \ \ . \ \ .$	232

# Chapter 1

# Introduction

The aim of this research is to design, develop and explore a mobile augmented memory system for people with Traumatic Brain Injury (TBI). This thesis is an investigation using both design approaches in HCI qualitative methods and human-centred design approaches with the goal of augmenting human memory. The process involves 1) exploring the requirements and problems of TBI survivors with their memory impairments, 2) designing and evaluating the conceptual design, 3) implementing the application, and 4) evaluating an application with TBI survivors.

This research begins with the use of an interview user study, to investigate individuals with TBI and their memory impairments. The aim of this study is to explore information about the memory problems experienced by people with TBI and which aspects of their memory loss are most problematic for them and may be supported by an augmented memory system. Integrating the findings from the study and the results from literature reviews, the conceptual design of an application is accomplished. The conceptual design focuses on recording and training memories for TBI survivors. This research uses a user study to evaluate the conceptual design prototype. According to the results from the user study, an augmented memory prototype for mobile devices for individuals with TBI is created – titled MyMemory. This research uses psychological methodologies to measure the effectiveness of MyMemory which is evaluated with a group of participants with TBI.

This chapter first presents the motivation of the study and then defines the objective and hypothesis of this research. The subsequent section defines five research questions to be addressed. The last section outlines the structure of the thesis.

#### 1.1 Motivation

Every day 90 New Zealanders sustain brain injuries that lead to long lasting cognitive difficulties including memory and concentration problems (Barker-Collo, Wilde and Feigin, 2008; Hewitt, Evans and Dritschel, 2006). Feigin et al., presented a hospital-based study showing that 790 out of 100,000 people are diagnosed with Traumatic Brain Injury (TBI) per year globally and the numbers increase gradually year by year (Feigin, Theadom, Barker-Collo, Starkey, McPherson, Kahan, Dowell, Brown, Parag, Kydd, Jones, Jones and Ameratunga, 2012).

Acquired brain injury, an injury to the brain occurring after birth, is one of the most common causes of disability and death in young adults (Feigin, Barker-Collo, Krishnamurthi, Theadom and Starkey, 2010). TBI is one of the most common causes of acquired brain injury type around the world. Given this, people can spend a significant proportion of their life with on-going cognitive difficulties. The memory impairments that result from brain injury take many forms depending on the nature of the injury (Dritschel, Kogan, Burton, Burton and Goddard, 1998). They include relatively minor memory slips and lapses, such as those we all experience from time to time (e.g., forgetting a person's name). To more severe problems such as anterograde amnesia which is an inability to form new memories. Clearly, memory problems may severely hamper an individual's ability to live independently and may leave then unable to carry out even simple domestic chores, such as cooking. This affects not only the person with the injury but also their close friends and family.

Computer science studies have focused on the issue of designing for personal memories. A special journal issue from 2012 focused on ways of using digital media to support people remembering everyday experiences (Taylor & Francis, 2012). van den Hoven, Sas and Whittaker (2012) described how ordinary people collected vast amount of digital media such as photos, videos, text and music files to help them recall. Based

on this concept, a new 'lifelogging' tool was designed using a wearable camera which makes it effortless to record everything in the life of the wearer. In Section 3.2 we explain why lifelogging technology is nor suitable for TBI survivors.

Augmented autobiographical memory systems support people in remembering events of their lives (van den Hoven and Eggen, 2008; Berntsen, Rubin and Ebrary, 2012). Capturing memories for life has become a U.K. Grand Challenge in computing (Fitzgibbon and Reiter, 2003). Existing research in augmenting memory aims to digitally capture everything we do and see, recording memories as video streams. These systems focus on technological challenges and their support for longer term recollection is doubtful (Sellen and Whittaker, 2010).

Research into augmenting memory predominantly uses video recordings or photos. Even though 'capturing everything' is a major focus of existing systems, they lack explicit evidence of potential benefits for memory. Similarly, automatic archiving of digital photos and other memorabilia has been of limited use (Sellen and Whittaker, 2010; Petrelli and Whittaker, 2010).

Sellen and Whittaker argue that a useful system should focus on using contextual information as cues to trigger memory (Sellen and Whittaker, 2010). Schweer designed a desktop-based memory system, Digital Parrot that uses users cues to trigger memories (context-driven) (Schweer, 2011). This research explores to which extent these key insights of augmented memory system research can be transferred to help people with memory problems due to TBI. Using a human-centred approach, we aim to develop a mobile system for TBI survivors for capturing, storing and retrieving cues that trigger human memories.

## 1.2 Objective and Hypothesis

The main objective of this research is

to explore the effect of memory impairments in the lives of people with TBI, and to design and develop an augmented memory aid to help alleviate these effects. Some of the biggest concerns of the TBI survivors we interviewed refers to the limitation in using available memory aids. Many cannot use a desktop-based system, because it displays too much information at once, which gives them headaches. Some of them use text messages on their mobile phones to preserve their memories. Often they rely on external help to preserve their memories. Many can remember how to use mobile devices for saving memories. Some even reported remembering some memories without checking them again after saving on a mobile device. Thus repetition is seen to be the key for the memory of TBI survivors.

The memories preserved by TBI survivors are related to their past events which is episodic memory, part of the autobiographical memory. Episodic memory is essential to the performance of numerous tasks, such as recalling the name of someone you have previously met, remembering the current date, or remembering to go to an appointment in the near future (Ranganath, Flegal and Kelly, 2011; Berntsen et al., 2012). Unlike everyday tasks; most of them are the one-off events thus TBI survivors find them difficult to remember. However, Berntsen et al. (2012) has pointed out that cognitive training can improve episodic memory. Numerous studies (Svoboda and Richards, 2009; Svoboda, Richards, Polsinelli and Guger, 2010) stress that individuals with memory impairments are able to improve their memory ability through the use of a mobile device. Therefore, the central hypothesis underlying this research is that

a digital system designed specifically for TBI survivors to train their memory will improve their ability to remember.

This section explained the objective of our research and proposed the hypothesis to guild this research. The next section provides the research questions that are generated to defend the hypothesis.

## 1.3 Research Questions

The main objective of this thesis is to explore the use of a digital system to support people with TBI. To verify the hypothesis, we develop the following five research questions:

- 1. What kind of memories do TBI survivors remember or forget?
- 2. How can a mobile system help TBI survivors remember?
- 3. What kind of special requirements do TBI survivors have for the design of an augmented memory aid?
- 4. What kind of information display will TBI survivors accept?
- 5. Can memory training using a mobile system make a difference for TBI survivors?

Each question is developed in more detail below.

# 1.3.1 Question 1: What kind of memories do TBI survivors remember or forget?

The memory dysfunctions of people with TBI may vary as lesions in different areas of brain affect the survivors' memory function differently (Eysenck and Keane, 2010; Baddeley, Eysenck and Anderson, 2009). Furthermore, TBI generally accompanies other symptoms that make the memory problem more complex and varying for an individual with TBI. Therefore, clarifying which memories TBI survivors remember is essential in this research.

Currently, there is a lack of detailed and accurate information about the memory problems experienced by those with TBI. This thesis will therefore begin by addressing this lack of information through literature reviews and interviews with people with TBI. The answer to this question contributes to cues for TBI survivors triggering their memories efficiently. These cues build a foundation for our augmented memory system.

There are two approaches used to attempt to answer this question. Firstly, the research presented in this thesis reviews the background of cognitive psychology and examines existing digital aids from a cognitive psychology perspective to answer this research question. We outline the background of cognitive psychology that leads us to understand the

#### Chapter 1 Introduction

memory process and system, eventually focusing on the cognitive psychology of TBI. Secondly, the use of an interview user study explores effects caused by the memory impairments for TBI survivors and the memory strategies or aids TBI survivors use. Using these two complimentary approaches provides a more holistic overview of the memory issues encountered by people with TBI.

# 1.3.2 Question 2: How can a mobile system help TBI survivors remember?

It is known that TBI survivors cannot accept too much information displayed at once; and most of them rely on preserving their memories on mobile devices (Hinze, Chang and Starkey, 2011). Therefore we believe that an application on mobile devices has the potential to improve their memory impairments but the design needs to be specialized. The aim of this question is to explore how TBI survivors use a mobile system to help their memory impairments.

A lot of research works have been done on investigating the use of mobile devices for supporting TBI survivors with memory impairments. However, they all focused on everyday tasks only. The aim of this research is to investigate the relationship between the mobile system and the memory of personal events for TBI survivors.

There are two approaches used for answering this question. Firstly analysing existing digital aids whose goal is to help individuals with memory problems, such as Alzheimer's disease patients and average people having memory problems. These existing digital aids may not be an ideal solution for TBI but they provide potential concepts for designing the augmented system for mobile devices.

We then focus further through an analysis of existing digital aids that support TBI survivors in improving their memory impairments. We then verified this answer through our user study that explores and observes the TBI survivors specific needs for a mobile system. The results from the two approaches suggested how a mobile device may be used to help TBI survivors with memory impairments. As a result, we developed a conceptual design model for an augmented memory system for TBI sur-

vivors.

# 1.3.3 Question 3: What kind of special requirements do TBI survivors have for the design of an augmented memory aid?

The conceptual design model incorporates the cues identified from the first question and addresses the requirements discovered from the second question. The initial conceptual design model is explored for a paper prototype. Through several design steps, a final design was developed. The conceptual design model is a fundamental part of an application development process.

The conceptual design developed relies on strengths of existing work and the repetition concept explored from the interview user study. The repetition concept establishes a training tool in the conceptual design. We execute a user study to evaluate the usability of this conceptual design that can guide us to the next research question.

# 1.3.4 Question 4: What kind of information display will TBI survivors accept?

TBI survivors may have vision problems as a result of their TBI. Displaying effective information to trigger TBI survivors' memory is a challenge and an important issue in this research.

The aim of this question is to evaluate a prototype of the conceptual design that satisfies the requirements for performance for TBI survivors. We use a user study to verify the conceptual design using a mock up tool, Balsamiq. We use scenarios to demonstrate the system's functionality and set tasks to test the system's usability. The results from the user study identify the shortcomings of the prototype in order to develop a better augmented memory system.

The answer to this research question not only verifies the usability of the conceptual design, but also ensures that the designed system can address requirements of TBI survivors from the answer to the second research question.

# 1.3.5 Question 5: Can memory training using a mobile system make a difference for TBI survivors?

Previous studies advocate that repetition can improve memory impairments but they focus on applying this concept to everyday tasks. This research introduces a training tool connected to repetition and uses it to train TBI survivors' autobiographical memory.

This question is examined in two ways. Firstly using the conceptual design with the user study tests the usability and the interface. Secondly we use an implementation of the conceptual design in the evaluating user study. The implementation of the conceptual design, MyMemory, utilizes the repetition function in the training tool of the memory system. The training tool includes flashcards and widgets. The prototype incorporates the cues identified for TBI survivors for an augmented memory system, with the requirements modified to satisfy the TBI survivors using a mobile device.

MyMemory was evaluated in a user study following a single case ABAB design in this research. ABAB design is a psychology methodology which observes the participants behaviour changes with and without treatment. 'A' denotes the phase to gather the baseline information (i.e., without MyMemory) and 'B' denotes the phase to measure the effect of the treatment (i.e., with MyMemory). This design repeats both phases twice. Due to the low participant numbers and time restrictions of the research, this study methodology is an appropriate approach to produce results which are sufficient for this research (Heffner, 2015; Svoboda and Richards, 2009) (more details in Section 8.2.2). The answer to this question clarifies that the training tool influences not only the TBI survivors' memory ability but also their well-being and people around them.

# 1.4 Structure of this Thesis

This section explains how the research questions and contributions of this research shape the structure of this thesis.

Chapter 2 provides a literature review of the relevant elements of cognitive psychology, and the memory process and structure. Then we re-

view the common issues of TBI survivors and compare the memory impairments of Alzheimer's disease and TBI.

Chapter 3 describes existing augmented memory systems for different people's needs, including average people, Alzheimer's disease and TBI. Examining these digital aids allows a comparison, of the structure of an augmented memory system in the different aspects that they support to develop our conceptual design.

Chapter 4 uses interviews to explore the memory impairments of TBI survivors in their daily lives and investigates the specific requirements for a mobile system.

Chapters 2 to 4 answer the first and second research question, from the three aspects. The first aspect is from the cognitive psychology background to understand the memory, brain and TBI in Chapter 2. The second aspect is from the related work from a computer science perspective to perceive how digital aids assist people with different requirements in an augmented memory system in Chapter 3. The third aspect is from our interview user study to elucidate the obstacles caused by the memory deficits with TBI survivors in Chapter 4.

Chapter 4 and Chapter 5 together answer the third research question. Chapter 5 describes the conceptual design of the implementation named MyMemory that is based on the results from the interview user study on Chapter 4.

Chaptes 5 and 6 contribute to answer the fourth research question, the special requirements TBI survivors need of an augmented memory aid. It includes describing the conceptual design of the application that bases on the results from the interview user study on the previous chapter in Chapter 5. Examining the usability of the conceptual design enhances the implementation in Chapter 6.

Chapter 7 and 8 complete the answer to the fifth research question. Together they show a new augmented memory system, MyMemory, to support TBI survivors' memory for their daily life. MyMemory has the training system that specialises in improving the TBI survivors' memory ability. Chapter 7 introduces MyMemory, an implementation of those aspects of the conceptual design and the results from the related user

## Chapter 1 Introduction

study. In Chapter 8, we use the psychological ABAB single case design for methodology with appropriate questionnaires to test the effectiveness of MyMemory.

Finally, Chapter 9, is a summary of the contributions of the thesis and answers to the research questions in this thesis. We also describe its limitations and point out opportunities for future work.

# Chapter 2

# Background

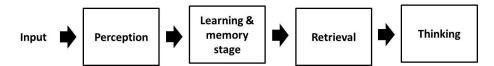
This chapter addresses the first research question: "What kind of memories do TBI survivors remember or forget?" To answer this question, this chapter introduces the relevant background from cognitive psychology on memory and TBI.

The start of the chapter reviews the cognitive psychology research related to how the brain processes information. Section 2.2 focuses on memory process and memory systems. It further discusses the autobiographical memory, and memory and TBI. Section 2.3 presents the epidemiology literature, symptoms, issues and treatment of people with TBI. These studies provide additional information to understand obstacles and issues for people with TBI, with consideration of a treatment. Section 2.4 compares differences of the memory impairments between people with TBI and Alzheimer's disease (AD).

# 2.1 Cognitive Psychology

Cognitive psychology is the study of mental processes that affects human behaviour. These processes cause that human being can think and make sense of the world around them. In order to further investigate, psychologists constructed a model to explain cognitive processing. This model includes four stages in sequential order see Figure 2.1.

The first stage begins by processing a new piece of sensory input. This means that the brain takes in information from the sense organs and then analyses the content of information in an initial stage of perception. More specifically, the brain is already extracting meaning from the input



**Figure 2.1:** The main sequential stages of the cognitive process. Reprinted from *An introduction to cognitive psychology: processes and disorders* (p. 2), by D. Groome, H. Dewart, A. Esgate, K. Gurney, R. Kemp, and N. Towell, (1999), East Sussex, UK: Psychology Press. Copyright 1999 by Psychology Press. Reprinted with permission.

in order to attempt to understand the incoming information. The process of perception heads the process of making a record of the input received, and we call this process the learning and memory stage. The creation of a memory and its retention for later use is the main purpose of learning and memory stage. Retrieval aims to access information that has previously been stored. That is to say, we retrieve to provide the basis for further activities. Additionally, retrieval is also used as part of thought. Stated another way, thought is not only the retrieval of the old memories but it also manipulates information to help us to deal with current problems or situations (Eysenck and Keane, 2010; Groome, Dewart, Esgate, Gurney, Kemp and Towell, 1999).

Indeed, cognitive processes are not as simple as shown in Figure 2.1, as they are in reality much more complex and interactive. However, Figure 2.1 gives us the basic structure to understand the cognitive processes. The learning and memory stage is essential in the cognitive processes, without it people are like a new born baby. The brain is the most important organ because it manages a person's physical and psychological system. Therefore, the subsequent section will discuss the structure of the brain and the implications of brain injury on cognition.

#### 2.1.1 The Structure and Function of the Brain

It has been established that the left and right hemispheres of the brain have particular specialisations. The nerves from the brain cross over to control the opposite side of the body, which means the right-handed people have a dominant left hemisphere. In general, the left hemisphere is more concerned with the input of language or speech and the right

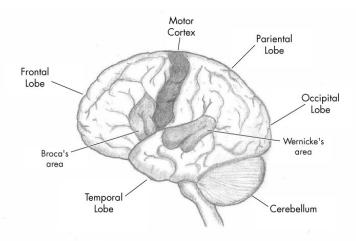
hemisphere is more involved with non-verbal input (e.g., recognizing faces) (Ley and Bryden, 1982; Groome et al., 1999; Eysenck and Keane, 2010). Interestingly, the right hemisphere of the brain controls the musculature on the left side of the face and the right hemisphere of the brain also processes the right field of version, which views the left hand side of a conversational partner's face. Browndyke suggested that, because of this loop in facial expression generation where the more expressive half of the face is processed by the hemisphere of the brain that is better able to recognise emotion and vice versa, facial expression asymmetry could have an impact on emotion recognition (Browndyke, 2002). Human facial expression are naturally asymmetric. The left hand side of the face tends to move more than the right and while this is more pronounced when the expression id faked the asymmetry is always there (Borod, Cicero, Obler, Welkowitz, Erhan, Santschi, Grunwald, Agosti and Whalen, 1998; Tcherkassof, Bollon, Dubois, Pansu and Adam, 2007). While facial expressions are generally shown more strongly on the left hand side of the face, facial expression recognition occurs primarily in the right hemisphere of the brain (Ley and Bryden, 1982).

The brain is divided into four lobes, each of which has different functions Figure 2.2 shows the four lobes: frontal lobe, temporal lobe, parietal lobe and occipital lobe.

The frontal lobe includes the motor cortex and Broca's area. Broca's area is associated with the motor region to control speech production. It is typically situated in the left hemisphere of the brain (Broca, 1861) (Parkin, 1997; Willingham, 2004). The frontal cortex is another part of frontal lobe; it seems to be involved with the central executive system. The central executive system is responsible for making conscious decisions, impulse control, planning and organisation and plays an important role in overriding automatic processes and responses.

The temporal lobes include the main auditory cortex and Wernicke's area. Wernicke's area is particularly concerned with interpreting the meaning of speech content (usually in the left hemisphere) (Wernicke, 1874). Milner (1966) found that temporal lobe lesions are often associated with severe amnesia; therefore, the temporal lobes are known to

#### Chapter 2 Background



**Figure 2.2:** A side view of the human brain. Reprinted from *An introduction to cognitive psychology: processes and disorders* (p. 9), by D. Groome, H. Dewart, A. Esgate, K. Gurney, R. Kemp, and N. Towell, (1999), East Sussex, UK: Psychology Press. Copyright 1999 by Psychology Press. Reprinted with permission.

be particularly important in memory (Groome et al., 1999; Willingham, 2004).

The parietal lobes contain the somatic sensory cortex. The function of the somatic sensory cortex is to receive tactile input from the skin as well as response from muscles and internal organs. This region is also important for the perception of pain (Parkin, 1997; Eysenck and Keane, 2010). Some studies discovered that other parts of the parietal lobes may be involved with short-term memory (more details in Section 2.2).

The occipital lobes are mainly concerned with visual input processing. Weiskrantz (1986) suggested the phenomenon of blindness results from damage to the occipital cortex. This results in severe impairments of visual perception; however, there is often still some underlying visual input ability at an unconscious level (Willingham, 2004; Robinson-Riegler and Robinson-Riegler, 2008).

Every area of the human brain has specific functions and therefore different types of brain damage may cause different effects on cognition. The next section will discuss several examples of these effects observation of which provided a contribution to cognitive psychology.

# 2.1.2 The Effects of Brain Damage on Cognition

Milner (1966) observed the patient HM, who had suffered extensive lesions of the temporal lobes in both brain hemispheres caused by brain surgery to treat severe epilepsy. The effects of brain surgery had made HM lose his memory (Eysenck and Keane, 2010). However, HM was able to retain information for a few seconds despite being diagnosed with an incapability of holding anything in his memory. This meant that certain memory functions were still intact. On the basis of these observations, psychologists deduced that HM's lesion had caused severe impairment in his long-term memory, but no apparent impairment of short-term memory . This finding suggests a degree of independence between short-term memory and long-term memory (Asbcraft, 1998; Groome et al., 1999).

Warrington and Shallice (1969) added further findings that supported the results of Milner's study by observing patient KF. KF suffered impairments of short-term memory but retained an intact long-term memory (Robinson-Riegler and Robinson-Riegler, 2008; Wang, Lin, Lin, Chang and Cheng, 2008). This was an exact reversal of the situation of impairment of HM. Their observations supported the argument about separation of short-term memory and long-term memory: not only can they be separately impaired but they also most likely have separate storage mechanisms (Asbcraft, 1998).

The human brain is like the control center of cognitive functions. Different areas of the brain get injuries which cause different results and reactions for an individual. Therefore, the cognitive impairments of brain injury caused is a huge and complex topic. In this research, we only focus on TBI survivors with memory impairments. The next section will address memory, one important part of this research, in more detail.

# 2.2 Memory

The study of memory focuses on the memory process and memory systems. Memory process means that the human brain processes information to remember. Memory systems include three sub-systems: sensory memory, short-term memory and long-term memory. We call working

#### Chapter 2 Background

memory, short-term memory in this thesis. The distinction between them is based on the time-span of maintaining information. We will outline details of memory systems. However, before we explore memory systems we need to understand how the brain transfers information into memory; that is called the Memory Process.

# 2.2.1 Memory Process

Through cognitive processes, we can learn new experiences or have knowledge. To be recorded as a memory it has to pass through the processes for remembering otherwise the memory would be lost. Memory processes have four stages: (Groome et al., 1999; Robinson-Riegler and Robinson-Riegler, 2008; Eysenck and Keane, 2010; Willingham, 2004).

#### 1. Attention

Sampling the incoming information from different organs such as seeing the image from eyes or listening to the voice from ears.

### 2. Encoding

Transforming and working with the information as processed by visual sensory memory such as seeing the image.

#### 3. Storage

Consolidating encoded information with previous memories means repetition or integrating new information with stored memories.

#### 4. Retrieval

Accessing the stored relative information is repetition.

The whole process is important and failure of any step could result in forgetting (Wang et al., 2008). Therefore forgetting not only occurs in the storage step, it also may be the result of poor encoding at the beginning or unsuccessful retrieval. Using a computer analogy we can explain forgetting as like not being able to output a file we want. The reason may be that we input the wrong file at the beginning (improper encoding); the storing process was not complete (incomplete storage) or we output the wrong file (unsuccessful retrieval).

Memory process is difficult to observe. Therefore, psychologists have four ways of testing memory performance (Asbcraft, 1998; Groome et al., 1999; Eysenck and Keane, 2010). These are:

#### 1. Free recall

In free recall participants are presented with a sequence of items, which they are subsequently required to recall without any help and in any order they wish.

#### 2. Cued recall

In cued recall participants are also presented a sequence of items that they are required to recall, but this time with given reminders or Retrieval Cues which help to jog their memories.

#### 3. Serial recall

Serial recall is the opposite method of free recall. Participants are required to recall the test items from their own memories in the order items were presented.

#### 4. Recognition

In a recognition test the original test items are re-presented at the retrieval stage, and participants are merely to indicate whether or not they recognise them. School teachers apply this method to students' learning results.

In these tasks, recognition is easiest and serial recall is hardest. Free recall differs greatly from cued recall in the cue to trigger memories. These tests make psychologists consider if the memory has a separated storage system. The subsequent section addresses the Three Store Model of Memory which is the paradigmatic model to clarify each memory system.

# 2.2.2 Three Store Model of Memory

Everyone has the experience of remembering some things forever while some other things only for several minutes, which we call forgetting. This

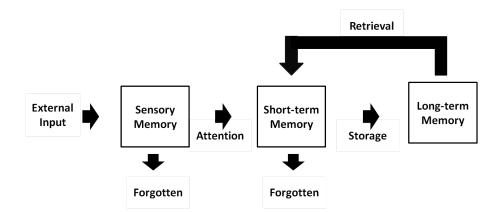
situation is further complicated by the discovery that our memories comprise not one, but several interrelated memory systems. The common word which is now used to explain multi memory systems is Model (Baddeley et al., 2009; Eysenck and Keane, 2010). The particularly influential version of the model is the three store model of memory model.

William James (1890) used a spatial analogy to describe memory; in his book - *Principles of Psychology* (James, 1890), he compared the recall of information to the way we look for a lost Object in our house. James had given a clear definition of two memory systems in his book:

'an object of primary memory is not thus brought back; it never was lost; its date was never cut off in consciousness from that of the immediately present moment.'

He noted some memories hold an awareness for a short time; hence he termed it as Primary Memory. In James's system, new items enter as primary memory, where it is either rehearsed to become a memory or forgotten. Rehearsed items enter secondary memory in the permanent storage. In here, secondary memory is not only a large repository for permanently storing but is also able to be retrieved for using (Parkin, 1997). Based on James's theory plus concepts of computer storages, Atkinson and Shiffrin (1968), proposed the Three Store Model of Memory (also know as Buffer Model), which represents the memory process as a series of Stores and each is a different stage in the processing of information. This model is based on the traditional concept of information-processing, where information passes through a series of systems chronologically (Parkin, 1997; Robinson-Riegler and Robinson-Riegler, 2008).

Figure 2.3 presents the structure of the three store model of memory. Sensory memory systems include a series of organs for receiving information, which is the first processing stage. The next movement is that information is passed on to the short-term memory system for temporary storing. Information in short-term memory will remain for several minutes then decay; rehearsal is the only way to maintain information in long-term memory system (Groome et al., 1999; Baddeley et al., 2009; Eysenck and Keane, 2010).



**Figure 2.3:** Three Store Model of Memory. Reprinted from *Cognitive Psychology: applying the science of the mind* (p. 137), by G. Robinson-Riegler and B. Robinson-Riegler, (2007), USA: Pearson Education Inc. Copyright 2007, by Pearson Education, Inc. Reprinted with permission.

### 2.2.3 Sensory Memory

The Atkinson-Shiffrin model defined the sensory memory as that the sense organs have a limited ability to store information about the world in a fairly unprocessed way for less than a second. The sensory memory includes the visual system which possesses visual stimuli (iconic memory) such as shape, size, colour and location (but not meaning), whereas the hearing system processes auditory stimuli (echoic memory) (Willingham, 2004; Wang et al., 2008). Iconic memory and echoic memory are what most researchers refer to as sensory memory systems in the psychology study because these are able to be observed by using equipment.

# Iconic Memory

Iconic memory is where the memory system receives visual input from eyes and holds it for a brief period of time (Willingham, 2004). Baddeley et al. (2009) used the example to explain iconic memory; it is like waving a light in a dark room and it leaves a trail. If the light is waved slowly, there would be a clear trail. The results show that when the image persists long enough to be remembered it becomes iconic memory, otherwise if the image rapidly fades it is forgotten. The existence of sensory memory had been experimentally demonstrated by George Sperling

in 1960 (Baddeley et al., 2009). He undertook an experiment where he presented his participants with a visual array of 12 letters in three rows of four for only 50 milliseconds, and then asked for recall. The results indicated that participants could report no more than four or five items. Sperling found the reason to explain this was that memories have gone before people can report them.

In order to avoid the problem of forgetting during reporting, Sperling used the same array but reduced the number of items to be recalled and did not tell participants in advance which items will be selected. Therefore, only one of the three lines was required to be reported by participants. In the meantime, he added a signal tone immediately afterwards when each line was presented; a high tone for top line, a medium tone for line two, and a low tone for line three. As usual, he did not tell participants in advance which line would be cued. This experiment named was Partial Report and the results showed participants could report nine items at most (Wang et al., 2008; Baddeley et al., 2009).

The difference between these two experiments is that in one the recall tone is presented. In the first experiment, participants relied on their short-term memory for reporting and the experiment was termed as a Typical Result (4.5 items). However, in partial reporting where the recall signal is given after the stimulus terminating after less than a second (50-100 milliseconds) the recalled number could reach Nine. Therefore, more reported items in the partial report show other memory systems are involved. Long-term memory is not the answer because no rehearsal occurs; iconic memory is now presumed as one of sensory memory systems (Parkin, 1997; Wang et al., 2008; Baddeley et al., 2009).

## Echoic Memory

In 1967, Ulric Neisser's argument described the hearing of intrinsically temporal events as echoic memory (Asbcraft, 1998; Baddeley et al., 2009). Neisser assumed that there is a Buffer for temporary storage, which is available in the auditory cognitive system. Cognitive psychology named that buffer as auditory sensory memory; it is also called echoic memory (Asbcraft, 1998).

Murdock conducted tasks related to echoic memory in 1967. He presented a long telephone number with visual and auditory presentation to participants and tested the pattern of errors. The result with visual presentation showed the rate of error increasing systematically from beginning to the end. Otherwise, with auditory presentation the last one or two items in the list are much more likely to be correct than are items in the middle of list; that is the auditory recency effect (Baddeley et al., 2009). Crowder and Morton (1969) carried out an extensive series of suffix effect experiments; they found a visual or non-speech auditory suffix (e.g., a buzz) does not disrupt performance whereas a spoken suffix does. Therefore, the *recency effect* from Murdock's task would be reduced/e-liminated by interferences which are proved by Crowder and Morton's experiments and termed as precategorical acoustic store (PAS) (Asbcraft, 1998; Baddeley et al., 2009).

Sensory memory has been studied extensively in visual (iconic memory) and auditory (echoic memory) modalities. For iconic memory, Sperling's experiment found the size of iconic memory is 4.5 items and participants could see more than they could repeat orally (Willingham, 2004; Eysenck and Keane, 2010). For echoic memory, Murdock's task found the auditory recency effect, establishes the advantage of the later items over items in the middle. This is termed the auditory recency effect. Furthermore, Crowder and Morton found precategorical acoustic store (PAS), which proposes that the auditory recency effect will be negatively affected by speech-based interferences. Overall, sensory memory occurs when organs are receiving stimuli; it is in the shallow level of memory, thus lasting no more than seconds (Robinson-Riegler and Robinson-Riegler, 2008).

# 2.2.4 Short-term Memory

In a memory system, short-term memory is the temporary storage of small amounts of information over brief periods. Another role of shortterm memory is passing on rehearsed information to long-term memory. Research is this area has used verbal material, and even when the stimuli are not verbal, people still will use verbal rehearsal to help retain

#### Chapter 2 Background

information in short-term memory. However, short-term memory is not limited to verbal material; it has been extensively studied for visual and spatial information (Groome et al., 1999; Baddeley et al., 2009).

James (1890) provided two definitions of short-term memory (in his book) discussed in Asbcraft (1998). He described the nature of short-term memory as the part of memory:

- 1. Where information is recalled from long-term memory.
- 2. Where information is part of our conscious experience right now.

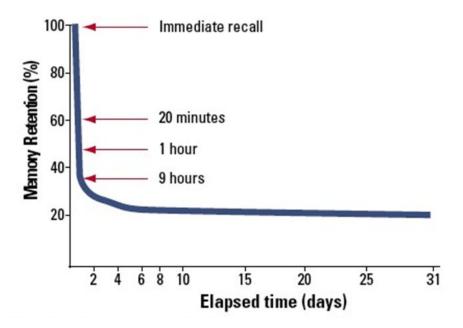
In brief, short-term memory is like a goalkeeper for processing information before it becomes long-term memory. In other words, the information is held by short-term memory longer, it gets more opportunities to be transferred into long-term memory. Therefore, the next sections discuss two factors related to information of short-term memory.

#### Rehearsal

Rehearsal is the process where information is kept in short-term memory through repetition (Robinson-Riegler and Robinson-Riegler, 2008). When the information is repeated each time that information is re-entered into short-term memory. Once people are aware of thinking about the meaning of that information which means it is successfully stored in long-term memory (Asbcraft, 1998; Groome et al., 1999; Robinson-Riegler and Robinson-Riegler, 2008).

Rehearsal has been widely used for a learning technique due to the significant results discovered on the rehearsal and forgetting curve. The forgetting curve was published by Herman Ebbinghaus, his discovery of the forgetting curve and spacing effect are important concepts in the study of cognitive psychology, see Figure 2.4 (Asbcraft, 1998; Groome et al., 1999; Robinson-Riegler and Robinson-Riegler, 2008). Figure 2.4 shows how information is lost over time if there is no attempt to retain it.

Spaced repetition is a learning technique that is based on rehearsal. Rehearsing information to be learned in order to keep them on the top of the forgetting curve (Gwern.net, 2015). It requires users to rehearse



**Figure 2.4:** Forgetting curve. Retrieved from http://peakmemory.me/2013/06/29/hermann-ebbinghaus-and-the-forgetting-curve/. Copyright 2013 by Peakmemory. Reprinted with permission.

information to be learned at different and increasing spaced intervals of time or a set uniform amount of time<sup>1</sup>. This technique has been successful in helping mild or moderate dementia patients remember particular objects names, daily tasks, information about themselves and other facts and behaviours (Camp and Schaller, 1989; Cherry and Simmons-D'Gerolamo, 2005).

# Magical Number

As noted previously, we know that short-term memory is the limited-capacity memory component for temporary information storage and manipulation. Some psychologists then started to study the limitations in short-term memory capacity. Simply a series of items (e.g., digits or letters) is presented to participants to read; then they are required to repeat them immediately, in the correct order. As there is no time delay, immediate memory span completely depends on short-term memory. Thus, this has become widely accepted as measuring the capacity of

<sup>&</sup>lt;sup>1</sup>Spaced retrieval. Retrieved from https://en.wikipedia.org/wiki/Spaced\_retrieval

short-term memory (Groome et al., 1999; Asbcraft, 1998; Baddeley et al., 2009; Eysenck and Keane, 2010).

Below is an example of a short-term memory test. The digit test involves reading each sequence then closing your eyes and trying to repeat the sequence back. Please use Figure 5.1 to do the digit span test. Read the four digits in the top row of the list below, then cover up the list and try to write them down. If you get them all right, then move on to the next row. Keep on going until you start getting some of the digits wrong. Your digit span is the largest number of digits you can get right in one trial.

# Digit span test

**Figure 2.5:** The example of digit span test. Reprinted from *Memory.* (p. 20), by A. Baddeley, M. W. Eysenck and M. C. Anderson, (2009), USA: Psychology Press. Copyright 2009, by Psychology Press. Reprinted with permission.

Most observations of the experiment show that when the sequences are short, people remember 100 percent of the digits correctly. When the number of digits increases, the rate of correct recall of digits decreases, and it will stop at around seven digits. Psychologists did similar studies with different stimulus types (e.g., letters), and the range of recall is around five to nine items (Groome et al., 1999; Willingham, 2004; Baddeley et al., 2009).

George Miller reviewed such data, and summarized that short-term memory is limited to Seven Items, Plus or Minus Two. In 1956, he proposed a paper titled 'The Magical Number Seven, Plus or Minus Two:

Some Limits on Our Capacity for Processing Information', discussed in Asbcraft (1998). He clearly indicated that there is a finite span of immediate memory, which is about seven items in length for many different kinds of test materials. In other words, immediate memory cannot process large quantities of new information and also preserve that information accurately.

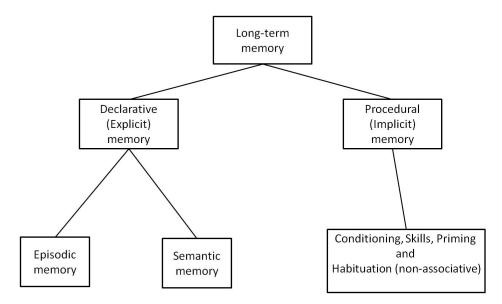
In fact, people are able to receive large amounts of stimulation in sensory memory systems; they also can retain vast quantities of processed information in long-term memory permanently. However, short-term memory (immediate memory) has a problem holding more than seven items. Short-term memory is like a bridge between sensory and long-term memory, but this bridge will close when more than seven items pass into short-term memory from sensory memory systems. Miller termed this phenomenon as Bottleneck (Asbcraft, 1998; Willingham, 2004).

As a result, Miller (1956) found a way to overcome this bottleneck. He proposed to group more complex items of more than seven digits into several units and that each unit should follow the rule of magic number  $(7 \pm 2)$ ; this process is named Recording.

# 2.2.5 Long-term Memory

In this section, we discuss that long-term memory enables storing information over long periods of time, which underpins the knowledge people have of the world and that it differs from person to person. L. R. Squire in 1989 proposed the taxonomy of memory (Robinson-Riegler and Robinson-Riegler, 2008; Baddeley et al., 2009). Squire indicated that long-term memory has two main components: declarative (explicit) memory and procedural (implicit) memory, as shown in Figure 2.6.

Figure 2.6 sketches the long-term memory structure. Declarative memory comprises episodic memory and semantic memory that denotes what people can consciously remember and intentionally recall. It includes two categories of memory: episodic memory, referring to personal experiences and events, and semantic memory, referring to knowledge of the world. In contrast, procedural memory involves situations in which



**Figure 2.6:** Taxonomy of Memory. Reprinted from *Memory.* (p. 10), by A. Baddeley, M. W. Eysenck and M. C. Anderson, (2009), USA: Psychology Press. Copyright 2009, by Psychology Press. Reprinted with permission.

some form of learning has occurred, but which is reflected in performance rather than through overt remembering, such as riding a bicycle or playing piano (Groome et al., 1999; Baddeley et al., 2009; Eysenck and Keane, 2010).

# Autobiographical Memory

Autobiographical memory consists of episodes recollected from an individual's life (Brewer, 1988; Groome et al., 1999; Conway, 2001; Baddeley et al., 2009). It certainly depends on the episodic and semantic memory systems. For semantic memory, autobiographical memory includes remembering facts about ourselves, such as our name, when we went to school, and where we live. For episodic memory, autobiographical memory involves recollecting an episodic experience, such as remembering coming to work today. Therefore, autobiographical memory helps us create a coherent representation of ourselves and our lives.

In 2000, Conway and Pleydell-Pearce (2000) proposed a model in which autobiographical memory is described as being constructed within a self-

memory system (SMS), which includes an autobiographical knowledge base and the working self. The autobiographical knowledge base provides information about the self can be categorized into three broad areas: lifetime periods, general events and event-specific knowledge. Lifetime periods refer to the general knowledge of what happened in different periods in an individual's life. General events mean events that happened within a specific lifetime period and event-specific knowledge is detailed information for an individual event. Therefore, these three areas are organised in a hierarchy within the autobiographical knowledge base and work together to construct the overall life story of an individual (Conway and Pleydell-Pearce, 2000; Conway, 2005). The working self is similar to working memory; it is a set of personal goals and concepts that are used to shape the individuals memory and concept of the self. It uses the cues to activate the autobiographical knowledge base to encode and recall the specific autobiographical memories (Conway and Pleydell-Pearce, 2000; Conway, 2005).

Autobiographical memory is difficult to study because there are no records from the time that the memories are initially encoded, and hence we cannot check their accuracy. There are three general methods of tackling the problem of studying autobiographical memory (Eysenck and Keane, 2010; Baddeley et al., 2009). One method is to use diaries, in which participants record events and subsequently try to remember them. This method can grab qualitatively rich content but is one that places great demands on the participants. A second approach is the probe memory, whereby autobiographical memories are associated with a cue word, that involve asking for memories from a specified life period. For example, asking for participants' evoked memories when they are shown a cue word - river, and then analyse the nature of their responses. A third method is to ask for memories associated with either a specific time period or major public event, which are termed flashbulb memories. For example, what did you do on the date of the 911 attack on New York? These methods aim to investigate autobiographical memory but all of them refer to semantic and episodic memory (Baddeley et al., 2009; Eysenck and Keane, 2010).

#### Chapter 2 Background

Although autobiographical memory evokes important events for us, sometimes we fail to remember due to forgetting over time or ageing for most people. Some people fail to remember their autobiographical events, which is caused by either brain damage or emotional stress. For brain damage, we know lesions in different areas of brain affect patients' memory function differently (Baddeley et al., 2009; Eysenck and Keane, 2010). A general forgetting of a memory is caused by wrong encoding, incomplete storage or unsuccessful retrieval. Here we will discuss two general causes of false autobiographical memory. One is post-traumatic stress disorder (PTSD), which is an emotional disorder caused by a dramatic and stressful event. For example, rape results in persistent anxiety and often accompanies vivid flashback memories of the event. Another is false memory syndrome that has resulted from therapists' claims to have uncovered forgotten memories of child abuse in their patients. Accordingly, we need to consider influences of PTSD or false memory syndrome of TBI survivors when discussing their autobiographical memory (Conway and Pleydell-Pearce, 2000; Conway, 2005; Baddeley et al., 2009).

Autobiographical memory consists each person as an individual because it involves a personal aspect of semantic memory and recollecting an episodic experience. Compliant with the theory of memory processing, generally people will remember their autobiographical memory accurately because they consciously pay a great deal of attention to processing information into long-term memory. However, autobiographical memory can be affected by emotional stress or brain damage (Conway and Pleydell-Pearce, 2000; Baddeley et al., 2009). In this section we focused on two causes of emotional stress: PTSD and false memory syndrome, both of which result in the false autobiographical memory. Therefore, we need to consider influences of these causes for TBI survivors and their autobiographical memories.

Previous research suggests that people with TBI fail to spontaneously use specific autobiographical memories to support planning in unstructured situation (Dritschel et al., 1998; Conway and Pleydell-Pearce, 2000; Conway, 2005; Knight and O'Hagan, 2009). Hewitt et al. (2006) found the intervention was effective at increasing the number of episodic mem-

ories recalled of people with TBI. The approach were used by verbal cues to trigger TBI survivors' memory, with a corresponding increase in the effectiveness of the plan and number of relevant steps in the plan. Hewitt et al. (2006) used the procedure with three phases. The first one was giving questions to TBI participants and taping their answer. Questions are relative to problem-solving (e.g., how would you organise a move to a new place to live?). The next stage was training participants and following detailed protocols. Participants were given the example of answering similar questions associated with the episodic memories of when this had been done in the past. Then when given another examples, this time they were able to give answers with episodic memories from their own personal experience. In the last phase participants were given the same questions after 30 minutes and asked to answer these questions again. The results showed participants' memory abilities can be trained by repeatedly using the same material. Relevant steps could jog their own specific personal experiences.

#### Retrieval

In this section, we focus on the retrieval of memory. Long-term memories are not only capable of storing huge amounts of information but also require effective retrieval. However, retrieval sometimes fails even given proper encoding and good storage. Thus, we need to understand how retrieval takes place before we can understand how retrieval fails.

The general principle of retrieval processes is that there is a progression from one or more cues to a target memory, with the aim of making that target available to influence ongoing cognition. In this process, the target refers to the fact that we are usually seeking a particular memory, such as a particular fact, idea or experience. When we search for such a particular memory, we usually have some idea of what we are looking for. For example, you knew you were searching for a talk at lunch that happened yesterday. This specification can be the words to link the relevant memory which is termed retrieval cue, or simply cue. The successful cues consist of the incidental context at retrieval and their match to those present at encoding, such as environmental, state, mood, and

cognitive context (Groome et al., 1999; Baddeley et al., 2009; Eysenck and Keane, 2010).

Sometimes we retrieve consciously what happened in times past but also are influenced by memory without being aware of it. Therefore psychologists have devised several tasks for testing retrieval. In general, all retrieval tasks are classified into two fields: direct tests and indirect tests (Groome et al., 1999; Baddeley et al., 2009; Eysenck and Keane, 2010). Direct tests focus on measuring retention of episodes, and usually use the spatiotemporal context as a cue. Context cues are especially important in direct tests such as free recall, but also are needed during cued recall and recognition. Free recall required participants to retrieve an entire set of studied items in any order without overt cues (Baddeley et al., 2009). In daily life we often retrieve information in no particular order, such as recalling the items on a grocery list that you left at home. However, everyone uses their own strategies for storing memory in some unconscious order. This test is sensitive to one's skills at organizing information at encoding and selecting strategies at retrieval. By contrast, cued recall provides additional cues, and very often requires particular items in memory. Cued recall tests tend to mimic situations when the memory recalled a particular item or experience in response to a cue. Cued recall requires context as a cue but context associated with specific information for focusing a search. Therefore, cued recall is often easier than free recall; it does not depend as heavily on retrieval strategies to recall items. Recognition tests are usually the easiest type of direct tests because they simply require a decision. The general example is that of teachers giving students an examination to test how much students understand. However, indirect tests measure the influence of the past with tasks that do not require reference to recalling. Context is not intentionally used as a cue, thus indirect tests provide evidence for the unconscious influence of experience on behaviour, and some studies also find the evidence fully intact in amnesic patients (Groome et al., 1999; Baddeley et al., 2009; Eysenck and Keane, 2010).

Everyone has experiences such as seeing a person on the street and wondering whether they have met them before. This situation is known

as recognition memory, which means we use our memories not to generate things but to make a decision about whether we have encountered a stimulus. The retrieval process of recognition memory is characterized by a single detection model, which provides a way of separating true memory from guessing biases. That is where we can recognize having seen a stimulus when it seems familiar to us, an assessment that occurs quickly and automatically. If we recognize a stimulus which has appeared recently, the process might demand more attention and time to distinguish it from a previous assessment of familiarity (Groome et al., 1999; Baddeley et al., 2009; Eysenck and Keane, 2010).

# 2.2.6 Memory and TBI

Section 2.1 presents a description of how the different area of the brain manage the different cognitive functions. A well-known case study in psychology describes the experiences of a patient refereed to as 'HM'. HM and his brain injury was used to prove the concept of different brain areas. HM had surgery to remove both of the medial temporal lobes of his brain to alleviate his severe epilepsy. After the surgery, which was successful to control his epilepsy, the removal caused anterograde amnesia. He was unable to develop any new events on his memory (Souchay and Moulin, 2007). Therefore, cognitive impairment caused by brain injury is a complex topic. In this research, we only focus on TBI survivors with memory impairments.

Many TBI survivors have memory problems, the short-term memory impairment is one of cognitive impairments in TBI and this research focuses on it. The short-term memory impairment means that short-term memory loses the temporary storage function thus the new memories will vanish before being stored into long-term memory (see Section 2.2.1). More specifically, the memory of TBI survivors will end in the short-term memory stage (see Figure 2.3). The solution is using an external memory storage instead of their own temporary storage (short-term memory). Then TBI survivors' memory could move to long-term memory which means they are able to retrieve the memories later.

It is an aim of the research to help TBI survivors to remember their

autobiographical memories. External memory storage can support TBI survivors with memory impairments of short-term memory. Combination of the rule of magic number (7 +/- 2) for their short-term memory and the retrieval requirements of long-term memory into an external memory storage for TBI survivors may produce an efficient memory aid. This research uses these concepts within the conceptual design described in Section 5. The next section will review the literature of the TBI situation in different aspects.

# 2.3 Traumatic Brain Injury

TBI is defined by the World Health Organisation (WHO) as 'An Acute Brain Injury Resulting from Mechanical Energy to The Head from External Physical Forces' (Feigin et al., 2010). In the UK, Australia and North America, the TBI numbers reported by hospital-based data is 200-300 people per 100,000 each year (Barker-Collo et al., 2008). Studies indicate that TBI is a leading cause of death and disability in adults throughout the world. TBI has serious and long-term effects on the lives of survivors, their families and friends, and community.

This section discusses four aspects of TBI: 1) the statistical data of New Zealand investigates the epidemiology on TBI, 2) the symptomatology of TBI, 3) the social issues that are caused by TBI, and 4) the existing treatments for TBI.

# 2.3.1 Epidemiological Literature

Full and accurate information about TBI incidence does not exist, because the estimates of TBI incidences are derived from hospitalization data, and official statistics that are prone to diagnostic and selection biases. Moreover, the inconsistent and inaccurate diagnosis of TBI is another reason for inaccurate figures (Kraus and Chu, 2005; Feigin et al., 2010, 2012). Even so, the results from these studies are shocking and worth taking into consideration. Kraus and Chu (2005) reported the brain injury incidence rates in 1996 in USA as 618 per 100,000 population. They further indicated the brain injury fatality rate as 14 to 30

per 100,000 population per year. WHO indicates TBI will be the third leading cause of premature death across all ages by 2020 (Feigin et al., 2010).

According to New Zealand's health database, incidence rates for the total population of New Zealand ranged from 226.9 per 100,000 in 1997/1998 to 349.2 in 2002/2003 (Barker-Collo et al., 2008). Besides, Barker-Collo et al. (2008) signified that the estimated cost of TBI on the health system is over \$100 million a year, and it is expected that figure will rise. Feigin et al. (2012) published the latest population-based study of the total incidence of TBI in New Zealand, which has increased to 790 per 100,000 population in 2010/2011.

In this section we concentrate on the epidemiology in New Zealand, and specially discuss the age, gender, ethnicity and causes of injury.

## Age

The study of Barker-Collo et al. (2008) reported the trends in head injury incidence in New Zealand in 2003/2004, the overall incidence rate of TBI for the New Zealand population was 226.9 per 100,000 in 1998/1999 increased to 349.2 in 2003/2004. In 2003/2004 data, the first high risk age is 15-24 years. The peak of the incident rate reaches 50 per 100,000 at age 15 years. Then the rate declines slowly but still remains around 30 per 100,000 until the 25 years age. After the age of 25 years, the rate decreases rapidly below 20 per 100,000 in those aged 35 and lessens 10 per 100,000 gradually up to 60 years age. Of interest is the second high risk age in the incidence rate, which is infancy (<5 years). The rate occupies over 40 per 100,000 in 2003/2004 data.

Four years later, Feigin et al. (2012) studied the head injury incident rate in New Zealand during 2010 to 2011. They did a population-based study in Hamilton (urban) and Waikato District (rural) with the New Zealand population census data for 2006 using age and sex structures as denominations. The total incidence rate of TBI per 100,000 was reported as 790 in 2010/2011. The most common two age groups of TBI are 0 – 4 years and 15 – 34 years. Comparing with the previous study the peak of age extends 10 years to 15 – 34 years. Moreover, the sec-

ond large age group varies from infancy in 2003/2004 to 5-14 years in 2010/2011.

TBI may lead to long-term cognitive dysfunctions which affect survivors, their family and community. Outcomes from TBI vary depending on the severity and location of the injury. Special equipment and rehabilitation are common requirements for post-TBI people for improving their cognitive functions. These services mean expense and time for at least two yeas for post-TBI survivors (Kuan, 2004). Therefore, results of the incidence age range is significant. Typically people in this age range are seen as contributors to society and the economy. The prevalence of TBI in this age range is therefore a major concern.

#### Gender

The study of Kraus and Chu (2005) reported that males are at approximately twice the risk of TBI compared to females in USA. However, the gender ratio varies with age. The incidence rate of infancy (<5 years) is similar. After this, the rate increases faster in males resulting in an incidence over double that in females, particularly obvious during adolescence Feigin et al. (2010).

There are similar patterns discovered in the work of Barker-Collo et al. (2008) in New Zealand during 2003 to 2004. The overall population shows the incidence rate of males was significantly higher than for females. The difference is small in infancy (<5 years) and after 50 years age between the males and females. Nevertheless the rate of incidence in males is slightly higher than females. The significant difference occurs in the age group 15 – 30 years. At the age of 15 years, the peak for the incidence rate in males almost reaches 80 per 100,000 but the rate of females is only a quarter of males. After this, the ratio keeps the same pattern as usual but the difference sharply reduces to 10 per 100,000 on average between males and females. After 70 years, the rates for males and females presents almost the same.

The study of Feigin et al. (2012) discovered similar results as work by Barker-Collo et al. (2008) and Feigin et al. (2010). The overall population of the incident rate for males was over 1.7 times more than for females.

The difference is small in infancy (0 - 4 years); it is getting bigger and a marked gap appears at 15 - 34 years age. After the age of 35 years, the gap shrinks gradually until the age group of older than 65 years, the gap nearly vanishes.

As discussed above, male adolescents between 15 - 34 years old are the highest risk group. We investigate the next factor, that is the ethnic origin associated with the age and the gender for TBI.

### **Ethnicity**

According to the 2006 New Zealand census data, the ethnicity group in New Zealand includes European, Maori, Pasifika, Asian and other. New Zealand's Maori population shows similar patterns of TBI with regard to males and females (males:90%, females:60%), with the peak incidence occurring in those aged 15 to 25 years old. However, the overall incidence of TBI in Maori (689/100,000) and Pacific Islander (582.6/100,000) populations exceeded those for the remaining population (435.4/100,000). Moreover, Maori males experience a second peak from 30 to 34 years of age that was not apparent for the wider population. This phenomenon was first observed in the 2003/2004 data (Barker-Collo et al., 2008).

In 2010/2011 data, Feigin et al. (2012) observed a similar distribution with regard to the Maori population of TBI. The total incident of TBI in Maori people is significantly higher then all other ethnic groups. TBI incidence in Maori people older than 35 years is larger than in individuals of the same age in other ethnicity groups.

#### Causes of TBI

The most common causes of TBI are motor vehicle accidents and interpersonal violence. Other causes include industrial or sporting accidents, falls, assaults, and bicycle accidents. Feigin et al. (2010) stated that the alcohol is a major cause of TBI resulting in falls, motor vehicle accident and assault. Kraus and Chu (2005) studied the population-based in USA that supported that alcohol is the main cause of TBI.

Feigin et al. (2012) proposed four most common causes of TBI for New Zealand in 2010/2011 data; they are falls, exposure to mechanical forces, transport accidents and assaults. Fall is the main cause of TBI in infancy (76%) and in adults older than 65 years (82%). Exposure to mechanical force is the most common cause in children aged 5 – 14 years (30%) and adolescents (48%). Transport accidents account for most TBI case in people aged 15 – 64 (25%). In adolescents (15 – 34 years) assault is the major cause of TBI (28%). Unlike previous studies, falls are the main cause of TBI in children whereas transport accidents and assaults are common causes of TBI in adolescents.

## 2.3.2 Symptomatology

The brain injury may damage nerve cells, which not only affect physical abilities but also a wide range of cognitive functions (Gentleman, 2001). These cognitive dysfunctions could be diminished by some medical treatments or through long-term rehabilitation but most of them exist in the TBI survivors' life forever. This section will discuss symptoms resultant from TBI and how they affect TBI survivors' lives.

A TBI can be classified as mild, moderate or severe. The research of Feigin et al. (2010) showed that 70 – 90% of people with TBI have a mild injury and 5 – 20% have moderate or severe injuries, irrespective of age. They further indicate that 40 – 80% of people with mild TBI suffer post-concussive symptoms which manifest in physical, cognitive, and behavioural difficulties. Medicines and therapy can reduce the physical or behavioural difficulties but not the cognitive issues. As noted, the cognitive difficulties include the inability to concentrate and impaired problem-solving ability. The thesis of Kuan (2004) indicated that 50% of people with moderate TBI report concentration and memory difficulties, and they become irritated very easily. Some noted that these problems persisted even two years post-TBI.

Table 2.1 describes each recovery level from TBI with recovery time and symptoms (Kuan, 2004). As can be seen, memory impairment is a symptom across all levels. However, at the severe level of injury, the first concern for those people is physical treatment and usually involves a long

**Table 2.1:** Recovery statistic and symptoms for TBI.

Level	Recovery rate	Recovery time with	
		symptoms	
Mild	90% will recover fully after 6 months	4 months:	
		Headache and	
		Memory impairment	
Moderate	38% will recover well after 3 months	1 month:	
		Fatigue, Memory impairment	
		and Difficult concentrating	
		3 months:	
		Headache and	
		Difficult remembering	
Severe	Most will require a long-term recovery plan for their		
	physical or psychological ailments memory impairments		

recovery time. Therefore this research excludes these severe patients. Kuan (2004) found that 54% of people with moderate TBI cannot return to their previous lives/works due to memory dysfunction.

Gentleman (2001) concluded common neurology symptoms include spasticity, language deficits, swallowing impairment, visual disturbance, hearing loss and anosmia. Spasticity and swallowing could be controlled by use of oral drugs or diet changes. Others can be improved by rehabilitation. However, the impaired cognition after TBI mostly affects attention, memory function, perception, information processing, problem solving ability and executive function. According to studies (Gentleman, 2001; Kuan, 2004), the natural recovery from cognitive deficits is in the first six months after injury, but the recovery can continue more slowly for up to two years.

Ogden (2012) recorded her experiences in her book – *Trouble in mind:* stories from a neuropsychologist's casebook. She observed patients when she was assisting or treating patients with brain injury. Their behaviours, emotions, or thinking abilities had become disordered, disrupted, or unusual as a result of brain injury. Fatigue and headache are the common symptoms when people suffered brain injury.

Vani Rao and Spiro (2005) indicated the fatigue is the symptom many people suffer most after brain injury. Fatigue affects the recovery course and disrupts rehabilitation in people who survive TBI. Fatigue, the heaviest burden for TBI survivors, usually comes on when they find themselves growing stressed, anxious or trying to do more than one task at once. At that time, rest is the most effective solution to ameliorate the fatigue. According to the interview we did (discussed in Chapter 4), most TBI-participants reported they have to give up on the idea of getting back to the 'old them' because of fatigue. Regular rest is an essential part of their routine.

Headache is another common symptom presented by TBI survivors, proved by the work of Ward and Levin (2005). They found approximately 80% of TBI survivors with headaches will naturally improve by the end of the first year. However, there are more than one-fifth of people with TBI whose headaches fail to be solved, thus turning to a chronic problem. They also declared that headache is a complication of TBI with other symptoms: psychiatric symptoms (anxiety, depression, irritability, mania and difficulty concentrating), sleep disturbances, seizures, dystonia, tremor, vertigo, tinnitus, hearing loss, blurred or double vision and so on.

People with TBI must not only overcome physical impairment to regain their mobile ability but also fight psychological symptoms. Sometimes these symptoms change TBI survivors's lives forever. Chapter 4 will report the results from the interviews we conducted regarding the impacts of TBI.

#### 2.3.3 Social Issues

TBI affects not only the survivors themselves but also the people around them. The first impact hits their family directly. This impact on the family can be categorised into three broad phases, the acute phase, the rehabilitation phase and the reintegration phase (Cavallo and Key, 2005). The acute phase focuses on the medical stabilization of the survivor which demands time and energy consumption for the family. Secondly is the rehabilitation phase where the family roles are reorganized. Someone starts to be a caregiver taking care of their TBI relative. According to the results of the interview users study (discussed as Section 4.5), the

person usually is a female family member such as the mother, wife or daughter. The reintegration phase means the individual recovers from the brain injury and attempts to return as much as possible to a level of independence and productivity in the community. In this phase, the family structure already reorganized changes for settling down the TBI survivors in the family that usually take several years.

Here, we focus on the issues in TBI accompanied with memory problems. Knight and O'Hagan (2009) identified the social problems which are caused by autobiographical memory deficits. Their study examined the autobiographical memory of TBI participants and their ability to recall memories associated with famous names. Participants were first asked whether they recognized each name as being of a famous person and could state the individual's achievement. For those names they correctly identified, they were asked to recall a memory associated with the person. The findings suggest that participants are able to recognize most of the famous names of persons who are referred to in social conversation or the media (Knight and O'Hagan, 2009). In other words, their semantic memory for knowledge may be reduced but it does not affect their recollection. However, they had difficulties to recall general or specific personal memories of the person whose names they recognised. It should be noted that participants were consistently impaired in the ability to provide autobiographical episodic memories of events that occurred, before, during and after the injury. The profound effect on persons with TBI is difficulty in new learning or communicating with others. The circumstance makes TBI's interpersonal exchanges frustrating and leads to increased social isolation.

#### 2.3.4 Treatment

The human brain still is a mystery to the current medical researchers. The reason is not only does the brain have a complex structure with the muscles, vessels and neural network but also the experiences on human clinical trails are restricted by ethics. Therefore, medical treatment usually takes a long time to observe its effectiveness on the brain injury patients. Margaret Brimble got New Zealand's top science award, the

Rutherford Medal, in 2012, for her works on a TBI drug that has so far proved effective in reducing inflammation and injury-induced seizures in USA (Priestley, 2012).

For TBI survivors, rehabilitation is the general treatment. Gentleman (2001) summarized the three basic approaches used in rehabilitation: 1) reducing disability and maximizing activity, 2) acquiring new skills and strategies to reduce the impact of disability, and 3) altering the physical and/or social environment to minimize the handicap from a given disability and maximize participation. Overall the rehabilitations are of two major types: physical rehabilitation and cognitive rehabilitation.

Physical rehabilitation can improve and help TBI survivors regain their mobility. The improvement can obviously be witnessed (Kuan, 2004). Cognitive rehabilitation is more complex and comprehensive than the physical rehabilitation due to intervention which needs to be individualized for each TBI survivor to fit their psychological condition (Gordon and Hibbard, 2005). It is also difficult to observe the improvement compared with the physical rehabilitation. Jonathan M. Silver and Yudofsky (2005) studied psychological therapies that they can improve TBI survivors' psychiatric disorders (e.g., depression, pain disorder, and obsessive-compulsive disorder). The goal of these therapies covers the individual, behavioural, family therapy and the symptoms of TBI. Pollack (2005) further clarified that cognitive rehabilitation should include psychiatric treatment. Because TBI requires not only the survivor and family to sustain the giant impact from the injury but also they have to accept this change forever.

This section discusses the relative information that investigates the TBI situation in New Zealand; then moves to explore the symptoms coming with TBI from different aspects: real-world patients and the neuropsychological casebook. The following section describes the family changes due to TBI and the social issues which are caused by TBI with memory impairments. According to the previous studies, we understand there are no treatments guaranteed to cure TBI or its symptoms. Reducing symptoms is the goal of these treatments or rehabilitations.

The next section discusses Alzheimer's disease, which has some simi-

larities in memory symptoms to TBI but they have different causes and different long-term effects.

# 2.4 Comparing TBI with Alzheimer's Disease

Alzheimer's disease (AD) is a progressive irreversible brain disease that impacts on daily living through memory loss and cognitive changes. The American Health Assistance Foundation indicates that the common early symptoms of Alzheimer's disease include confusion, disturbances in short-term memory, problems with attention and spatial orientation, changes in personality, language difficulties and unexplained mood swings Souchay and Moulin (2007); Bright Focus Foundation (2011). In addition, there are similarities in memory symptoms for TBI survivors and AD patients but there are different causes and results for them.

In this section, we discuss the memory dysfunctions which accompany Alzheimer's Disease in comparison to those of TBI. For people with AD, a new collection of digital aids have been developed by lifelogging technology, location network and multi-modal sensors. We will argue in Section 3.2.1 that systems for people with AD that support their memory impairments are not suitable for people with TBI.

**Table 2.2:** Comparisons of AD and TBI.

	AD	TBI
Risk age range	60 years and older	15–25 years old
Nisk age range		young adult
Population (2011)	47,000	88,000
Memory symptom	Dementia	Memory impaired
Aims of memory aids	Living functions	Cues retrieval

Table 2.2 shows comparisons of AD and TBI in risk age range, population, memory problem and aims of memory aids. AD normally occurred to the older people over 65 years of age, TBI happened on the adults of 15 – 25 years old. In the 2011 demographic of New Zealand, AD occupied 1% of population<sup>2</sup> and TBI 2%. As TBI injury is a brain injury, memories could

<sup>&</sup>lt;sup>2</sup>Dementia: continuation of health and ethnic inequalities in New Zealand. Retrieved from https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019

revive or improve with medication, surgery or therapy. However, AD is caused by brain cells retrograding or dying and cells cannot revive. AD patients can use medication to slow the progression of the disease and delay cognitive decline (Bright Focus Foundation, 2011). Overall, AD patients cannot recover. A digital memory aid only works for mild AD patients (Oriani, Moniz-Cook, Binetti, Zanieri, Frisoni, Geroldi, De Vreese and Zanetti, 2003) (see in Section 3.2.1). The purpose of a digital aid for AD is assisting the living function. A digital aid for TBI focuses on reminding them with context cues. According to the above discussion, the solutions for AD are not solutions for TBI.

## 2.5 Discussion

Based on the summary of previous sections, a concept for memory was developed, called 'Memory Box Concept'. This section presents this concept and uses it to explain differences of the memory impairment for TBI and AD.

# 2.5.1 Memory Box Concept

In the memory box concept, an event represents a box which is only filled with the related data of the event. The memory process is like a production process. This process has three stations: Station 1 (sensory memory), Station 2 (short-term memory) and Storage Room (long-term memory). These stations are created and managed by our brain, and cannot be repaired by any surgeries or medications. The goal of Station 1 and Station 2 is filling and checking. Each station has a restricted time to achieve the criterion for filling. If a box cannot get passed to the next station, it will be abandoned automatically. There is only one rule for the filling of the box which is that material has to be related to each other and for one particular event. Thus, same event data can be stored into the same box. The memory ability is about the filling speed at every station. Figure 2.7 metaphorically depicts the overall process of the memory box concept.

When people sense the data it means the memory process constructs a

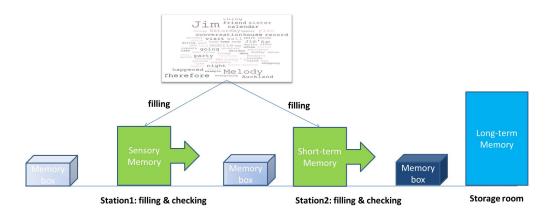


Figure 2.7: Memory box concept.

box. The box is delivered to Station 1. As it fills in with the related data to the required quantity of the box (or over) then it will be pushed into the next station. The box has to be filled up again before leaving Station 2. Due to the limited time of filling, speeding up the filling procedure is the only solution. At the station it will start to fill in with the same event data which is called Rehearsal as mentioned in Section 2.2.4. If the rehearsal produces specific rhythm it can enhance the effectiveness of the filling process. This kind of rhythm is named Spaced Repetition as presented in the Section 2.2.4. Once the box is filled up then the process will pass it to Storage Room to preserve.

## 2.5.2 Memory Box Concept with TBI

As previously mentioned, lesions in different areas of brain affect the different TBI survivors' memory functions. However, some studies suggested that working memory (a.k.a. 'short-term memory') impairment is a core cognitive deficit in TBI (McDowell, Whyte and D'Esposito, 1997; Mcallister, Flashman, Sparling and Saykin, 2004). They did neuropsychological tests to show that impairments in short-term memory are a core component of the cognitive deficits associated with TBI. Hence, this research focuses on short-term memory impairments in people with TBI.

The memory box concept of TBI with memory impairments leads to the process producing a damaged box at the very beginning. Figure 2.8 shows it as a box with a hole on the left. A damaged box implies that

#### Chapter 2 Background

the TBI survivors have difficulty to concentrate. The box can be filled in and pass Station 1 checking point because the hole does not affect the filling quantity. This proves the sensory memory function of TBI survivors is working just fine. With the quantity of filling increasing, the problem shows up at Station 2. The hole makes the box unable to be filled up. In addition, each station has a restricted time for filling process. In the end, the filling process of the box can never be completed and the box will be discarded automatically.

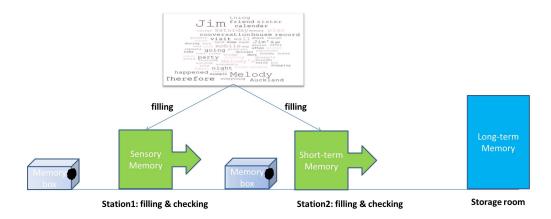


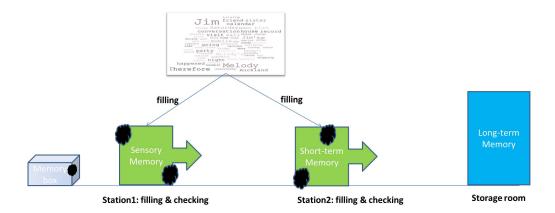
Figure 2.8: Memory box concept for the memory impairments of TBI.

As shown in Figure 2.8, the process of box ends at Station 2. Station 2 – short-term memory is the main problem in the TBI survivors' memory process.

# 2.5.3 Memory Box Concept with AD

The memory box concept of AD is presented graphically in Figure 2.9. Two points are worth making about Figure 2.9: a damaged box and two dysfunctional stations. It implies that the AD patients not only have the external problem (a damaged box) but also the internal problem (two dysfunctional stations).

A damaged box means AD patients have concentration difficulties. Two dysfunctional stations indicate AD patients cannot fill related data into the same box. Therefore, these impairments affect the filling processing resulting in a box that cannot pass Station 1 (see Figure 2.9). It costs AD



**Figure 2.9:** Memory box concept for AD.

patients the entire ability of forming new memory. However, the Storage Room is the only undamaged place in this production process. It explains why AD patients are not able to remember their present but can remember their past, these past-experience memories are preserved well in Storage Room.

The memory box concept of TBI and AD, unambiguously explains the different situations responsible for their memory impairments. The solution for TBI survivors is fixing the box and passing it to Station 2 (short-term memory). It is simpler than the problems of AD patients. AD patients need to repair the box and also recover the filling function for the first two stations. Therefore, the lifelogging technique is a suitable approach to support AD patients' memory. It can save all memories for AD patients, which replaces Station 1 and 2.

# 2.6 Summary

This chapter contributes to answering the first research question identified in Section 1.3.1, i.e., "What types of memories do TBI survivors remember or forget?" by reviewing the cognitive psychology research to understand TBI survivors' memory impairments. The answer included the memory process and types, and the literature of TBI, which aims to explore differences of processing memory in the average people and TBI survivors. We also studied AD which has similarities of memory impairments, and compared with TBI. In the end, we developed the Memory

### Chapter 2 Background

Box Concept to describe the memory process and differences in AD and TBI.

Memory Box Concept with TBI focuses on short-term memory impairment in TBI and explains how short-term memory is a cause of TBI survivor's memory dysfunction. Short-term memory dysfunction also affects TBI survivors in so that they could remember regular events (i.e., everyday tasks) but not every event that occurs such as meeting someone in the supermarket. Therefore, TBI survivors have trouble to remember these irregular events. These irregular events are contributors to their autobiographical memory. Autobiographical memory defines us and it is the key that refers to past experiences and knowledge an individual has. Therefore, many digital memory aids are designed to help people remembering their autobiographical memory, including average people, AD patients and TBI survivors.

The next chapter will discuss the existing digital memory aids for different types of people with their memory problems. We also discuss the positive results of digital aids for improving the memory ability for TBI and AD.

# Chapter 3

# Related Work

This chapter addresses the second research question: "How can a mobile system help TBI survivors remember?" and also contributes to answering the first research question: "What types of memories do TBI survivors remember or forget?". The chapter reviews the related works, which aims to help users improve their memories. The related works are aimed at AD patients, average people and TBI survivors.

This chapter is divided into two areas: the research of cognitive psychology and the research of computer science. It starts by reviewing cognitive psychology's research that aims to investigate how digital aids affect the memory impairments of TBI survivors in Section 3.1. It also includes the experiences of TBI survivors with mobile technology. The chapter then considers the computer science's research on existing digital aids aimed at improving people's memories. Section 3.2.1 reviews the digital aids specialized for AD patients for their memory dysfunctions. Section 3.2.2 inspects the digital aids that focus on helping TBI survivors with their memory problems. Section 3.2.3 analyses the digital aids that are designed for people with their autobiographical memory. The comparison of works is mentioned in Section 3.3. The chapter concludes with a summary in Section 3.4.

# 3.1 Research of Cognitive Psychology

This section looks into the research of cognitive psychology that aim at using digital aids for TBI survivors to improve memory ability.

### 3.1.1 Digital Aids for TBI

TBI survivors sustain memory dysfunctions affecting their living independence such as forgetting to turn off the oven before they leave the house. Hewitt et al. (2006); Knight and O'Hagan (2009) studied how TBI survivors can use memory aids to improve these problems. Attention has centred on two concepts for digital aids: the portable device and the reminder of everyday tasks. Following sections will discuss work representing these two concepts.

#### Portable Device

Wilson, Evans, Emslie and Malinek (1997) showed that four problems occur when people with memory impairments used memory aids:

- · forget to use them
- are unable to programme them
- use them in an unsystematic way
- · are often embarrassed by them

Studies (Wilson et al., 1997; Tracy K. Wade, 2001; Glisky, Wilson and Kapur, 2004) discovered that portable devices with specialized software can solve the above problems. NeuroPage is the successful evidence as reported by Wilson et al. (1997). They examined the effectiveness of NeuroPage in improving everyday memory problems of people with organic memory impairments see Figure 3.1. NeuroPage is like a normal pager, which has built-in specialized scheduling software; and the user can enter their reminders or cues from a computer. NeuroPage uses audible alarms or vibrations with an accompanying explanatory message for the reminder. For the entire process no further human interfacing is necessary to remind users. Therefore, NeuroPage was the first proven portable device as a memory aid for helping people with memory impairments in the early 90's.

Along with rapid advances in information technology, mobile devices have become the mainstream of portable devices. The definition of a

### 3.1 Research of Cognitive Psychology



Figure 3.1: Example of NeuroPage screen. Reprinted from Assistive Technology For Cognition (ATC), by Mark Harniss, Kurt Johnson, & Pat Brown, 2015, Retrieved from http://cognitivetech.washington.edu/presentations/summer\_institute\_04\_files/textmostly/slide14.html. Copyright 2015 by Assistive Technology For Cognition (ATC). Reprinted with permission.

mobile device is a small size computer which aims to save data and is able to be carried around, such as personal data assistants (PDA) and smartphones<sup>1</sup>. Several studies (Tracy K. Wade, 2001; Glisky et al., 2004; Hart, Buchhofer and Vaccaro, 2004) all showed positive outcomes from using a mobile device as a memory aid for an individual with memory impairments. Researchers summarized three features of the mobile device which satisfied requirements of use as a memory aid (Wilson et al., 1997; Tracy K. Wade, 2001):

- the mobile device is a convenient and efficient device for storing and retrieving information,
- the mobile device integrates multiple functions, not used solely as a memory aid, and
- using mobile devices is part of everyday life.

Further, Hart et al. (2004) used a survey study to investigate TBI survivors experiences and attitudes regarding the use of mobile devices for their memory impairments. They found TBI survivors use mobile devices

<sup>&</sup>lt;sup>1</sup>Mobile device definition. Retrieved from https://en.wikipedia.org/wiki/Mobile\_device

as a memory aid for Remembering Things People Tell Them and an organizational aid for Keeping Track of Things They Need. TBI survivors reported the use of mobile devices can help them be more independent and efficient in their everyday tasks. Using a mobile device as a memory aid helped them in a more timely fashion. The study of Hart et al. (2004) clarified that mobile devices are acceptable or desirable as memory aids for TBI survivors. A lot of research work has been focused on mobile devices in rehabilitation programs to support TBI survivors with memory deficits.

## Reminder of Everyday Tasks

In subsequent years numerous studies were carried out on the effectiveness of TBI survivors using mobile devices to improve their everyday tasks (Ferguson, Friedland and Woodberry, 2015; Stapleton, Adams and Atterton, 2007; DePompei, Gillette, Goetz, Xenopoulos-Oddsson, Bryen and Dowds, 2008; Svoboda et al., 2010; Svoboda and Richards, 2009). The focus of these studies is TBI survivors using the reminders function on the mobile device to complete everyday tasks. The advocated theory of these studies is the cued recall of the memory process. The cued recall is when the memory recalled a particular item or experience in response to a contextual cue associated with specific information (see Section 2.2.5).

The study of Ferguson et al. (2015) required TBI participants to enter required pre-tasks into the calendar with a prompting alarm of five minutes on the mobile device. When the alarm prompted, they were asked to complete the task within the certain time. The results of Ferguson's investigation supported the positive gains of using mobile device-based reminder prompts which can help TBI participants to complete the pre-tasks punctually. In this study, they further investigated the caregiver strain and quality-of-life. The results explored using mobile devices can reduce TBI participant reliance on caregivers and enhance more independent ability of everyday activities. The sutdy of Stapleton et al. (2007) also showed similar results for using mobile devices which benefit TBI participants and caregivers. They discovered more positive outcomes

appeared from the use of reminder functions on a mobile device in TBI survivors who are in receipt of 24-hour care. DePompei et al. (2008) published a paper showing that mobile devices can enhance the independence of people with traumatic brain injury. They executed trials and follow-up studies to observe the accomplishment rate of students with TBI or Intellectual Disability (ID) using the mobile device. Overall results show a positive performance, and using mobile devices can increase independence of people with TBI or ID. These studies identified the reminders function on a mobile device is a cost-effective and accessible tool for TBI survivors with memory impairments.

These studies are based on the cognitive psychology research, which showed that mobile devices benefit TBI survivors to improve their memory deficits and enhance their independence in their everyday tasks. The next section will inspect the existing digital aids for supporting AD patients with their memory dysfunctions, improving the quality of lives for TBI survivors and an augmented memory system for autobiographical memory.

# 3.2 Research of Computer Science

This section analyses the digital aids that are designed for helping people with AD, improving memory ability or augmenting autobiographical memory. The focus of the analysis in these digital aids are the functionality, the data structure and interface performance.

# 3.2.1 Digital Aids for AD

Existing digital aids for AD are of two main types: Memory-based Supports and Location-based supports. Table 3.1 summarizes the digital aids for AD. All aids have one aim which is helping AD patients to regain a sense of normalcy in their lives and to reduce the caregiver or family load. Most memory supports use the lifelogging technology to record personal experiences, and then these recordings are presented to the person with AD to help them with their everyday tasks (Lee and Dey, 2007, 2008). The locating supports use the location network or multi-

### Chapter 3 Related Work

modal sensors to track individuals with AD who lose orientation or have difficulty remembering direction (Zagami, Parl, Bussgang and Melillo, 1998; Giraldo, Helal and Mann, 2002). The following sections address these two types of digital aids.

Table 3.1: Digital aids for AD by types.

	Help with	Digital aids
Memory-based support	Retrieving autobiographical memory	Lifelogging technology
Location-based	Locating AD patients' location	Personal location unit
support	then provides assistance	mPCA

### Memory-based Supports

Lifelogging technologies automatically capture an overwhelmingly large amount of data for people with AD; they are difficult to review and engage with vast amounts of content. Lee and Dey (2008) designed and improved a lifelogging system to follow a three-step process of automated passive capture, hybrid cue selection and progressive revealing of cues review.

They designed their system based on Microsoft SenseCam which combines voice recording and Global Positioning System (GPS) logger for capturing photographs, ambient voice and sounds, and location information. It can record a vast amount of data that could potentially be used as cues to recollect an experience.

The next step is filtering the lifelogging data and extracting the cue to trigger recollection. Lee and Dey (2007) characterized good memory cues as recognizability, distinctiveness and personal significance which are effective for triggering recollection. They designed the system with these characters of memory cue and they also found four types of cues: person (e.g., daughter, grandchildren), object (e.g., birthday cake, Christmas gift), place (e.g., the dining room, the museum) and action (e.g., driving home, playing the piano). The system accepts that the experience can be constructed by more than one or two types of cues. Although the system uses a hybrid cue selection strategy, humans are better at identi-

fying these characteristics of cues. Thus, they designed CueChooser for the caregivers to determine the final selection of lifelog data to construct the memory cue.

The final step focuses on persons with AD using the system to refresh and exercise their memory of recent experiences in their lives without caregivers' helps. MemExerciser is designed for people with AD who can recollect associated details without repeated help from a caregiver. This can increase the independence of people with AD, which also reduces the burden of the caregiver.

Lee and Dey (2008) designed a system that utilizes lifelogging technologies to record experiences. The system focuses on helping people with AD to overcome memory impairments. Most AD people struggle with long-term memory loss, which means they would lose their personal experiences and the general knowledge about the world. Thus these systems record whole experiences of the person with AD for them to review then recall the memories. The previous section noted that people with TBI more frequently have short-term memory problems. Short-term memory impairments mean that people still have general knowledge about the world but they cannot remember (i.e., learn) new information. This system therefore helps a person with AD to recall their long-term memory but it may not be appropriate for individuals with TBI who may only require help with their short-term memory.

# Location-based Supports

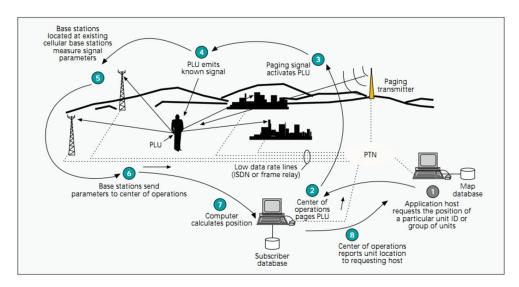
Locating supports aim to help the caregiver or family to locate a person with AD or assist persons with AD to find the correct location. This section reviews two digital aids of location-based supports for AD patients.

Zagami et al. (1998) used location network technology to design a personal location unit (PLU) – bracelet for people with AD to wear. If the person with AD gets lost, then the caregiver can activate the bracelet to locate them.

Figure 3.2 shows that the location network starts when the caregiver requires the position of individual with PLU then the centre of operation (2) uses a paging signal (3) to activate the personal location unit (PLU)

#### Chapter 3 Related Work

which activates and transmits a signal (4). The surrounding stations receive the PLU signal (5) then perform simple processing and send the data to the centre of operations (6). The centre of operation calculates the position (7) and sends the results to the caregiver or emergency response agency (8).

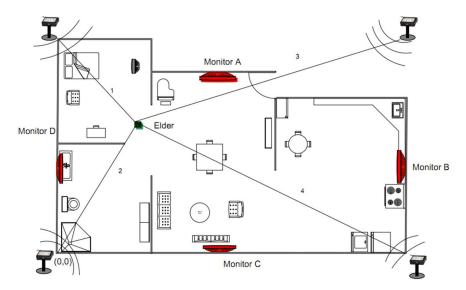


**Figure 3.2:** Person location/tracking using the location network. Reprinted from "Providing universal location services using a wireless E911 location network", by J. M. Zagami, S. A. Parl, J. J. Bussgang and K. D. Melillo, 1998, *IEEE Communications Magazine*, 36, p.70. Copyright 1998 by IEEE Communications Magazine. Reprinted with permission.

Giraldo et al. (2002) present a different locating support – mPCA. mPCA is a hybrid electronic aid for assisting individuals with AD to regain independence in their lives. mPCA uses the smart phone to interact with the sensors in the house. mPCA has four sensors for locating the person with AD who has the smart phone and four monitors for capturing attention, recording person's activities or playing teaching video.

mPCA captures the attention of the person with AD before it exercises any assistance. It is based on locating support then assisting the person with AD to overcome difficulties in their daily lives. Thus, mPCA has four assistances:

1. A reminder for critical tasks (e.g., take medications).



**Figure 3.3:** Smart elder house. Reprinted from "mPCA–A mobile patient caregiving assistant for Alzheimer patients", by C. Giraldo, S. Helal, and W. Mann, 2002, *First International Workshop on Ubiquitous Computing for Cognitive Aids (UbiCog'02)*. Copyright 2002 by First International Workshop on Ubiquitous Computing for Cognitive Aids (UbiCog'02). Reprinted with permission.

- 2. A teaching tool to perform step by step tasks (e.g., demonstrate using microwave oven).
- 3. A location tracking mechanism (e.g., locate the medicine).
- 4. A monitoring tool to record the activities performed by the person with AD (no interaction with the person with AD).

Existing digital aids for AD aims to help AD patients regain a sense of normalcy in their lives and reduce the caregiver or family load. There are two types of aids: memory and locating supports. Lifelogging technologies automatically capture everything for supporting AD patients' memory. Then this technology relies on the caregiver selecting the valuable data for emphasising AD patients' memories. Locating supports use the location-based technologies for the caregiver or family to trace the location or provide assistance to the person with AD. It is of much benefit to AD patients and family to support their memory dysfunction. However, most TBI survivors do not get the same benefits as AD patients from these

aids. Thus the next section discusses research regarding digital aids for TBI.

## 3.2.2 Digital Aids for TBI

Section 2.4 addressed differences of causes and memory impairments between AD and TBI. Overall the purpose of the digital aid of AD is assisting their lives. A digital aid for TBI survivors is a memory aid to support their memories. Furthermore, a memory aid has various goals such as reminder, memory storage or memory training tool. Therefore, most of the existing digital aids are not specialized for TBI survivors. However, BrainLine (BrainLine, 2015) reported a list of mobile applications that are helping people with a brain injury, and their families and caregivers. The scope of mobile applications cover reading, communication, memory, behaviour, organization, location monitoring, reminder, brain training and so on. Memory and reminder are two types of mobile applications we review in this section.

# Memory-based Applications

Table 3.2 displays the five applications with a brief description and the devices required. The goal of these applications is improving short-term memory.

Awesome Memory uses the card games to flip two cards at one time for finding a pair of matching cards. Flashcards Deluxe is a flashcards application, users can create their own flashcards for studying or learning new things. n-back is an application which is based on n-back theory. The n-back task is an assessment to measure working memory <sup>2</sup>. Penultimate is a digital handwriting application. Users can write their notes or sketch their ideas on it. Spaced Retrieval Therapy is an application that is designed for memory training for people with dementia and brain injury. Spaced Retrieval Theory is an application that is based on a proven method to help people with dementia or other memory impairments. It

<sup>&</sup>lt;sup>2</sup>The n-back task: the subject is presented with a sequence of stimuli, and the task consists of indicating when the current stimulus matches the one from n steps earlier in the sequence. Retrieved from https://en.wikipedia.org/wiki/N-back

**Table 3.2:** Digital aids recommended for improving TBI survivors' memory.

Name	Description
	It is a card game to help users improve their
Awesome Memory	memory. Flipping two cards finds
	pairs of matching cards.
Flashcard Deluxe	It is a flashcard application and users are allowed
Plasificata Defuxe	to create their own flashcards for remembering.
n-back	This application is based on n-back task which
II-Dack	helps to improve working memory.
Penultimate	It is a handwriting application that provides users
1 enumnate	handwriting strategies to take notes.
Spaced Retrieval	This application is based on spaced retrieval.
Therapy	It is an enhanced interval timer with independent
inerapy	data tracking and prompts.

works on up to three objects at once and keeps track of expanding intervals. It automatically increases the time between prompts with correct responses and decreases it with incorrect.

Awesome Memory and n-back are developed as digital games for training people short-term memory. Flashcards Deluxe and Penultimate both provide recording functions that are all transformed from a paper-based version. Spaced Retrieval Theory is one application that is designed for people with dementia or other memory impairments. It is based on the spaced repetition described in Section 2.2.4. The theory of spaced repetition is rehearsing information in order to keep it in short-term memory until it is passed into long-term memory. Spaced retrieval is repeating the object with different intervals of time, according to the response to increase (correct) or decrease (incorrect) the time.

# Reminder-based Applications

ExpiryDate is an application for iPhone (KCSOFT, 2012). The aim of it is helping users to manage expiry dates of everything (see Figure 3.4). ExpiryDate uses an intuitive concept to design it. It uses time-bricks to display the stored information. Each time-brick includes the item image, name and the expiry date. The item with nearest closing time will be listed on the top and increase its image size to attract attention. Under

#### Chapter 3 Related Work

the intuitive concept design, it requires basic information related to the item. The required information includes the image, type, title (item's name) and the expiry date. For the type, it has options with the icon and text for selecting. These icons help users to recognize it more easily.



**Figure 3.4:** Example screenshot of ExpiryDate. Apple Inc (2012). The pop up window. Retrieved from http://itunes.apple.com/tw/app/expirydate. Copyright 2012 by Apple Inc. Reprinted with permission.

ExpiryDate is one custom-made memory system for people with brain injury. It has simplicity, requiring only the basic information and clear information display. However, the reminder function is not enough for most people with brain injury. More specific requirements would be found in our interview user study (see Section 4).

Unlike digital aids for AD patients which aim at retaining their memory ability, existing digital aids for TBI survivors focus on improving their memory ability. In addition, these digital aids for TBI survivors usually combine with the memory theory from cognitive psychology area which have training functions. Therefore, the conclusion is that digital aids for TBI survivors are not memory aids. A memory training tool could be included. After reviewing digital aids for TBI survivors the next section will inspect the digital aids for autobiographical memory, which is the

focus of this research.

## 3.2.3 Digital Aids for Augmented Autobiographical Memory

This section focuses on the existing digital aids for autobiographical memory. There are two digital aids reviewed: SenseCam and Digital Parrot.

#### SenseCam

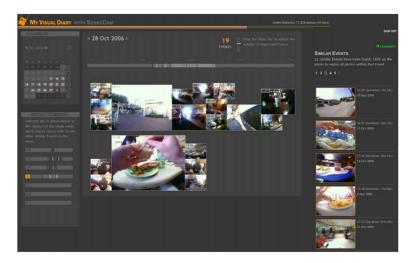


**Figure 3.5:** The photo of SenseCam. Reprinted from "SenseCam: A wearable camera that stimulates and rehabilitates autobiographical memory", by S. Hodges, E. Berry, and K. Wood, 19(7), 686. Copyright 2012 by Taylor and Francis. Reprinted with permission.

SenseCam, is a wearable digital camera to capture photographs automatically, developed by Microsoft Research Ltd (Hodges, Berry and Wood, 2011). Its operations are sensing the environment then taking photos every 30 seconds, see Figure 3.5. Therefore, SenseCam can log hundreds of images, which is at least one image captured of an event that happened. When users review that image it can bring them back to the time of encoding. Incidentally, both healthy users and memory-impaired patients discovered that SenseCam images are a powerful trigger of autobiographical memory. Moreover, the SenseCam browser is developed by Doherty, Moulin and Smeaton (2011) and Doherty, Pauly-Takacs, Caprani, Gurrin, Moulin, O'Connor and Smeaton (2012) which is based on SenseCam technique see Figure 3.6. They apply a series of automatic content analysis techniques to structure the images into Event. A

### Chapter 3 Related Work

SenseCam browser also provides the function of suggesting the relative importance and selecting representative images for each event.



**Figure 3.6:** The photo of SenseCam browser. Reprinted from "Automatically assisting human memory: A SenseCam browser", by A. R. Doherty, C. J. Moulin and A. F. Smeaton, 19(7), 789. Copyright 2012 by Taylor and Francis. Reprinted with permission.

SenseCam techniques use images as a cue because it captures a moment of memory. This image of a moment of memory is a key to trigger people's memory. The lifelogging is developed by SenseCam technique, which uses to support the person with dementia such as AD patients, as described in Section 3.2.1. The following section reviews the Digital Parrot that is designed for augmenting autobiographical memory, but using contextual cues technique. Studies of SenseCam were focused on improving AD patients' memory ability. For example, Woodberry, Browne, Hodges, Watson, Kapur and Woodberry (2015) found AD patients using the SenseCam to remember events which was better than reviewing a written diary. Browne, Berry, Kapur, Hodges, Smyth, Watson and Wood (2011) also suggested the SenseCam was good for the rehabilitation of patients with memory retrieval difficulties. The SenseCam browser offers an efficient way to manage the large amount of SenseCam images. It also benefits the lifelogging platform. Lee and Dey (2008) designed a memory-based support for AD patients which is based on the lifelogging technology to record AD patients' memory, as mentioned in Section 3.2.1.

## Digital Parrot

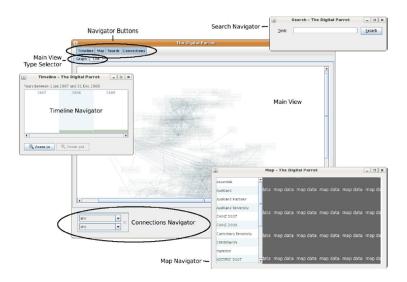
Digital Parrot is Andrea Schweer's PhD project which was finished in 2011 (Schweer, 2011). It is an augmented memory system aiming to help people remember. She created it with Java on a desktop based system. The insights of Digital Parrot are based on computer technology and cognitive psychology. The computer technology includes data models, storage mechanisms, visualization and access paradigms. The cognitive psychology uses concepts of the human memory process and characteristics for designing the system.

A memory network is the significant element of the Digital Parrot. Schweer (2011) used special events and relevant information to build a memory network for stored information. The relevant information combines contextual cues that involve semantic concepts with associations between information item. Contextual cues refer to time, location, other people or weather conditions for users to retrieve memory items (Schweer, Jones and Hinze, 2009). Semantic information is about the items in the system. Association is the relationship between memory items (Schweer, 2011). Schweer (2011) used these contextual cues to be filters to search the stored information. Therefore, Digital Parrot has an exhaustive cues environment to retrieve memories and Schweer used these cues, being different types of filtering for users to search memories.

Schweer (2011) designed the Digital Parrot's interface for retrieving the stored data. It includes the main view and four navigation tools in the system (from right to left on Figure 3.7): type navigator, timeline navigator, map navigator and textual search. Users are able to use timeline, type and textual search to check the stored memories in the system. The main view shows a memories graph view which includes semantic information and associations. In the graph view, Schweer (2011) suggests the memory structure consisting of information item (nodes) and connections (edges) which builds the graph structure of the Digital Parrot in graph view.

Digital Parrot on Android (DPA) was finished by James Richmond in 2012. Richmond (2012) implemented the Digital Parrot of Schweer (2011) onto an Android mobile device. DPA inherited the conceptual structure

#### Chapter 3 Related Work

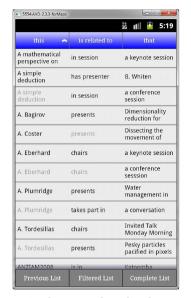


**Figure 3.7:** The Digital Parrot: Main view and all navigators. Reprinted from Augmenting Autobiographical Memory: An Approach Based on Cognitive Psychology (p.105), by A. Schweer. Copyright 2011 by Andrea Schweer. Reprinted with permission.

and all functions from Schweer's work. Therefore we focus on the interface design and information display in this section.

The main view of DPA is the list display as seen in Figure 3.8a. DPA inherited the design of information displayed from the work of Schweer (2011) except the graph view of the memory network. Richmond (2012) inherits ways to display information in the list from the design of Schweer (2011) such as triple column, alphabetical sorting and grouping the repeating data. DPA allows users to group data from the different columns (grouping by 'this', 'is related to' or 'that') as well. Users can long press any item and a pop-up displays the entire text of the item. Richmond assigned the other purpose of the pop-up to display associated information of the pressed item. The example of Figure 3.8b shows date, time and location (the associated information) with a keynote session (the pressed item).

Options menu is a button only for the Android devices. Richmond made this options menu always available regardless of whether DPA is displaying information. The options involve whole filtering functions from Digital Parrot (Schweer, 2011) which consists of 'Graph', 'List', 'Timeline',





- (a) The main list display.
- **(b)** The long press on the item.

**Figure 3.8:** Example screenshot of selection filtering. sReprinted from *Digital Parrot on Android*. (p. 12 – 13), by J. Richmond. Copyright 2012 by James Richmond. Reprinted with permission.

'Map', 'Connection' and 'Search'.

The Digital Parrot on Android (Richmond, 2012) inherits conceptual structure and all functions from the Digital Parrot created by Schweer (2011). Richmond's work focuses on transferring the interface and information display to fit the small screen performance. The goal is to use related cues to trigger people's memory. Their target users are average people who may have a bad memory but not any cognitive impairments. Therefore, for the person of AD or TBI, DPA provides an overwhelming information display and a complex interface design, which may not support their memory impairments.

### 3.3 Discussion

Digital aids for supporting AD patients and TBI survivors are designed using different concepts. For AD patients, the goal is retaining their memory ability. For TBI survivors, the aim is improving their memory ability. Therefore, the digital aids are not only acting as a memory aid

but also have the memory training functions. These memory training functions are based on the cognitive psychology theory of memory retrieval. Reminders to complete everyday tasks is a focus of the research using mobile devices of TBI survivors. However, everyday tasks are a small part of memory deficits for TBI survivors.

There are some similarities in memory symptoms of TBI survivors and AD patients but they have different causes and different long-term effects. A digital aid may support mild AD patients in remembering for living (Oriani et al., 2003). A digital aid for TBI survivors acts as a trigger for recalling memories. Lost orientation and difficulty in recognizing direction are the inevitable symptoms for individuals with AD. Locating supports focus on finding people then sending the assistances which are useful for people with AD. We understand identity of locations and issues of locating people are not a problem for most individuals with TBI. Therefore, locating supports cannot solve the cognitive problems of people with TBI but may provide additional help if needed.

There are two different types of digital aids that we have discussed for supporting autobiographical memory. The SenseCam focuses on capturing the image of the moment of the memory being a cue to trigger memory. The Digital Parrot uses contextual cues to trigger memory. Both of them collect amounts of data that are overwhelming for TBI survivors.

The episodic memory of autobiographical memory is the major challenge for TBI survivors' memory deficits. The use of a mobile device in supporting autobiographical memory for TBI survivors as a research field has not yet been much explored. This research will aim to retrieve the autobiographical memory of TBI survivors using a digital system on the mobile device.

# 3.4 Summary

This chapter contributes further to answering the second research question identified in Section 1.3.2, i.e., "How can a mobile system help TBI survivors remember?" by studying the research of cognitive psychology and computer science to understand different digital aids to support peo-

ple with different memory impairments. This chapter also provided additional answers for the first research question – "What kind of memories do TBI survivors remember or forget?" by reviewing the goal of digital aids are designed to support the user for specific uses.

The research of cognitive psychology clarified two concepts which are important for a digital aid to support TBI survivors with memory impairments. These are the 'portable feature' and 'reminding functions'. The research in computer science focus on supporting autobiographical memory for AD patients and TBI survivors. There are some similarities in memory symptoms for people with TBI and AD patients but they have different causes and different long-term effects. The digital aids for AD patients are for remembering and subsisting but for TBI survivors they are a trigger for retrieving memories.

Lifelogging technique is a feature of SenseCam for capturing all experiences to support AD patients in the memory-based aids. The Digital Parrot uses the contextual cues to create the memory network for retrieving their memories. These two works include detailed data for the memory that is good for people reviewing their memories but it is overwhelming for TBI survivors.

Comparisons of the digital aids for AD patients or those aimed at autobiographical memory showed that these are not a solution for TBI survivors for their memory impairments. AD patients need a digital aid to retain their memory ability for subsisting. TBI survivors require the digital aid for improving their memory ability for remembering. These digital aids for autobiographical memory constitutes too much information that lead to other symptoms of TBI survivors, such as headaches.

The next section will describe an interview user study which was designed for exploring TBI survivors' memory impairments and their special requirements of an augmented memory aid.

# Chapter 4

# Interview User Study

This chapter aims to answer research question three: "What kind of special requirements do TBI survivors have for the design of an augmented memory aid?". It also provides additional answers to research questions one and two: "What kind of memories do TBI survivors remember or forget?" and "How can a mobile system help TBI survivors remember?". In an interview user study, we investigate TBI survivors' use of their own memory aids/strategies to cope with difficulties caused by memory impairments. The study received ethical approval from the Psychology Research and Ethics Committee, School of Psychology, University of Waikato in 2012 (see Appendix A.1). An interview user study was executed by the face to face interview and an on-line questionnaire survey. The study was completed in 2015.

The chapter is structured as follows. Section 4.1 explains the purpose of the study and the importance of this research. Sections 4.2 to 4.4 report the method (recruitment and study questionnaire), procedure and materials of the study, respectively. Section 4.5 divides participants into two groups: TBI-participants and Caregiver-participants and addresses their demographic information. Section 4.6 reports results of themes identified from the study to analyse the data. Section 4.7 reports results about symptoms how affect TBI survivors' behaviour. Section 4.8 highlights that there are outcomes worth noting which are important for TBI survivors with memory problems. Section 4.9 summarises the chapter.

An early version of parts of this chapter was previously published (Hinze et al., 2011).

# 4.1 Goal of the Study

The overall aim of the research is to develop augmented memory aids to assist TBI survivors, with a particular focus on autobiographical memory. The aim of this particular part of the research was to find out more about memory impairments post-TBI. This study aimed to:

- Investigate which aspects of memory impairment participants and/or their caregivers find most distressing and disruptive.
- Find out what types of information are most helpful in assisting participants to retrieve memories.

Findings from this study will provide first-hand knowledge of the issues faced by TBI survivors with memory impairments. These findings assist in the development of an appropriate memory aid for them.

## 4.2 Method

The study method involves two stages: recruitment and interview. Recruitment includes the way participants are selected and how meetings are arranged with them. The purpose of the study is to explain to participants, ensuring that they completely understand the study and their rights prior to executing the interview. The interview user study with open questions is the best way for us to gather the information we need, as the TBI survivors can concentrate on answering questions and their behaviours also can be observed (Paterson and Scott-Findlay, 2002; Ward, Shum, Dick, McKinlay and Baker-Tweney, 2004; Carlsson, Paterson, Scott-Findlay, Ehnfors and Ehrenberg, 2007; Dalemans, Wade, van den Heuvel and de Witte, 2009). There is literature to support the interview technique as the best method for all participants in such studies (Holtzblatt, Wendell and Wood, 2004; Blandford, 2014; James Cook University, School of Business/IT, 2016). An alternative, such as a written questionnaire is not appropriate because TBI survivors have multiple impairments (e.g., poor eye sight or hand dexterity impairments) meaning it is difficult to read or write. The following sections describe this in detail.

The methodology used to analyse the interview material was based on methods of coding data for computer science studies. Studies have shown that using grounded theory to analyse collected data and grouping the data into similar concepts/categories, can be used to develop a theoretical framework (Cunningham, Bainbridge and Masoodian, 2004; Hinze, Chang and Nichols, 2010). Heimonen's study presented the concepts of the taxonomy of the information which consisted of categorising the data similarity (Heimonen, 2009). Levine, Svoboda, Hay, Winocur and Moscovitch (2002) used a similar methodology to analyse their interview studies which aimed to analyse the data of the autobiographical memory in psychologically.

#### 4.2.1 Recruitment

The study used open recruitment; adults over 16 years old were recruited using a poster (see Appendix A.2 and A.3) and a newsletter (see Appendix A.4). Recruitment of 28 participants took 3 years.

Recruitment presented a challenge because the Privacy Act 1993 states organisations cannot provide details of any individuals. In this instance doctors, hospitals and TBI organisations could not provide details of patients or clients with TBI. Additionally, the Waikato District Health Board has strict ethical approval processes of their own which means we can not recruit participants in hospital areas without getting their ethical approval. Due to the vulnerability and, in cases, isolation and loneliness of these individuals with TBI (described in Section 2.3.3) it was apparent that this form of recruitment was ineffective. This meant recruitment relied on potential participants responding to the posters, newsletter or hearing about the study.

The local head injury community THINK! Head Injury Society Waikato Inc (2013) was also contacted for permission to display the posters, put information in their newsletter, and forward the study information to their clients. The local newspaper also mentioned the study information in an interview of a TBI-participant (see Appendix A.5). Potential participants were encouraged to contact us to arrange a time and location for a meeting via email or phone. Location and time are decided by

participants (e.g., at the University of Waikato or other public place).

## 4.2.2 Potential Participants

The participant selection was based on responses provided by participants. Exclusion occurred when the potential participant lost contact after the email for arranging time and location, and for those under the age of 16. Following this process, three participants from the initial responders were excluded from the study, one due to being under 16 and two who lost contact.

The participants were interviewed individually, with three participants having their caregivers present. The interviews were carried out at University of Waikato or participants' homes. On average, two emails were sent to confirm the meeting time with participants. Three days before the meeting, one reminder was sent to the participant, and one day before a reminder by text message.

The participants were invited to answer questions from the questionnaire which was then completed by us. The questionnaire was divided into four sections: general questions; living and work arrangements; situation support questions and information; and additional information. Section 4.2.3 explains the purpose of questions and lists them. Two participants outside of Waikato District used an on-line survey version for the same questionnaire used for the interview (see Figure 4.1).

### 4.2.3 Semi-structured Questionnaire

In qualitative research, interviews are an established way to gather data about participants' perceptions and experiences (Blandford, 2014). Blandford (2014) describes three types of interviews: the structured interview, the unstructured interview and the semi-structured interview. The structured interview uses a designed questionnaire which participants are required to answer. The responses of the structured interview usually meet the interviewer's expectations. The unstructured interview is like a conversation in which participants discuss a particular topic with the interviewer. The semi-structured interview combines characteristics from

How do	o you remember?
	Memory System for Brain Injury hD research from The University of Waikato
*Required	
Personal	Information and Brain Injury Experience
Gender *	
<ul><li>Female</li></ul>	
Male	
How old are you	
How old are you What is your or	gin? *
How old are you  What is your or  If you select Otho  NZ European	gin? *
How old are you	gin? *

Figure 4.1: Screenshot example of an on-line survey.

the other two interview forms. The semi-structured interview uses a prepared list of topics and open-ended questions that are to be covered during the interview, in a particular order. Observation of the participant's behaviour is included in results from the semi-structured interview (Cohen and Crabtree, 2008). Therefore, the semi-structured interview is more flexible in how, and in what sequence, questions are asked, thus producing varied responses by the participants.

Our interview user study is based on a questionnaire, thus enabling TBI participants to follow and concentrate on the interview without much extra effort. The questionnaire consists of four sections that were designed with mostly open-ended questions. The four following sections describe which questions were asked.

#### General Questions

General questions relate to a participant's TBI history. The data from this section can identify the demographic information of TBI in NZ. Also observation of TBI participants of retrieving memory is the main focus of this section. The details include the TBI survivor's personal information and their TBI histories. The details of this questionnaire are shown in Appendix A.8.

## Living and Work Arrangements

Exploration of living and working arrangements of TBI participants aims to understand how memory impairments affect their daily lives.

Moreover, TBI participants are able to discuss or demonstrate their memory aids/strategies due to questions mentioned. The questions of living and work arrangements include – what are your living arrangements or have you returned to the pre-injury/previous job? The details of this questionnaire are shown in Appendix A.8.

## Situation Support Questions and Information

Situation support questions and information are designed to discovery the behaviours of TBI participants using their memory ability. In this section, there are three types of event presented: a doctor's appointment, a lunch date with friends and an appointment with clients. Participants are required to describe three different time-frames for each event: Before, During and After. The details of this questionnaire are shown in Appendix A.8.

#### Additional Information

This section contains one question only for the goal of gathering data before the closure of the interview. It is an open-ended question: "Is there anything else you would like to tell us about your memory problem?". TBI participants describe the things they thought important and useful for their memories.

# 4.3 Procedure

There are two stages in the study: the ethical consideration and the interview. At the start of the study, we explained the purpose of the study and informed the participants of their rights (see Appendix A.6), as well as give them time to ask question and obtain their consent (see

Appendix A.7). Then the procedure moved to the interview stage.

Participants were asked to answer the questions contained in the questionnaire. Photographs were taken of memory aids/strategies that participants currently use (only things with them at that time). With the participants consent the interview were audio recorded. Questionnaire answers were written during the interview.

The same process was followed for participants doing the on-line survey via emails. Participants were required to read the documents of the ethics consent then send an email to confirming they understood their rights and the study. The statement is:

I am *NAME*. I have read the information sheet for participants and understand that taking part in the study is voluntary.

NAME ADDRESS

Then the outline questionnaire was made available.

# 4.4 Apparatus and Materials

The following apparatus and materials were required to carry out each interview. Apparatus was set up similarly at each interview location:

- · Dictation machine
- Digital camera
- · Black pen

Materials included:

- · Information sheet
- Ethics consent form
- Interview questionnaire

# 4.5 Participants

We interviewed 27 participants, of which 20 were participants with TBI, six were caregivers/supporters, and one had multiple sclerosis (MS). We acknowledge that MS is degenerative and the experiences are not necessarily the same as with TBI. However, the MS participant volunteered and was keen to contribute to the study if possible. She had more than 40 lesions on the brain that caused memory impairments identical to TBI participants in the study. There is also an expectation that this research may benefit people with other types of memory problems. This study divides participants into two categories: TBI-participants and caregiver-participants, and the following sections summarise data for each.

## 4.5.1 TBI-participants

Table 4.1 provides a brief view of the data for TBI-participants, 13 males and eight females. Ten participants reported their TBI was the result of motor vehicle accidents, four were sporting accidents, two were the result of brain surgery, two were child abuse which caused multiple concussions, one was a bike accident and one was MS resulting in the brain injury. Twelve participants self-reported that they had caregiver or family support; six caregivers were also interviewed in this study (see Section 4.5.2). The average age at accident occurred was 25 and the total age range from 3 to 59. For the severity level of TBI, eight participants were diagnosed mild, 12 were moderate<sup>1</sup> and one was unknown – the MS patient. Eight participants were tertiary students, three of them were part-time students with part-time jobs and one was a full-time student and also the solo parent of two children under the age of 12. Two participants had full-time jobs (secondary teacher and manager of a tyre company) and four participants had part-time jobs. Three participants

<sup>&</sup>lt;sup>1</sup>The categories of 'mild', 'moderate' and 'severe' for TBI severity are from the Glasgow Coma Scale which is one of systems that doctors use to diagnose the levels of Traumatic Brain Injury. It is based on a 15 point scale for estimating and categorizing the outcomes of brain injury on the basis of overall social capability or dependence on others. Mild refers to a score of 13–15, moderate refers to 9–12 and severe is 3-8. Less than 3 indicates a persistent vegetative state. Retrieved from http://www.traumaticbraininjury.com/symptoms-of-tbi/glasgow-coma-scale/

**Table 4.1:** TBI-participant demographics. \*: The caregiver participated in the study. F: Full-time jobs of 40hrs/week. P: Part-time job of 20hrs/week.

	;	cof oriting a	tate tille job of golles woods.				
P#	Age	Gender	Cause	Caregiver	Age at accident	Severity level	Current job
P1	35	M	Motor vehicle accident	Wife*	20	Mild	(F) Secondary teacher
P2	40	ഥ	Multiple Sclerosis cause brain injury	Son*	29	[MS]	<ul><li>(P) Tertiary student</li><li>(P) Office worker</li></ul>
P3	89	Σ	Motor vehicle accident	Daughter*	16	Mild	Retirement (P) Hospital volunteer
P4	61	Σ	Motor vehicle accident	Caregiver*	18	Moderate	Unable to work
P5	73	Σ	Motor vehicle accident	Wife*	33	Moderate	Retirement
P6	51	Σ	Motor vehicle accident	Wife*	15	Moderate	Unable to work
P7	22	Σ	Brain surgery	N/A	15	Mild	(F) Tertiary student
P8	24	ഥ	Child abuse causes repeated concussions	N/A	15	Mild	(F) Tertiary student
P9	39	Σ	Industrial accident Motor vehicle acident	N/A	20 32	Mild	(F) Manager
P10	33	M	Sporting accident	Father	25	Moderate	<ul><li>(P) Tertiary student</li><li>(P) Painter</li></ul>
P11	41	ഥ	Child abuse causes repeated concussions	N/A	က	Moderate	(F) Tertiary student Solo parent
P12	42	Щ	Sporting accident	N/A	13	Moderate	(P) Office worker
P13	23	Щ	Bike accident	Partner	15	Mild	(F) Tertiary student
P14	24	Щ	Sporting accident	Mother	16	Moderate	(F) Tertiary student
P15	61	Щ	Motor vehicle accident	N/A	26	Moderate	Unable to work
P16	09	Щ	Brain surgery	Husband	29	Mild	Retirement
P17	52	Щ	Sporting accident	N/A	44	Mild	Unable to work
P18	63	Щ	Motor vehicle accident	Husband	29	Moderate	(P) Nurse
P19	32	ഥ	Motor vehicle accident	N/A	21	Moderate	<ul><li>(P) Tertiary student</li><li>(P) Cleaner</li></ul>
P20	34	$\mathbb{Z}$	Sporting accident	Partner	33	Moderate	(P) Social worker
P21	50	ഥ	Motor vehicle accident	N/A	32	Mild	(P) Newspaper delivery Solo parent

### Chapter 4 Interview User Study

C3 C6 C5C2 C1C# **Table 4.2:** Caregiver-participant demographics. F: Full-time jobs of 40hrs/week. P: Part-time job of 20hrs/week. Gender Z H Z Ч ၂ ၂ participation Caregiver/family Length of time Caregiver Daughter Wife Wife Son Wife of support 0.3 years 35 years 7 years 7 years 5 years 7 years Housewife Current job Retired (F) Tertiary student (F) University staff (F) Tertiary student (F) University lecturer strategies Phone call Verbal reminder Text message Phone call Assistant Attend personally Verbal reminder Verbal reminder Verbal reminder Attend personally Verbal reminder Text message Anytime Occasionally Anytime Frequency One week prior Occasionally Once in the morning

were unable to work due to disability and three were retired.

### 4.5.2 Caregiver-participants

Table 4.2 lists a summary of data of Caregiver-participants. Two were males and four were females. All caregiver-participants were immediate family of TBI-participants, excluding C3 who was a personal caregiver. The length of time of support was 4 months to 35 years. Four caregiver-participants had full-time jobs and two had no official jobs. C5 was retired and C6 is a housewife, a mother of one child under the age of one and 24 hours caregiver for P6. Verbal reminder is the most common way to remind their TBI relatives. However, C1 and C2 reminded their TBI relatives by text message. C5 and C6 were present at every meeting of their TBI relatives. The frequency of reminders varied, from seven days prior or 12 hours prior to the event, depending on the caregiver, and time.

## 4.6 Results

This section reports the results of the study. These results were based on transcribed voice-recorded interviews, as described in Section 4.2. The results include the categories that were created to analyse the data. These results are important elements for developing the interface and functions of the new application.

The interviews lasted from 17 to 142 minutes were recorded and included the ethics consent and completed questionnaire. There were 1,711 minutes for 28 interviews and the average time was 74.4 minutes per interview. All interviews were audio recorded, and photos were taken of the memory aids/strategies.

# 4.6.1 Symptoms

Excluding the memory impairments, TBI-participants reported other symptoms as listed in Figure 4.2. Difficulty concentrating is a common symptom discovered in the study affecting 12 out of 21 TBI-participants. For TBI-participants, concentration is affected by certain levels of sound and

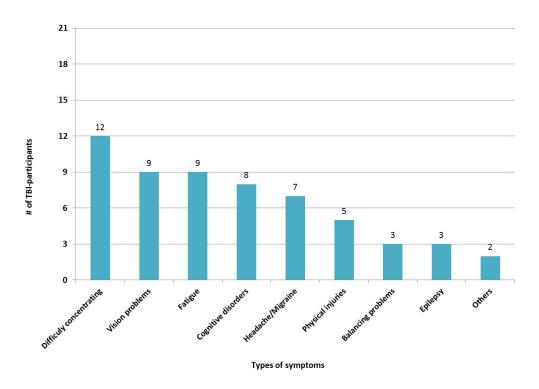


Figure 4.2: Symptoms distribution.

light. Moreover, sound and light are not only factors affecting TBI-participants' concentration but also cause physical discomfort, such as headache and fatigue. Vision problems and fatigue are the second most common symptoms presented in the study affecting nine TBI-participants. Vision problems include poor eye sight at night, light sensitivity and narrow vision. Fatigue is not an independent symptom but usually combined with other symptoms, as mentioned in Section 2.3.2. Cognitive disorders are a symptom that eight TBI-participants suffered, including major depressive disorder, anxiety and personality changes. Seven TBI-participants reported they experienced headache or migraine. Hearing problems, epilepsy, benign paroxysmal positional vertigo (BPPV), post-traumatic stress disorder (PTSD) and flat speech were reported by TBI-participants.

### 4.6.2 Particular Memory Problems

Particular memory problems experienced by TBI-participants were felt to be the main cause of disorder and distress in their lives. We classified three types of particular memory problems and give their definitions.

#### Remembering New Acquaintances

New acquaintance refers to those who TBI-participants have a short connection with. A short connection means they had an interaction of less than 30 minutes. It is notable that significant difference exists with facial recognition blindness, also called prosopagnosia<sup>2</sup>. People with facial recognition blindness have trouble recognising faces; however, people with TBI have trouble remembering people. Further, TBI survivors may be able to recognize new acquaintances when their memories were triggered by related cues.

#### Remembering Ad-hoc Events

An ad-hoc event refers to an event not regularly in TBI-participants' lives. These events are discussed during conversations and most of them relate to the near future.

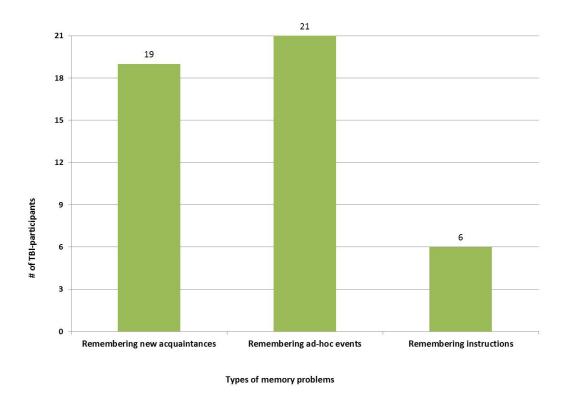
#### Remembering Instructions

Remembering instruction involves learning new things for TBI-participants. They include new routes from home to office, new schedule of daily life or new interface for software, e.g., Word 2010.

Figure 4.3 shows the distribution of TBI-participants with three types of memory problems. 19 out of 21 TBI-participants reported 'Remembering New Acquaintances' as the most distressing memory problem they had. They all admitted that without caregivers/supporters to give the related information they cannot recognize acquaintances. Triggered cues from caregiver/supporters do not work 100% of the time. 13 out of 21 TBI-participants reported that with cues the success chance is still less than 60%. It becomes a main obstacle in their work and social lives.

All 21 TBI-participants reported they needed to pay extra attention to 'Remembering Ad-hoc Events'. Without specific attention, they cannot remember these, even when given related cues. TBI-participants reported that their attention and concentration would be reduced when

<sup>&</sup>lt;sup>2</sup>Prosopagnosia. Retrieved from https://www.faceblind.org/research/



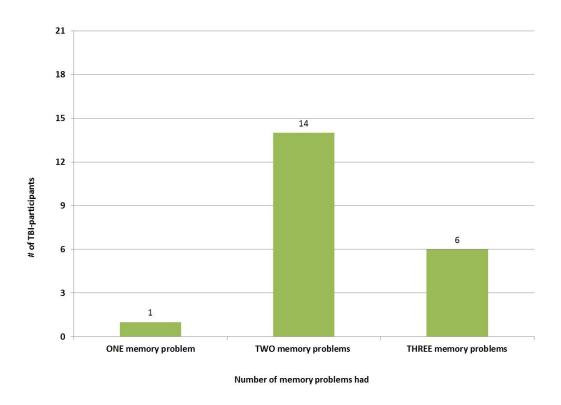
**Figure 4.3:** Memory problems distribution.

they are with family. They knew their family understands their memory problems and would support them anyway. For example, one TBI-participant stated he could remember the conversion with his colleagues yesterday but could not remember the chat with his wife in the morning. "I know she will tell me later so I do not need to remember it now", he said. Therefore, this problem happened often and caused an argument between TBI-participants and their family.

6 out of 21 TBI-participants reported they have difficulty in 'Remembering Instructions'. Interestingly all six of them were female. According to their self-reporting, their level of computer literacy were basic<sup>3</sup>. According to their descriptions, these instructions usually involve using new equipments, such as smart phone or GPS navigation systems. These TBI-participants reported they need help (caregivers reminder or taking

<sup>&</sup>lt;sup>3</sup>Definication of level of computer literacy. Retrieved from https://en.wikipedia.org/wiki/Computer\_literacy

notes) when they are remembering instructions. Kavakli (2015) reported that females accept the technology more reluctantly than males because of having less experience with computers. In this study, we found these six females had basic computer literacy which were enough for them to complete their work with computer. However, new technology is a different thing for them. While we do not have a large enough cohort of participants to state this is the significant finding but it enlighten other studies to do the investigation.



**Figure 4.4:** Number of memory problems distribution.

Most TBI-participants reported that they had more than one memory problem. Figure 4.4 displays the distribution of TBI-participants with symptoms. 14 out of 21 TBI-participants reported that they had difficulty 'remembering new acquaintances' and 'remembering ad-hoc events'. Six TBI-participants reported they had all memory problems. P10 was the person who had one memory problem only.

## 4.6.3 Coping Strategies

Tables 4.3 and 4.4 shows the data of TBI-participants detailing the time post-injury (years), their pre-injury memory aids/strategies and current memory aids/strategies they have. 13 out of 21 participants reported that they did not use any specific memory aids/strategies before the injury. Eight participants had used memory aids/strategies to support their memories and Paper-based materials are the most common aids such as a diary, a wall calendar or a desk calendar. P10 was the only person who used digital aids before the injury. He used the electronic diary with photos to record his travel memories.

After traumatic brain injury, survivors were compelled to change their behaviours in order to maintain their quality of life. Therefore, all TBI-participants began using memory aids/strategies to support their memory problems. Coping strategies include memory aids and strategies covering the activities, or material aimed at assisting survivors' memory aids. These strategies focus on the current effectiveness and which are mostly used by TBI-participants. Here we introduce three types of coping strategies that were classified from the study.

#### Prompt By Person

This means a personal message for prompting TBI-participants. The person involved is not just the caregiver/supporter but also includes relatives, friends, colleagues or the reception for confirming the appointment. The action of prompting involves talking to TBI-participants, making a phone call or sending a text message.

#### Physical Notes

Physical notes mean using a pen and writing down notes on physical materials. The physical materials consist of post-its, diaries, calendars, notebooks, flashcards, whiteboards and hands (see Figure 4.5). Some TBI-participants reported they wrote notes on any paper they can get such as a corner of the newspaper. Writing, reading and placement of notes are three essential elements that contribute positively for TBI-participants' memory.

	<b>Table 4.3:</b> S	dummary of memory aids or strategies of Tl	<b>Table 4.3:</b> Summary of memory aids or strategies of TBI-participants used by previous and current – 1.
# D	Time since	Pre-injury memory aids/	Current memory aids/
<b>⊧</b> ⊣	(years)	strategies	strategies
P1	13	None	Emails and wife's reminder via SMS and verbal
P2	11	None	Post-its paper-based diary, email, placement of items and son's reminders via SMS
P3	52	None	Electronic diary, emails and note on the mobile
P4	43	None	SMS from friends and family
P5	40	Paper-based diary and desk calendar	Wife's reminder and notes on the iPad
P6	36	None	Wife 24 hours care
P7	7	None	Desktop calendar and friends' reminders via SMS
P8	6	None	Whiteboard notes, flashcards and mobile phone reminders
P9	19	None	Emails and printout notes
P10	6	Photos with electronic diary	Note on the phone
P11	38	Paper-based of daily schedule or notes on the wall	Notes on the tablet and mobile phone reminders
P12	29	Paper-based diary	Note on the phone and mobile phone reminders
P13	∞	None	Notes on the paper, partner's reminder and mobile phone reminders
P14	ω	None	Paper-based calendar on the wall for monthly, desk calendar for weekly, paper-based diary for daily and mother's reminder
P15	35	Paper-based calendar	Paper-based calendar and labelled physical files with information

# Chapter 4 Interview User Study

Time since **Table 4.4:** Summary of memory aids or strategies of TBI-participants used by previous and current – 2.

Current memory aids/

P #

Pre-injury memory aids/

+ *	(years)	strategies	strategies
			Paper-based to-do list, husband's reminder,
P16	1	Paper-based diary	and sharing whiteboard notes (weekly)
			and calendar (monthly) with husband
P17	8	None	Mobile phone reminders and SMS from friends
D1 Ω	_	Daner-based diams	Paper-based notes on bench
1 10	H	r aber-nasen mary	and husband's reminders
P19	11	None	Mobile Phone reminders and parent's reminders
P20	1	None	Mobile phone reminders and partner's reminders
P21	18	Paper-based diary and working schedule	Practice routes (to work or to a meeting) and
1		t apos source and and morning conceans	friends' reminders via phone call





**Figure 4.5:** Left: example of writing notes on the hand (P2).

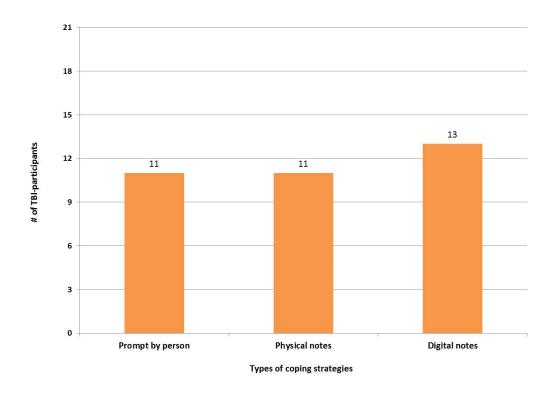
Right: example of writing notes on calendars: Weekly planner on the whiteboard, Monthly planner on the paper-based calendar (P16).

#### Digital Notes

Digital notes includes using applications or software on a mobile device or computer. Notes and the calendar with an alarm are two applications/functions TBI-participants reported that are commonly used on their mobile device.

Figure 4.6 shows the distribution of coping strategies that followed the definition of coping strategies mentioned in Section 4.6.3. The results were closely monitored in each strategy that was discovered in the study. 'Prompt By Person' and 'Physical Notes' were used by 11 TBI-participants. 13 TBI-participants reported using 'Digital Notes' to support their memory.

Figure 4.7 displays the distribution of the combination of strategies used. 13 out of 21 of TBI-participants used two strategies to assist their



**Figure 4.6:** Coping strategies distribution.

memory problems. The combination was 'Prompt By Person + Physical Notes' (4 out of 13), 'Prompt By Person + Digital Notes' (7 out of 13) and 'Physical Notes + Digital Notes' (2 out of 13). Seven TBI-participants used only one strategy to support their memories. Two relied on prompt by person (P5 and P6), two used physical notes only (P8 and P15), and three used digital notes (P7, P10 and P12). P11 was only participant who used three strategies to support her memories.

## 4.6.4 Factors of Memory

The recorded interviews were transcribed and analysed. We calculated the occurrence frequency and analysed the order, then identified six factors that affect the memory of individuals with TBI.

#### Location

The physical place in which the event occurs.

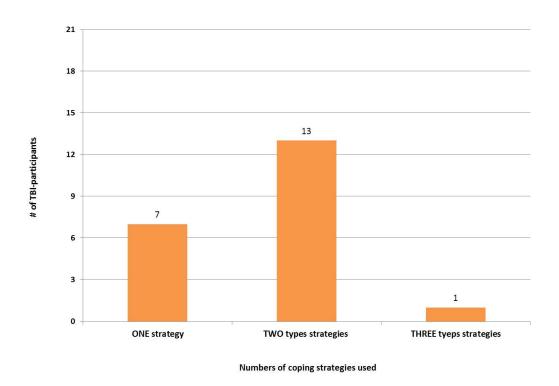


Figure 4.7: Number of coping strategies distribution.

#### Date/Time

The time at which the event occurs.

## People

The related people or people involved with the event.

#### Emotion

Feelings about the event.

#### Environment

The objects that related to the event.

## Activity

The activities involved during the event.

These factors were categorised into three tangible factors (Location, People and Environment) and three intangible factors (Date/Time, Emotion and Activity). These findings showed TBI-participants' memories are

## Chapter 4 Interview User Study

not only affected by the tangible objects. Table 4.5 presents the results for the six factors that affected the memory of TBI-participants for post events and up coming events.

**Table 4.5:** Factors affecting of TBI-participants' memory by post events and up coming events.

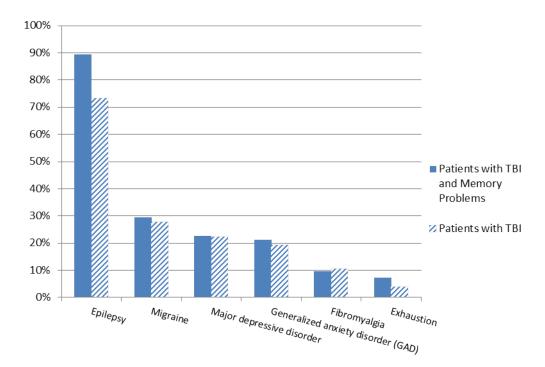
	Location	Date/ Time	People	Emotion	Environ- ment	Activity
Past event	42%	8%	42%	25%	25%	33%
Coming event	50%	42%	25%	8%	0%	42%

For remembering past events, Location and People (familiar)(42%) are equally important in triggering TBI-participants' memories. It was noted that Location seem to have a greater influence for individuals with TBI than for those without (Alallah, 2010). All participants reported difficulties in remembering people's names and faces and for unfamiliar people, 14 of 21 participants stated that Location is most important to trigger their memory. All participants agreed that Activity (33%) is the second most important factor. However, the MS participant (P2) reported differences: for her, Activity is the most important factor and Location is second. Emotion and Environment were also mentioned (25%): they are usually associated with big events rather than with everyday memories.

For up coming events, Location is the most important factor (50%) affecting TBI-participant's memories. TBI-participants reported this as the reason for certain activities, such as the clinic doing regular checking with GP (P9 and P16). Date/Time and Activity are equal as second most important (42%) factors affecting the memory of TBI-participants. P13 suggests Location (lecture room) and Date/Time (Wednesday 2pm) trigger her memories of her timetable (Activity). People are the third (28%) trigger for TBI-participants' memories, for up coming events. Environment has a zero effect on the memory of up coming events for TBI. They stated they cannot recall memories by environmental clues on up coming events.

# 4.7 Extra User Study

In order to understand how symptoms affect behaviours of people with TBI, we did a survey on PartientsLikeMe.com to collect more data about symptoms of TBI. PatientsLikeMe.com is a website for collecting and sharing real-world health experiences to help other patients with similar conditions. We registered with PatientsLikeMe.com as researchers, which allowed us to use their self-revealed medical data for statistics and research purposes.



**Figure 4.8:** An overview of symptoms reported by TBI patients with and without reported memory problems.

From the 131,974 patients registered with PatientsLikeMe.com, 282 report being people with TBI and of these, 207 report memory problems. Data from the website also confirms that brain injury does not occur in isolation and such an injury often leads to other conditions including: epilepsy, migraine, major depressive disorder, generalized anxiety disorder (GAD), fibromyalgia and exhaustion. Figure 4.8 gives an overview of symptoms reported by TBI patients (with and without reported memory problems). As can be seen, patients with and without memory problems

show similar rates of co-morbid disorders, PatientsLikeMe.com (2012).

It was found that brain injury caused other symptoms including difficultly concentrating, vision problems, fatigue and cognitive disorders, many of which lead to participants having to significantly change their lives. As a result of the information most TBI-participants self-reported and Caregiver-participants observed from our interview user study, one can conclude that memory problems, difficultly concentrating, fatigue and headache/migraine affected individuals with TBI together. We need more research about how these symptoms might be affected by the application we designed.

## 4.8 Discussion

The interview user study confirmed the results from a previous study related to effective ways of reminding people with TBI (DePomper, Gillette, Goetz, Xenopoulos-Oddsson, Bryen and Dowds, 2008; Levine et al., 2002; Stapleton et al., 2007). The studies by DePomper et al. (2008) and Stapleton et al. (2007) both presented that digital aids may have the ability to increase the independence of individuals with TBI. The TBI-participants strongly agreed that mobile technology has a positive outcome for their memory problems.

This section reviews the findings from the study and compared them with the existing related work. Five topics will be discussed: memory problems, memory strategies, technology experiences, factors of memory and features of application. These discussions support the contextual design of the new application on the next chapter.

## 4.8.1 Memory Impairments and other Symptoms and Issues

All TBI-participants described how their memory problems cause other problems and impact on their lives. For TBI-participants in work, their memory problems affect their social lives because they cannot remember information about people they meet occasionally or tasks assigned during a conversation. Therefore, they often lose confidence to make new friends or worry that employers will judge them as irresponsible. Sec-

tion 2.3.3 reviewed this memory problem resulting in the social isolation of people with TBI. For TBI-participants in the study, they missed social meetings because they needed to devote extra time to study or because they forgot the meeting.

TBI-participants for whom the injury occurred in early school age mentioned, attention lapses and slower processing which caused them to struggle with their academic performances. P3, P8, P9, P11 and P12 reported their teachers and parents may not be aware of the brain injury that can affect their academic performances. They were labelled a student with bad behaviour or difficultly learning. They stated their experiences studying were unpleasant. P9 and P12 further stated that they could not cope with pressures from studying, thus they dropped out of college.

It is worth noting the memory problems of P11. Repeated concussions in early childhood of P11 caused TBI plus attention deficit disorder (ADD), which means she cannot concentrate on forming new memories, while the post-traumatic stress disorder (PTSD) means she may recall unwanted memories (described in Section 2.2.5). Therefore, she needs to consciously organise every tasks in her life avoiding relying on routine.

All TBI-participants reported having more than one symptom. Excluding memory problems, difficultly concentrating is the most common problem associated with TBI. The results showed that difficultly concentrating usually caused fatigue and headache/migraine. Fatigue requires sufferers to rest frequently. Some TBI-participants described the worst result of fatigue as blacking out temporarily. Headache/migraine is one of the common symptoms in these participants and most participants described that migraine becomes worse under pressure.

## 4.8.2 Memory Strategies

Individuals with TBI have damaged different areas of their brain and each has different requirements and most have developed their own strategies to support their memory. In the study, the results were found that Keeping It Fresh is the major strategy for people with TBI. In cognitive psychology, this is referred to as Repetition. People with TBI have short-

### Chapter 4 Interview User Study

term memory deficits that impact on how they transfer information into long-term memory (Baddeley et al., 2009). Rehearsal/repetition involves receiving (e.g., seeing/hearing) the information repeatedly to prevent it from vanishing from short-term memory. This way they can keep the information longer in short-term memory and thus improve its chances of transferring into long-term memory.

TBI participants all agreed that post-it notes and fridge-memos are good memory aids for retrieval. Most participants post information on the fridge door or kitchen bench to see it as often as possible. Post-it notes are popular because they are produced quickly and removed easily. In addition, P8, P11, P16, and P18 place whiteboards in their room so they can review their schedule/notes. Several participants review the day every evening (in writing) and schedule their next day to refresh their memory of their plans (often including hand-written notes, drawings or reminders). These are other ways to implement rehearsal/repetition.

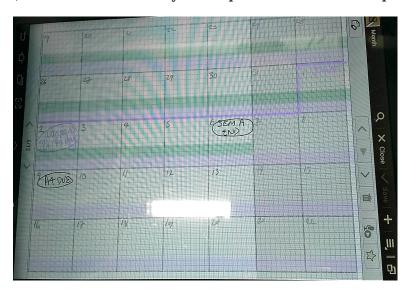


Figure 4.9: Example of handwriting and color coding notes on the tablet (P11).

There are a number of points worth noting. P11 transferred the written notes from a paper-based notebook to a tablet with handwriting function, see Figure 4.9. Figure 4.9 shows that P11 uses handwriting and color coding on notes on the tablet. P11 reported she relies on handwriting being a part of remembering memories, thus she draws her own schedule then fills in; not using the calendar function on the tablet. P13 draws the

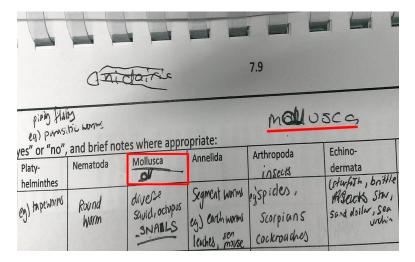


Figure 4.10: Example of drawing the symbol related to the word (P13).



Figure 4.11: Example of color coding related to organize their memories (P6).

symbol that is related to the word and also can represent its meaning for studying. Figure 4.10 illustrates the drawing symbol of P13 in her text book. P6, P11, P13, P14 and P15 agreed that color coding is useful for their memory problems. Figure 4.11 shows P6 uses color coding to organize his workspace. He uses one color drawer storing different components. In Figure 4.11, the green drawer stores tools for fixing cameras, the yellow drawer is for the external flash light and the red for the camera batteries and chargers. For his memory, it is the 'yellow'

drawer having the extra flash lights not the 'second' drawer.

These findings provided first-hand information about requirements of TBI survivors for their memory impairments. They are various but still have some common pattern. These findings are used to develop principles of conceptual design of the application in Chapter 5.

## 4.8.3 Technology Experience

All participants have experience in using smart phones. 15 use both mobile phones (Samsung Galaxy SIII and iPhone 3G/4) and desktop systems (Windows 7 and Mac OS X). None of them use popular applications for assisting their memories, such as Google Calendar<sup>4</sup> (online calendar) and Remember The Milk<sup>5</sup> (online to-do list and task management).

On the desktop computer, participants have their own favourite software to assist their memories. P9 uses Sticky Notes<sup>6</sup> in Windows 7 (see Figure 4.12) to track tasks: notes stay on the desktop to remind him and once finished they are deleted. P7 uses software named Rainlendar instead of Google Calendar, because it uses colours to highlight different events, and events and tasks can be kept on the desktop (see Figure 4.13). P8 uses a calendar on the Mac and also on the iPhone, which syncs between devices when updating events. P3 writes an electronic diary at the end of the day and includes plans for the future. C3 reported that P3 also uses email to help his memory because C3 may get over 10 mails from P3 per day. P2, P4, P12, P13, P16, P17 and P18 prefer to use text messages for memory cue storage. They keep these messages until they no longer need them (typically triple checking to confirm).

On mobile devices, most TBI participants use alarms to remind them of upcoming events. In addition, they all agree that the best display is a popup text reminder. However, they handle reminder situations differently: two participants set alarms without descriptions for daily activities such as taking medicine. They will only insert a description for unique events and then set more than one alarm. One alarm is generally set for early

 $<sup>^4</sup>$ Google Calendar. Retrieved from https://www.google.com/calendar

<sup>&</sup>lt;sup>5</sup>Remember The Milk. Retrieved from https://www.rememberthemilk.com/

<sup>&</sup>lt;sup>6</sup>Sticky Notes. Retrieved from http://windows.microsoft.com/en-nz/windows7/using-sticky-notes



Figure 4.12: Example of sticky notes on Windows 7 (P9).



Figure 4.13: Screenshots of Rainlendar (Rainlendar, 2012) (P7).

in the day, it is about 10 - 12 hours ahead; the other is set for 30 - 60 minutes. The number of alarms will increase for more important events. A calendar with alarm functions on the mobile are a common strategy for TBI survivors with their mobiles and the same results were investigated by the study. However, several examples are worth noting from the study. P1 relies on C1 to remind him. C1 described the reminder which happens early in the day and she usually sends text messages or gives a call one to two hours prior to events. P10 was the only participant relying on a standard mobile phone with no calendar for reminders. He inputs the associated information of the appointment (that is the Location, Time and People) and then saves them into the notepad on the mobile.

All information is categorised by date, followed by the time, and one record represents one event. For example, *G12Carole* (see Figure 4.14) means 'meeting with Carole at 12pm in G Block'. 10 out of 21 TBI-participants use the note application on their mobile devices but reported that sometimes the meaning of the notes are lost as they are not cate-



Figure 4.14: Screenshots of P6's mobile device.

gorised (e.g., shopping).

## 4.8.4 Factors of Memory

Levine et al. (2002) provided a review of the methods and findings related to using the new measure of the autobiographical memory – Autobiographical Interview. Autobiographical Interview uses scoring categories to analyse the data gathered. The data that participants were asked to retrieve were events from five life periods. Participants were asked to describe these events in detail. The scoring categories are five categories which existed on the autobiographical memory. There are 'event', 'place', 'time', 'perceptual' and 'emotion/thought'. The findings of Levine et al. (2002) support the factors of memory we identified in Section 4.6.4.

This research focuses on the autobiographical memory, therefore only factors with effectiveness to the memory for past events will be discussed. According to Table 4.5, the results presented the effectiveness of factors for a past event. Location and People had the same result (42%) which are both important to retrieve memories of TBI survivors. Activity had 33% in the second place for TBI survivors recalling memory. Emotion and Environment both had 25% being the third and date/time had 8% being the less important for TBI survivors memories. The following section will discuss them in detail.

## Location and People

Information about people is too complex and varied for people with TBI to absorb. The general information includes names and faces, and some-

times related information such as the person's size, their hair style, or clothes. This is too much to process as their short-term memory is easily disturbed while trying to transfer the information into long-term memory. Also, some of the factors could change such as hair colour or style. All participants reported they required their full concentration when they commit something to memory. As people in social occasions often do more than one thing concurrently, such as having a conversation during dinner time, this poses great challenges for people with TBI. P1 admitted he could not remember any personal information when people introduce themselves during an activity. C1 and C4 (caregivers) also reported how P1 and P4, respectively, found it hard to remember peoples' names and faces. Many others (e.g., P2, P8, P9 and P21) found they had the same problem when they interacted with people. P13 and P14 commented that they cannot recognise their tutor's face after one semester teaching. P4, P12, P15, P16 and P17 described how they lost their social ability post-TBI with the main reason being that they cannot retain new information about people, their conversations and activities.

In contrast, locations consist of simpler information such as a name or address, which is much easier for TBI patients to remember. All participants reported that they could remember a location or landmark they had visited and used them to trigger their memories. C1 described how location was the first cue used when she supported P1 retrieving his memories. P7 reported that location is the most effective cue for him. P21 usually used landmarks to trigger her memory. All TBI-participants reported that names or photos of locations are most effective for retrieving their memory.

## Activity

Activity was described as an effective cue to help retrieve memories. C1 reported that she often used previous activities to trigger P1's memory. For example, they met John at the wedding party and they talked about buying the house in Auckland. P1 could not remember John before C2 mentioned they had a conversation about buying the house in Auckland. If C1 mentioned they met John at the wedding party, P1 would remember

that he met John, but without any personal information.

The same experience with all TBI participants was observed. P8 described how she typically used a previous conversation to recall memories. P10 at first completely lost his memories after his brain injury. During rehabilitation he regained some of his memories. He told us that music, smell or photographs could bring him back to that time. P21 said: "familiar sounds or things can trigger my memories." P2 described activity as the main factor in their awareness of the present. Other Caregiver-participants (C2, C3 and C5) also confirmed that activity is a factor they use to remind someone. Furthermore, P2, P11 and P18 emphasised that they remember an activity better if it had meaning for them. Therefore, it can be assumed to be beneficial to include explicit interactions into the interface of a memory aid as hooks to form a memory which aids later recall.

#### Emotion and Environment

Emotion and environment have been found to be an important factor for triggering people's memory (Willingham, 2004; Eysenck and Keane, 2010) and this is also true for TBI survivors. Each participant was able to give information about their accident, which included dates and details and the participants who associated strong emotions with the accident (e.g., P1, P9 and P10) remembered most of their accident details, including the exact date and how and what happened during the accident. These three participants associated strong emotions with their memory of the accident. P1 gave as a reason that he appreciates his survival from a near-fatal car accident (happiness). P9 reported how the complicated and detailed documentations and various psychological assessments (for ACC) forced him to remember his accidents (anger). P10 said that the accident is a part of his life and he accepts all changes and overcomes all problems from the accident (contentment). Other participants, who did not have strong emotions connected to the accident had rather vague memories and their memory of the accident was more vague, e.g., they reported the time of accident as the year only. Moreover, C1 reported her observation that P1 could better remember those memories that involved strong emotions.

P2 and P11 both stated the environment is important for their memories. P2 put a glass of water on the bench to remind her to take pills; a glass of water is a trigger to retrieve her memory of taking medicine. Due to PTSD, P11's memories easily are retrieved by the environment. It should be a good thing for her memory problems; however, most of these retrieved memories were unpleasant memories and she tried to rid her mind of them.

### Date/Time

Time has different representations for individuals with TBI. For non-TBI people, time indicates a specific date or exact time frame (e.g. 1st of April or 5 pm on Friday). For people with TBI, time represents any portion of time of an event; such as "the afternoon we went to the supermarket" or "the morning of Dad's birthday". The participants reported that before considering the time of an event, they become aware of the event itself.

## 4.8.5 Features of Application

All participants were asked to describe their ideal application (see questions in Section 4.2.3). From the discussions, we identified three features:

#### Simple

TBI participants want applications without too many functions as otherwise these are too complex for them. Therefore, they do not use popular applications already in the market. Ten participants stressed that they do not need 'fancy' software with 'frilly functions' because they do not have 'extra' memory space to learn how to use them. They prefer an application with a simple display and 'enough' functions. For example, a reminder requires just an alarm and a pop up message.

#### Discreet

They want the application to be socially acceptable so as to not

cause embarrassment. This is a problem when remembering a person's information. For example, an application that can match the face and name from a phone contact when you take a picture of someone would be helpful but most likely not discreet enough to be acceptable.

#### Customisable

Each participant has their own approach to assist their memories and expects the software to support their strategies. People with TBI find it difficult to learn new strategies so keeping to known principles is best for them. For example, P8 usually uses visual reminders and hearing to assist recollection; she would like to have software which provides recording and replay of audio as a reminder.

# 4.9 Summary

This chapter contributes further to answering the third research question identified in Section 1.3.1, i.e., "What kind of special requirements do TBI survivors have for the design of an augmented memory aid?" by interviewing TBI survivors to investigate their special requirements on memory aids. The answer was found from the interview user study, which aims to explore the useful and effective requirements for supporting TBI survivors' needs. This chapter also provided additional answers for the first and second research questions – "How can a mobile system help TBI survivors remember?" and "What kind of memories do TBI survivors remember or forget?" by using the interview user study to analyse the information were recorded by TBI survivors using their memory strategy/aid.

The interview user study identified six factors that have impacts for retrieving memories of TBI survivors. This further confirms these factors are keys which can be effective to retrieve TBI survivors' memories. The results from our user study highlights other issues the participants have in addition to memory problems, such as social issues. Also discovered were new findings that people with TBI require of the application, such as an application with a simple display and functionality.

In summary of the study, an external memory storage is the key which can solve TBI survivors with memory impairments, the same result as discovered in Section 2.2.6. Without an external memory storage, TBI survivors have to keep their attention on the awareness level to remember experiences they had. This is a major cause of fatigue. Thus, an external memory storage for TBI is as a prosthetic limb to an amputee. Accordingly, it can be concluded that an external memory storage makes life manageable for TBI.

Overall the results shown here will become concepts and principles underpinning the contextual design in Chapter 5.

# Chapter 5

# Conceptual Design of MyMemory

This chapter introduces the conceptual design of the MyMemory prototype. The design is based on the results of the previous two chapters. The recommendations for improving TBI survivors' memory ability are derived from the results of the interview user study (see Section 4.8) and the constraints and strengths of existing digital aid works (see Section 3.3). This chapter explains how these recommendations are fulfilled in the MyMemory design, keeping in mind the role of external memory storage and training tool for a digital aid for TBI survivors. Thus finding an answer to the third research question raised in Section 1.3.3: "What kind of special requirements do TBI survivors have for the design of an augmented memory aid?". Also presented in this chapter is the conceptual design and information display based on TBI survivors' requirements. This contributes to answering the fourth research question, "What kind of information display will TBI survivors accept?".

The chapter is structured as follows. Section 5.1 gives scenarios to present the existing situations of TBI survivors and their family. Section 5.2 introduces the concepts and features employed in the design of the proposed MyMemory application. Section 5.3 explores MyMemory's initial design idea as a paper prototype. It also includes a scenario to exhibit the user interacting with the prototype. Section 5.4 states the modifications of the paper prototype following an expert walkthrough. Section 5.5 presents the final version of MyMemory in the digital paper prototype, which uses the scenario to describe how the user interacts with the digital paper prototype. Section 5.6 summarizes this chapter.

An early version of parts of Section 5.5 has been previously published (Hinze et al., 2011; Chang, Hinze, Bowen and Starkey, 2014).

## 5.1 Interaction Personas and Scenarios

In HCI, using personas is a well-established method to organize and communicate survey data. Putnam, Kolko and Wood (2012) found that using a modified persona was an effective way to describe the targeted end users. The personas usually represent a group of users who share common experiences, problems and behaviours when interacting with a particular product or service. Personas can be derived from quantitative survey data (Mulder and Yaar, 2007; Putnam et al., 2012; Cooper, 2014). Therefore, we believe that using persona is an appropriate way for this research to explain the targeted end users exact needs when introducing MyMemory's conceptual design.

This section introduces two personas – Jim, who suffered a brain injury over 20 years ago, and Melody, who is Jim's wife and has been supporting Jim's memory for five years. These personas along with two scenarios have been created based on insights from Chapters 2 and 4. Scenarios describe how TBI survivors' memory impairments affect their lives.

#### 5.1.1 Personas

Jim Clacy – TBI survivor: Jim, 38 years old, is a senior editor of ABB news. A brain injury when he was 18 years old created a watershed in his life. He was involved in a car accident, where he hit his head on the side window, smashing the window upon impact. This accident caused a total change in his life. Before the accident, he was a straight A student and the captain of the school rugby team. He was popular on the social scene. After the injury, he experienced sensitive hearing which caused him to avoid public places. Not only did his demeanour and interests change, but also it seemed as if he had become a completely different person after the accident. Memory impairments affected his academic performance. He struggled to be fully aware and attentive. His limited

memory capacity forced him to do one thing at a time. Thus, he chose to sacrifice his social life to focus on his academic success. Because he was self-conscious about his memory impairment he did not seek support from family or friends. This situation changed when he met his wife, Melody. He met her at his cousin's wedding five years ago. Melody became a personal assistant for him.

Melody Key – TBI caregiver: Melody, 35 years old, is a kindergarten teacher. She is an organized person who uses a paper diary and a mobile phone calendar to manage her life. After meeting Jim, she started to support Jim's personal life. The most common assistance was reminding him about personal dates (e.g., attending friend's birthday party), the words he said before and the person he just met. Both of them realized Jim's short-term memory does not function like that of average people. They used repetition as a way to enhance Jim's memory. Melody found that repeating twice was enough to support Jim's short-term memory, once on the day of an event before and again the morning of the day of an event.

#### 5.1.2 Scenarios

Do I Know You?: Remembering new acquaintances is one big problem for Jim. Due to his memory impairments he may not remember someone he just met five minutes ago. It causes huge pressure for him, unless Melody is with him.

Melody will give cues to trigger his memory about this person. The most efficient cues are "the place you met them" and "you were doing the activity with them". Without Melody, Jim sends an email or text message to himself. This contains a brief description about this person. For example, he had a meeting regarding his TBI and memory impairment. He sent an email to himself, the title is *Carole in the university* and the content is *I met Carole in the university*. She is the Ph.D. student doing TBI memory research. I met with her talk about my TBI history and memory problem. Or the text message is like *I met Carole for her research in* 

the university. She is doing TBI memory research.

However, this is not a really good strategy to manage his memory. His mail box got a hundred emails per day so that it is difficult to find the email he wanted. His mobile phone has a limited amount of storage for text messages, he has to delete previous messages to save new ones. In the end, Melody is the major solution to help him remember new acquaintances.

Easter Holiday Plan: Remembering ad-hoc events are often a cause for arguments during their conversation at home. For example, they celebrated Jim's dad 60th birthday last weekend. They and Jim's mum discussed a three day trip on Lake Tekapo for this Easter holiday. This conversation happened during the birthday dinner. Jim promised he would take care of booking the flight ticket.

On Friday night, Jim told Melody he planned a ski trip during the Easter holiday. Melody told him their Easter holiday had already been planned last week. As usual, Jim denied he knew about the plan and his promise about the tickets. Until Melody gave more related information, such as "we discussed with mum at the dinner" and "you told mum you would book the flight on Monday". Finally, Jim remembered the entire plan and his words. At this time, Jim used his smartphone to send an email to himself and the email title was *Easter Holiday Plan*.

On Monday morning, Melody sent a text message to Jim: *don't forget the Easter holiday plan*. At 4.30pm, Jim finished a regular meeting and returned to his office. The first thing he did was check his phone and he found Melody's text message. After he read it, he turned on his computer and found the email titled *Easter Holiday Plan*. Before he left the office, he finally finished his task about the 'Easter Holiday Plan'.

The personas and scenarios present the general situation of TBI survivors and caregivers. The concepts and features of MyMemory is designed to solve the sorts of problems mentioned in the scenarios. The conceptual design of MyMemory is designed to satisfy requirements of TBI survivors for a memory aid.

# 5.2 Concepts and Features of MyMemory

Chapter 2 highlights the importance of autobiographical memory for a person to identify who are they. In Chapter 4 we identified issues with autobiographical memories: that they are memories TBI survivors want to remember but cannot. We identified short-term memory dysfunctions as a reason for this. Chapter 4 concludes that rehearsal is the most common strategy TBI survivors use to cope with their memory impairments. Section 3.2.2 identified spaced retrieval as a common technique for rehearsal in related work.

This section introduces the concepts and features of MyMemory. The concepts of MyMemory are based on Memory Box Concept mentioned in Section 2.5.1. The features of MyMemory include its roles and tasks for TBI survivors. It provides an account of how MyMemory satisfies TBI survivors' requirements on the memory aid.

## 5.2.1 Concepts of MyMemory

Section 2.5.1 presents Memory Box Concept that is using a production line filling the memory box to depict the memory process. There are three steps for remembering, see Figure 5.1. The memory box needs to be passed between two checking stations (sensory memory and short-term memory) and successfully delivered to the room for storing (long-tern memory). Passing Station 1 means that the person is able to remember the information of the event he/she received within a short time (e.g., remembering a vehicle's registration number after it just went by), which is sensory memory, and also step one of the memory box concept. Passing Station 2 represents that the person remembers more details and for longer (e.g., remembering your new car registration number), which is short-term memory, and step two of the memory box concept. Delivering the memory box to Storage Room is the last step of the person remembering the event for a long time (e.g., remembering your mobile number).

These memory boxes are people's memories and people can retrieve a box from the Storage Room to review the memory, i.e., recalling. There

#### Chapter 5 Conceptual Design of MyMemory

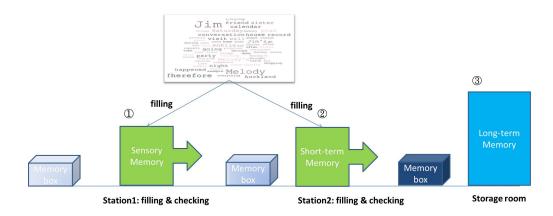
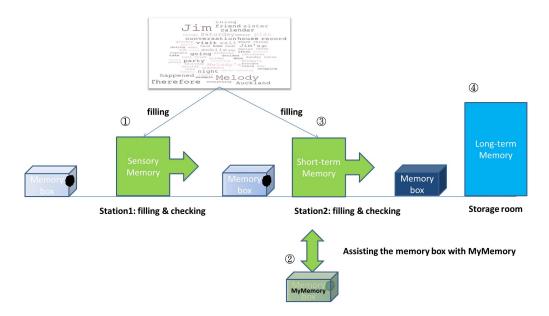


Figure 5.1: Memory Box Concept for average people's memory.

are no restrictions for people retrieving a box to fill the related data. When a box is frequently retrieved, it is located at the front of the queue in Storage Room. This is 'rehearsal' and explains why rehearsal is a key for remembering. Otherwise, a box without retrieval is dumped automatically, i.e., forgotten.

Figure 5.2 shows the memory box concept of TBI associated with MyMemory, which focuses on short-term memory impairment in TBI. The concept has four steps. A TBI survivor's memory box is intrinsically deficient at the start. When TBI survivors experience an event their memory box starts filling with the related data, which is the first step, similar to the memory box concept mentioned previously. The deficiency does not affect the memory box passing through Station 1. It explains that most TBI survivors can remember the thing for few seconds, i.e., their sensory memory is functioning. However, TBI survivors' memory box cannot be filled up due to their memory impairments. It means the box cannot pass Station 2 (short-term memory) and subsequently go to Storage Room. Therefore, it explains that the lack of short-term memory results in TBI survivors' memory impairments. The purpose of MyMemory is designed to support TBI survivors' short-term memory.

Using the Memory Box Concept, we can think of MyMemory as a new box wrapping up the TBI survivors' damaged memory box before it gets passed to Station 2. Once associated with MyMemory's memory box, TBI survivors can fill up the memory box and pass it to Station 2. This is the



**Figure 5.2:** Memory Box Concept of TBI associated with the MyMemory.

new step two and three for TBI survivors for the memory box concept. Step four is delivering the memory box to Storage Room.

Without MyMemory's box, TBI survivors' memory box cannot arrive at Storage Room. This means TBI survivors cannot remember the event. Simply stated, MyMemory is an external storage for storing a memory box with related data. Therefore TBI survivors can repeatedly review the event data on MyMemory without retrieving it from Storage room.

What is in the memory box of MyMemory and how does it work for TBI survivors' short-term memory? The next section explains in detail.

## 5.2.2 Features of MyMemory

The following features of an augmented autobiographical memory aid for TBI survivors from Chapter 3 and 4 are used in MyMemory: 1) a digital memory aid, 2) an external memory storage, and 3) a memory training tool. Figure 5.3 shows the features of MyMemory with roles and respective tasks.

MyMemory acts as an external memory storage and memory training tool for TBI survivors. There are different tasks for these roles. The tasks of the external memory storage are recording and displaying events.

#### Chapter 5 Conceptual Design of MyMemory

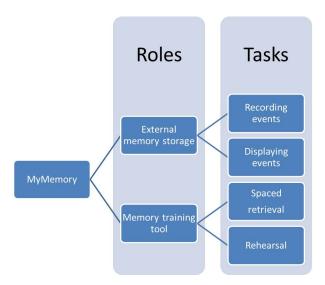


Figure 5.3: Features of MyMemory.

Recording and displaying events are based on the factors of memory and the features of application resulting from the interview user study in Sections 4.8.4 and 4.8.5. Returning to the concepts of MyMemory, the external memory storage is designed to support the TBI survivors' damaged box in passing to Station 2.

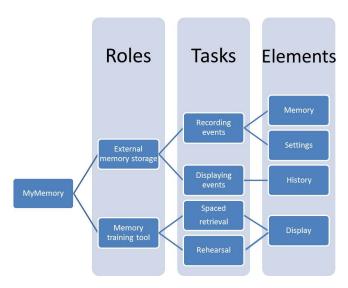
The memory training tools involves two tasks: rehearsal and spaced retrieval. Section 2.2.4 described rehearsal as a method to process information from short-term memory into long-term memory. Spaced retrieval is a learning technique that employs digital aids for people with memory impairments. We reviewed these in Section 3.2.2.

Based on these concepts and features, the conceptual design of MyMemory was developed as an augmented autobiographical memory for TBI survivors to assist with improving their memory ability. Most importantly, the design of these components make MyMemory compatible with TBI survivors' needs for a digital aid. The next section discusses a paper prototype of MyMemory.

# 5.3 Paper Prototype of MyMemory

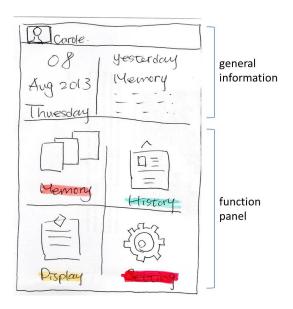
This paper prototype shows the initial design of MyMemory. According to the four elements discussed in Section 5.2.2, MyMemory is composed

of: 'Memory', 'History', 'Display' and 'Settings'. Figure 5.4 shows the structure of MyMemory's roles, tasks and elements.



**Figure 5.4:** MyMemory's structure of roles, tasks and elements.

The purpose of 'Memory' and 'Settings' is executing the recording events task. 'History' focuses on the displaying of events task. 'Display' is focusing on the spaced retrieval and rehearsal tasks. The aim of each element is performing its task based on the requirement that resulted from Chapters 2 to 4.



**Figure 5.5:** Paper prototype of MyMemory's main screen.

## Chapter 5 Conceptual Design of MyMemory

The main screen is shown in Figure 5.5. It is divided into two parts: the general information and the functional panel. The general information shows the user's photo and name at the top. The next area has the current date on the left and the previous day's event records on the right. The functional panel contains four functions: 'Memory', 'History', 'Display', and 'Settings'. The following sections introduce the interface layout and its feature for each function. The personas and scenarios from Section 5.1 are used to illustrate each element.

## 5.3.1 Memory

The function accessed via the 'Memory' element provides an interface for the event data entry. It is designed with four screens to guide the user entering related data of an event. Figure 5.6 shows the paper prototype of the 'Memory' element. The first screen includes prompts for the location, occasion and subject of the event. The second screen provides prompts for the date and time. The third screen requests information about the involved activity and people. The last screen allows specification of the user's emotion and notes about the event.

For TBI survivors, an icon-based interface is significantly superior to text-based for presenting the information, as elicited from the interview user study in Section 4.8.2. Therefore, each prompt is shown by both icons and text on the interface. More selecting and less typing can speed up the user recording event data which helps avoid TBI survivors' memory slipping away. The interface design also meets the Simple and Discreet requirements of as specified by TBI survivors in Section 4.8.5.

Scenario walkthrough: On Jim's dad's 60th birthday, Jim, Melody and Jim's family had a celebration party at his dad's house. After dinner, Jim's mum told them about the Easter holiday plan. She planned a three day trip on Lake Tekapo which is their favourite place. When they were young, the family usually went there in the summertime each year. Since Jim and his brother moved out, they had not been to Lake Tekapo for five years. Therefore, they were really excited about this trip. Jim told them that he would take care of booking flight tickets. Before leaving the

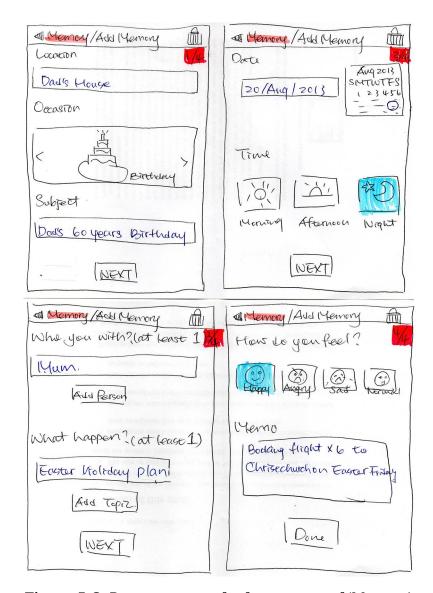


Figure 5.6: Paper prototype for four screens of 'Memory'.

dining room, Jim took out his mobile and turned on MyMemory to record this event.

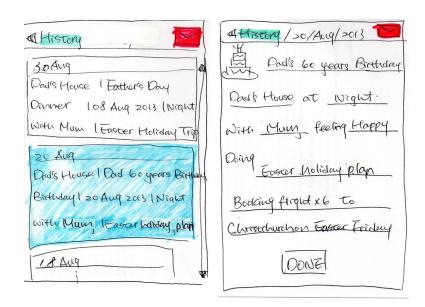
He typed the related information about the event's 'Location', 'Occasion' and 'Subject': *Dad's House, Birthday* and *Dad's 60th birthday*. Going to the second screen, the current date was displayed on MyMemory so Jim directly moved to the 'Time' and selected the night icon. On the third screen, he entered *Mum* and *Easter holiday trip* for prompts of *Who are you with?* (Involved Person) and *What happened?* (Activity). Going to the fourth screen, he recorded his 'Emotion' as *happy* and made the

## Chapter 5 Conceptual Design of MyMemory

'Note' – *Booking flight* \* 6 to *Christchurch on Easter Friday*. He clicked the 'DONE' button to save. Figure 5.6 illustrates this event data. He closed MyMemory and went to the living room to join the others for his dad's birthday cake.

## 5.3.2 History

The function accessed via the 'History' element gives access to stored event data. Figure 5.7 (left) shows the interface of the memory store. Each text block represents one event; the text blocks are presented sorted by date. The text block displays brief information for each event. Selecting the block will open a new screen to display the details of the event, see Figure 5.7 (right).



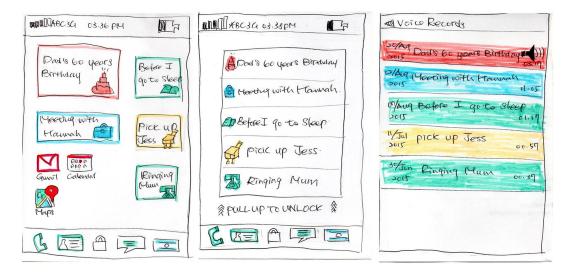
**Figure 5.7:** Paper prototype of 'History'. Left: Overall stored event data list. Right: The detail of single event data.

The detail screen of the event also provides a shortcut for editing the event. Considering the difficulties TBI survivors have in concentrating, the edit function allows direct changing of the event data rather than requiring the user to go back to the main screen via 'Memory'. The envelope icon top right wraps the event into an email, ready to send. The email set up can be accessed via the 'Settings'.

Scenario walkthrough: The next day – Saturday morning, Jim had his breakfast at home. He also turned on MyMemory and went to 'History' checking the recorded event data. Clicking 'History' on the function panel, Jim found the event with Dad's 60th birthday and Easter Holiday Plan. He clicked this event checking its detail (see Figure 5.7). After reading, he clicked the envelope icon to send the email to himself and Melody reminding both of them.

## 5.3.3 Display

The function accessed via the 'Display' element provides an interface for the training tools. We designed three different types of training tool: 'Post-its', 'Screensaver' and 'Voice Records'. 'Post-its' and 'Sreensaver' are based on the concepts of Rehearsal, and Magic Number for managing the quantity of displayed data (see Section 2.2.4). Figure 5.8 illustrates the 'Post-its' (left) and 'Screensaver' (middle). Both of them utilize the strategy that are Keeping It Fresh to display the information constantly on the mobile device. Setting up 'Post-its' presents the information on the home screen and wrapping the memories' subject into one text block, displays this on the 'Screensaver'.



**Figure 5.8:** Paper prototype of 'Display'. Left: 'Post-its' on the phone's home screen. Middle: Text box on the 'Screensaver'. Right: Voice Records.

### Chapter 5 Conceptual Design of MyMemory

'Voice Records' enable the user to record a voice note for each event. Figure 5.8 shows the screen of the Voice Records (right). This may benefit some TBI survivors for whom hearing is essential for their memories. This element was developed within the conceptual design, but not developed in the implementation of digital MyMemory's prototype. Because most TBI-participants did not suggest it is a useful/helpful function in MyMemory in the interface user study (see Section 6.6).

Scenario walkthrough: On Sunday night before Jim went to sleep, he turned on his mobile phone checking tomorrow's schedule. He read the email with Dad's 60th birthday and he closed the email. He clicked the 'Display' on the function panel of MyMemory and selected the Dad's 60th birthday. Both the 'Post-its' and 'Screensaver' showed this event. He also clicked the event title – Dad's 60th birthday and made the voice record. He said: "Booking six flight tickets for Easter holiday". Figure 5.8 illustrates the 'Post-its', 'Screensaver' and 'Voice Record' for Dad's 60th birthday.

On Monday morning, Jim checked his email at his office. He read the email *Dad's 60th birthday* again. He checked the flight ticket's price and wrote down some information on the paper post-its. He posted it on his monitor and left the office for a meeting. At 4.30 pm, Jim finished the regular meeting and returned back to his office. The first thing he did was turn his mobile on and he found the 'Post-its' with the cake icon displaying *Dad's 60th birthday* on his phone's home screen. He also found the paper post-it with the information about the flight displaying on his monitor. He turned on his computer and booked the flights. After five minutes, he received the e-tickets and forwarded them to his family before he left the office. Melody told him when he got home that his mum called saying how excited she was to receive the email.

## 5.3.4 Settings

The function accessed via 'Settings' element provides an interface for recording the user's personal contact data. Many TBI survivors have trouble remembering their contact information, see Section 4.8.4.

MyMemory uses 'Settings' to keep the users email and mobile number. They can directly click the envelope icon for sending selected memories via email. Figure 5.9 shows the 'Settings' paper prototype.



**Figure 5.9:** Paper prototype of the 'Setting'.

# 5.4 Expert Walkthrough of MyMemory

The paper prototype is the initial design which presents elements of an external memory storage in 'Memory' and 'History', a memory training tool in 'Display' and saving the contact information in 'Settings'. The expert walkthrough was designed to verify the usability and the initial layout of MyMemory.

We have presented the conceptual design of MyMemory intended for supporting the memory of TBI survivors. Its design is based upon knowledge of cognitive psychology for the memory process, and HCI information for the interface and usability design. We invited experts to execute a pilot user study in order to clarify the deficiencies in MyMemory.

Three experts did the usability test for MyMemory. One Associate Professor of Psychology and two senior Computer Science lecturers. We

gave them a demonstration of the conceptual design of MyMemory on the paper prototype and answered their questions. After the discussion, they provided the feedback, including identified functional shortcomings and inadequacies in usability. We analysed this feedback and provided modifications.

This section describes modifications found necessary from the expert walkthrough. The following sections explains each change made.

## 5.4.1 Using Activities to Describe Functions

- 1. Re-naming each function. The initial design uses a noun to name each function; however, the terms do not describe the function's activity. For example, adding memory is called 'Memory' on the initial design which does not express its function of adding new memory. Thus, the term was changed to 'Adding Memory'. 'History' in the initial design means the display of all recorded memories in MyMemory. However, the word history has the meaning of a macroscopic view related to a human's past, not just for a personal past experience. Therefore, it was renamed as 'My Memories'. 'Display' in the initial design is used for the function with the rehearsal concept, such as 'Post-its', 'Screensaver' and 'Voice Records'. In order to precisely present the rehearsal concept for these functions, the name was changed to 'Training'.
- 2. Re-naming the prompt. The initial design of 'Memory' uses 'Location', 'Occasion' and 'Subject' as the prompt, names which users have difficulty understanding the first time. These prompt names were modified into the colloquial terms: 'Place', 'Event' and 'Purpose'.

Alterations of names are demonstrated in the final design figures, see Section 5.5.

## 5.4.2 Pagination vs Long List for Adding Memory

Due to the difficulty TBI survivors have concentrating, the initial design used a four-short screens design to record events (see Section 5.3.1).

However, having one-long scrolling interface is a more traditional design for the small size screen of mobile devices. Chittaro and De Marco (2005) further found that a scrolling interface is a more effective interface design. In order to explore the most convenient interface for 'Adding Memory', we provided two designs: multiple-short screen and one-long screen. Executing the user study will help determine the most appropriate design for the implementation of MyMemory.

## 5.4.3 Pop-up Window for Confirmation

In the initial design, there are no confirmation messages, in order to avoid interference. Once the user accomplishes each activity, the screen returns the user back to MyMemory's main screen. However, this may cause confusion as to whether the memory was saved or not. After consideration it was decided to include a confirmation message, because of its importance to confirm the progress. Section 5.5 will exhibit this popup window with the confirmation message.

## 5.4.4 Save Button in Adding Memory

The initial design concept assumed that the user would not interrupt the process of recording their memory until it was completed. However, there may be occasions which do not allow them to finish the process immediately. Therefore, a save button was added to 'Adding Memory' in the modification of the initial design. There are four screens in the 'Adding Memory' and each screen has a button for saving the current progress. The final design with the save buttons is shown in Section 5.5.

## 5.4.5 FlashCard Added as Training Option

In early childhood education, flashcards are a general technique for teaching children word, color and number recognition. There have been studies that have investigated flashcards as an effect tool to help children learn (Cook, 2013; Nist and Joseph, 2008; Skarr, Zielinski, Ruwe, Sharp, Williams and McLaughlin, 2014; Volpe, Mulé, Briesch, Joseph and Burns, 2011). Difficultly in concentrating and being distracted easily are com-

mon to both children and TBI survivors. Flashcards are a technique to assist children learning, due to the similarities it may also work with TBI survivors. In addition, some TBI participants reported that flashcards are a tool they use when they want to memorise proper nouns. The new prototype design is shown in Section 5.5.4.

This section summarised the expert walkthrough of the initial design and details changes made as well as the reason for these changes. The next section will show the final version with these alternations that are included in the digital prototype.

# 5.5 Digital Paper Prototype of MyMemory

This section illustrates the final version of MyMemory's conceptual design. It uses the digital prototype tool Balsamiq <sup>1</sup> to mock up the digital paper prototype. Each section introduces the function of the digital paper prototype's interface. It shows how to use these functions to perform the actions described in the scenario – *Easter Holiday Plan* in Section 5.1.

This prototype is the subject of the usability test. The usability test will be discussed in Chapter 6.

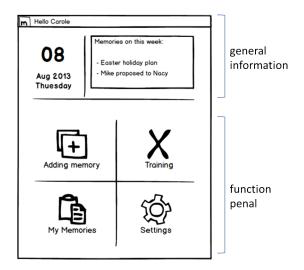
#### 5.5.1 Main Screen

Figure 5.10 shows the main screen of the final design of MyMemory. The main screen consists of two parts. The first part has the current date on the left and previous day's memories displayed on the right. The central panel is the second part that includes 'Adding Memory', 'Training', 'My Memories' and 'Settings'. The modification of the name and icon of the function from the previous section provides better legibility. Removing the user's photos gives a simpler and clearer display.

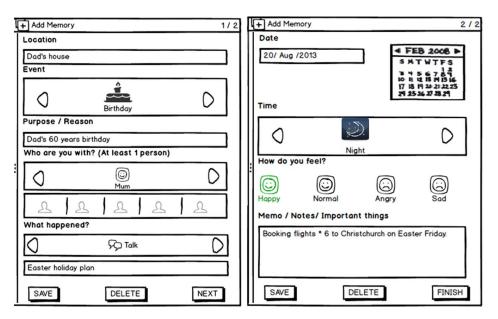
## 5.5.2 Adding Memory

Following the modifications described in Section 5.4.2, there are two designs for 'Adding Memory': one-long screen and two-short screen. Fig-

<sup>&</sup>lt;sup>1</sup>The goal of Balsamiq is to help people create software and websites that are easier to use. https://balsamiq.com/



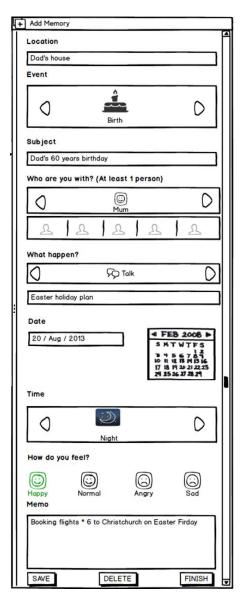
**Figure 5.10:** Digital paper prototype of MyMemory's main screen.



**Figure 5.11:** Digital paper prototype for two-short screens design for 'Adding Memory'.

ure 5.11 shows the two-short screen design that it is based on the factors of memory (see Section 4.8.4). The first screen (left in Figure 5.11) includes the tangible factors: Event's Location, Event, Event's Subject, Involved Person and Activity. The second screen (right in Figure 5.11) contains the intangible factors: Date, Time and Emotion. Each screen has a 'SAVE' button for the user to save incomplete recording for editing later.

## Chapter 5 Conceptual Design of MyMemory



**Figure 5.12:** Digital paper prototype for one-long screen design for 'Adding Memory'.

Figure 5.12 shows the one-long screen design. This design is a combination of two-short screens in one-long screen with scrolling to manage the screen. It also has the 'SAVE', 'DELETE' and 'FINISH' buttons for each feature at the bottom of the screen.

Scenario walkthrough: On Jim's dad's 60th birthday, Jim, Melody and Jim's family had a celebration party at his dad's house. Jim's mum planned

to go to Lake Tekapo in the Easter holiday. Everyone was so excited about this plan. Jim took charge of booking flight tickets. Before Jim left the dining room, he turned on MyMemory on his mobile to record this event.

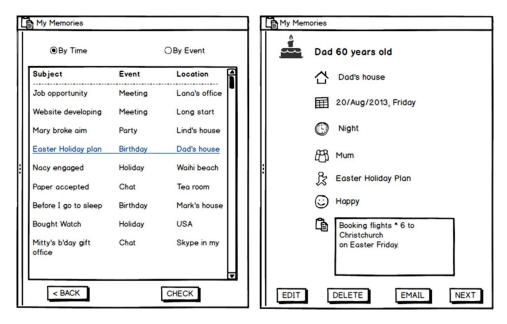
He typed the related information: 'Location', 'Event', 'Purpose', 'Who are you with?' and 'What happened?': Dad's House, Birthday, Dad's 60th birthday, Mum and talking – Easter Holiday Plan. After clicking the 'NEXT' button, the screen displayed the information of the event's 'Date', 'Time', 'How are you feeling?' and 'Note'. He did not change the date, selected night icon and happy face for 'Emotion'. He wrote the note: Booking flight \* 6 to Christchurch on Easter Friday. He clicked the 'FINISH' button for saving. He closed MyMemory and went to the living room to join the others for his dad's birthday cake. Figure 5.11 illustrates this event data.

## 5.5.3 My Memories

'My Memories' is the new interface element for 'History' in the paper prototype (see Section 5.3.2). The function of My Memories is displaying event data which is saved in the database of MyMemory. Figure 5.13 presents the overall event data list on the left and the detail of the memory on the right. Two sorting functions for searching the event shows on the left in Figure 5.13. MyMemory uses sorting functions for searching instead of a textual search function. Because of TBI survivors inability to find the exact key word for searching their memories. In order to keep information simple and clear, each event displays three related factors: 'Event's Subject', 'Event' and 'Event's Location'. According to the results from the previous study, these three factors are the most common elements TBI survivors recorded using their own memory aids. As a result Section 4.8.4 found 'Location' and 'Involved Person' both work for TBI survivors retrieving their memories. Therefore, sorting by location and sorting by person are two ways for reorganizing the recorded memories display.

Figure 5.13 right illustrates a memory with the detail. The goal of this screen design is the display of the summary of the memory. Moreover, 'My Memories' provides three features for this memory, 'EDIT',

#### Chapter 5 Conceptual Design of MyMemory



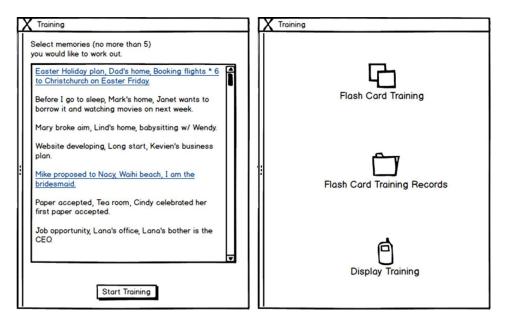
**Figure 5.13:** Digital paper prototype of 'My Memories'. Left: Overall recorded event data list. Right: The detail of the single event data.

'DELETE' and 'EMAIL'. 'EMAIL' is based on the TBI survivors strategy of backing up/sharing their memory via email. Clicking the 'EMAIL' button causes MyMemory to wrap the memory information into an email format for sending.

Scenario walkthrough: The next morning, Jim had his breakfast with Melody at home. He also turned on MyMemory and went to 'My Memories' checking the recorded event data. Clicking 'My Memories' on the function panel, Jim found the event with Easter Holiday Plan of Birthday at Dad's house. He clicked this event checking its detail (see right of Figure 5.13). Then he discussed this event with Melody, Melody asked him to share this event data with her. Therefore, he clicked the 'EMAIL' button sending the email to himself and Melody. Suddenly, Jim remembered he needed to talk to Melody about a job opportunity he discussed with Lana last Friday in her office and which he recorded in MyMemory. He clicked 'My Memories' on the main screen and used the sorting function – 'Sort by Time' to rearrange the order of all event data. He found the event data record with the subject Job opportunity (see left of Figure 5.13) and clicked to check the detail of the event.

## 5.5.4 Training

'Training' is the interface for presenting the training items and the training approaches. Figure 5.14 on the left shows the overall events in the database. Three factors represents the event: 'Subject', 'Location' and 'Note'. These are different to the factors used to present the event in 'My Memories'. The reason is that 'Note' often contains important information for the event. Thus it was decided to use 'Note' content instead of 'Event's Subject' in 'Training'.

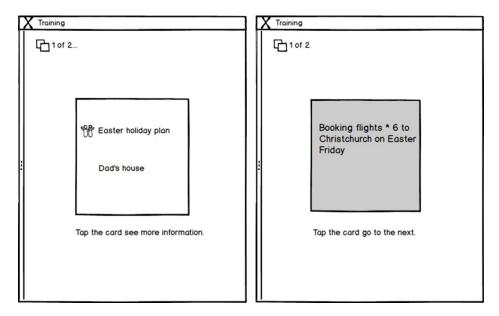


**Figure 5.14:** Digital paper prototype of the primary producer of 'Training'. Left: List overall recorded event data list. Right: Three things of 'Training'.

Figure 5.14 demonstrates the primary procedure of 'Training': 1) choosing no more than five events, then 2) selecting one training approach. Left of the Figure 5.14 shows two events selected and clicking the Training button goes to the next step. Right is the screen showing three things of 'Training': 'FlashCard Training', 'FlashCard Training Records' and 'Display Training'. 'Display Training' includes three training approaches. The following section will describe each approach. The next section describes 'FlashCard Training'.

## FlashCard Training

To extend the concept of 'FlashCard Training', MyMemory uses the event's 'Location', 'Purpose/Reason' and 'Note' as the content of the flashcard. Figure 5.15 displays an example of 'FlashCard'. Left in Figure 5.15 shows the flashcard which uses the 'Purpose/Reason' and 'Location' of the event as the cues to trigger the participant's memory. Right in Figure 5.15 shows the flashcard displaying the 'Note' of the event to confirm the participant's thoughts.



**Figure 5.15:** Digital paper prototype of the 'FlashCard Training'. Left: The flashcard one. Right: The flashcard two.

The example of the cue's flashcard (flashcard one) includes the 'Event's Subject': Easter Holiday Plan and the 'Event's Location': Dad's house, see left of Figure 5.15. The example of the flashcard of the confirmation (flashcard two) is the 'Event's Note' – Booking flights \* 6 to Christchurch on Easter Friday, see right of Figure 5.15.

## FlashCard Training Records

The purpose of the 'FlashCard Training Records' is to provide a record for participants to check their training results. 'FlashCard Training Records' displays the data regarding the event used for 'FlashCard Training', the

training times and the last training time. The participants can review this data to understand their memory ability.



Figure 5.16: Digital paper prototype of the 'FlashCard Training Records'.

Figure 5.16 shows the records for the previous flashcard training results. For example, *Easter holiday plan...(3)* means the user already used the flashcard training to train the event of Easter holiday plan three times. The record also presents the last training time for the event. The user used the flashcard to train 'Easter holiday plan' two days ago.

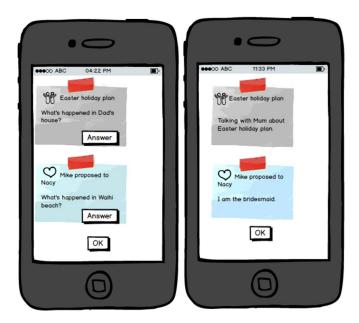
## Display Training

Display training includes three different types of training approaches. There are 'Post-its', 'Screensaver' and 'Voice Recording'. These approaches are based on Keeping It Fresh and they are designed to train TBI survivors' memory by constantly seeing or hearing the event data. The following sections discuss each approach and its design concept.

*Post-its* Figure 5.17 exhibits two selected events displayed as post-its on the mobile device's home screen. 'Post-its' training merges the question and answer technique which it uses for interaction with the user to enhance the repetition of the memory training.

Left in Figure 5.17 presents the 'Event's Subject' – Easter Holiday Plan and question – What happened in Dad's house? (Event's Location) Click-

#### Chapter 5 Conceptual Design of MyMemory



**Figure 5.17:** Digital paper prototype of 'Post-its'. Left: Questions on 'Post-its'. Right: Answers on 'Post-its'

ing the 'ANSWER' button, the 'Post-its' give the answer – *Talking* (Activity) with Mum (Involved Person) about Easter Holiday Plan (Event's Subject), see right in Figure 5.17.

Screensaver Most TBI survivors do not want other people to know about their memory impairments; therefore, discreetness was a main requirement for the application identified by the interview user study. In order to meet this requirement, users can deactivate the 'Screensaver' training. Figure 5.18 shows the screen with the control panel for the 'Screensaver': the switch to turn on/off and two screensaver types (banner or text box).

Figure 5.19 illustrates the 'Screensaver' as a banner (left) and text box (right). The banner design is based on the advertisement banner of the application. The digital prototype of the banner (left) displays the contents of one event. It includes the Event's Subject, one question which asks *Who did you meet at the event?* followed by the answer: *Mum* (Involved Person). The left bottom corner presents the number of selected memories. The arrow icon is used to go to the previous event

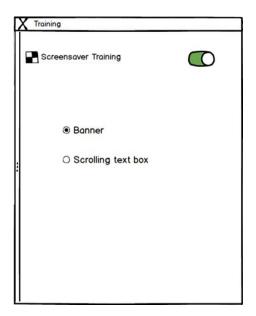
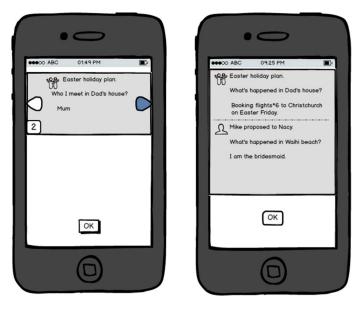


Figure 5.18: Digital paper prototype of the 'Screensaver' settings.



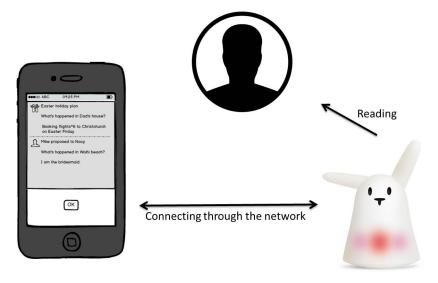
**Figure 5.19:** Digital paper prototype of two screensaver designs. Left: Banner design. Right: Text box design.

or the next. The digital prototype of the text box (right) presents the 'Event's Subject', 'Location' and 'Note' for one memory. The example in Figure 5.19 is about *Easter Holiday Plan*. The detail of the event in the text box includes: *Easter Holiday Plan*, *What happened in Dad's house?* and *Booking flights \* 6 to Christchurch on Easter Friday*. Both of them

#### Chapter 5 Conceptual Design of MyMemory

have an 'OK' button for going back to the mobile's home screen.

Voice Recording Because hearing their own voice is one way to retrieve memory, this function combines MyMemory with Karotz - Wifi Interactive Smart Rabbit, to output the voice notes. The main environment for recording is a private place, such as home. When users go back home, their mobile will connect to the Karotz rabbit through the internet and the rabbit will play their own voice to read notes. Figure 5.20 presents the schematic drawing of the Recording and Karotz.



**Figure 5.20:** Schematic drawing of the connection on 'Voice Recording' and Karotz.

Scenario walkthrough: On Sunday afternoon, Jim waited for Melody in the car after their grocery shopping. He turned on Training and selected two events: Easter Holiday Plan and Mick Proposed to Nancy. Then he chose to use the flashcard to train his memory. Figure 5.14 shows the 'Flashcard' with Easter Holiday Plan. When he finished training for the third time, Melody got into the car. Before he went to the bed, he turned on his phone and found the two post-its on the mobile's home screen. He read the 'Post-its' and clicked the 'ANSWER' button to check his answer. Figure 5.17 demonstrates these 'Post-its'. He found out he can remember

these two events after using the 'FlashCard Training' and 'Post-its'.

On Monday morning, the first thing Jim finished was booking six flight tickets to Christchurch. After five minutes, he received the e-tickets and forwarded them to his family before he left the office to attend the Monday morning meeting. He got a text message from his mum: "I cannot wait to meet you at the airport!". Melody also sent a text message to him: "Wow! I forget about it until I saw the email, thanks baby."

## 5.5.5 Settings



**Figure 5.21:** Digital paper prototype of the 'Settings'.

'Settings' is the interface that comprises the user name, the email address, the network provider, the fort color, the frequency for sending the memories for backup and the switch for connecting to Karotz. The frequency for sending the memories for back-up is for TBI survivors who use email as memory storage. MyMemory conforms to this behavioural pattern and is one of the features which can help TBI survivors adapt to using MyMemory more smoothly.

This section summarised the interface design's final version of the conceptual design. This version is the digital paper prototype of MyMemory. It makes the conceptual design closer to reality. The usability test uses it to evaluate MyMemory to see how well it fulfils the goal of an augmented

autobiographical memory aid for TBI survivors.

# 5.6 Summary

This chapter contributes to answering both the third and fourth research questions identified in Sections 1.3.3 and 1.3.4, i.e., "What kind of special requirements do TBI survivors have for the design of an augmented memory aid?" and "What kind of information display will TBI survivors accept?".

The answers presented in the conceptual design of MyMemory. It builds on the memory box concept discussed in Section 2.5, keeping in view the design concepts mentioned in Section 5.2.1. The design fulfils the requirements by providing the results for TBI survivors from the interview user study, see Section 4.8.

This interface design consisted of these stages: the paper prototype, expert walkthrough and the digital paper prototype. The paper prototype focuses on displaying the concept and elements of MyMemory and without great consideration for usability design. For example, the confirmation message within informs of the progress and the suspend feature which saves the incomplete activity.

The expert walkthrough clarified the deficiencies in the paper prototype. We did modifications of them and concluded: 1) the language problems regarding the names, 2) the legibility problems on the length of the screen display, 3) the message for stating the progress, 4) the function of dealing with the incomplete activity and 5) using the flashcard as a training tool.

The final version is a digital paper prototype that is developed using the Balsamiq mock up software which makes the design closer to reality. It is not only a modified version of the paper prototype but also clarifies the features of each function. The significant change is the paper prototype feature of 'History' being becoming 'My Memories' on the digital paper prototype. The function of 'Training' adds 'FlashCard' as a training tool. Furthermore, it considers the privacy issue to set a switch for the 'Screensaver' (on/off).

In summary, this chapter reported the progress of the conceptual design development progress. Using the personas and scenarios we explained how the end-user will work with MyMemory's function. The goal of the next chapter is the design of the study to examine the usability of the conceptual design.

# Chapter 6

# Interface User Study for the Conceptual Design of MyMemory

This chapter aims to answer research question four: "What kind of information display will TBI survivors accept?". It also provides supplementary answers to research question three: "What kind of special requirements do TBI survivors have for the design of an augmented memory aid?". The chapter presents the results of an interface user study that investigated the usability of the conceptual design of MyMemory. The study received ethical approval from the Human Research Ethics Committee, Faculty of Computing and Mathematical Sciences, University of Waikato in 2013 (see Appendix B.1). The interface user study was executed by the completion of tasks using the digital paper prototype of MyMemory.

The chapter is structured as follows. Section 6.1 explains the purpose of the study and the importance of this research. Sections 6.2 to 6.4 reports the method (recruitment and tasks for the study), procedure and materials of the study. Section 6.5 divides participants into two groups based on participant's condition: TBI-participants and Non-TBI-participants. Section 6.6 reports the results about the usability of MyMemory's conceptual design. Section 6.7 highlights outcomes which are worth noting and important for this conceptual design of MyMemory. Section 6.8 summarises the study.

# 6.1 Goal of the Study

The aim of this study was to examine the usability of MyMemory's design and interface concepts. Findings from this study provides the data and feedback for structuring the implementation of the MyMemory prototype on a mobile device. In particular, this study investigated the MyMemory design to:

- ensure it provides adequate functions supporting the external memory storage and memory training tool for TBI survivors.
- confirm it displays the information in a manner which is acceptable to TBI survivors.
- measure the usability for TBI survivors' need.

This study uses the digital paper prototype that was introduced in Section 5.5. The next section reports the method of the study, including the recruitment and tasks of the study.

## 6.2 Method

The study method involved two stages: recruitment and usability test. Recruitment included recruiting participants and arranging meeting times with them. The usability testing refers to the task form used in the study. The following sections explain both elements in detail. We calculated the score of teach question based on the answers which the participants gave. The calculation includes each rating given by participants and the average for each question. Most questions had a scale of zero to four as feedback of the MyMemory's usability. Some questions were designed with two options and the participant was required to explain their choice. We calculated the total votes of the options and reviewed their explanations.

#### 6.2.1 Recruitment

The study used open recruitment; adults over 16 years old were approached using email (see Appendix B.2) or verbal invitation. The study

also required the face to face interview; therefore, the participant needed to live within 50km from the University of Waikato. Arranging the meeting with the TBI-participants was a key point to determine the time frame of the study.

The selection criteria were based on responses provided. Potential participants were people with TBI who participated in the previous study and demonstrated interest in participating in the following study (see Appendix B.2).

We also invited people without TBI who were interested in exploring the novel application. These were caregivers from the previous study (described in Section 4.5.2), computer science students and cognitive psychology researchers.

The studies were executed individually, and carried out at the University of Waikato or the participant's house. On average, one email was sent to invite them and two emails were sent to confirm the meeting time. TBI-participants recruited were sent one reminder three days prior to the meeting, and one day before a reminder by text message was sent. Non-TBI-participants recruited were sent one reminder one day prior to the meeting.

The recruitment process was time-consuming and it was difficult to arrange meetings with TBI-participants. Most TBI-participants had their own schedule and health issues, which made it hard to arrange meetings with them. Health issues that some TBI-participants reported include their energy and concentration are only functioning at certain times, such as before 11am, or being ill with flu requiring a week for recovery. Therefore, successfully arranging a meeting took an average at least three changes, each change needed to three days waiting for a reply email. These reasons explain why the recruitment took eight months to only get nine participants.

The participants were asked to complete tasks that were described in a form. The form involved two parts: tasks and feedback. Section 6.2.2 explains the purpose of the tasks and lists them.

## 6.2.2 Usability Test

This study used the 'think aloud' technique, also named think-aloud protocols (Blandford, 2014; Nielsen, 2012). It is a technique in which the user verbalizes their thoughts while interacting with a design or executing certain tasks. Blandford (2014) described think aloud as the most commonly used technique to demonstrate people's use of a particular system. Think aloud technique requires three elements:

- Representative users
- Representative tasks to perform
- Users executing task and commenting aloud

The selection of representative users of this study was described in Section 6.2.1. The focus of this section is the representative tasks.

## 6.2.3 Tasks

The task form (see Appendix B.5) includes eight tasks and an experience feedback survey. Each task has instructions and a scenario to direct the participant. To measure a function's usability, a scale is provided with five levels and a question asking how useful or easy was the function to use. To understand the feedback of the user's experience, an openended question asking for suggestions for the function was asked. For the subsections each task includes at least one question with a scale to measure the function's usability and one open-ended question.

## Task 1 – Adding Memory

The aim of Task 1 is to examine the usability of 'Adding Memory" for recording event data. Task 1 has two parts. Part 1 asks the participant to record this usability study meeting in MyMemory. Part 2 asks which design is their favourite.

## Interface Design of 'Adding Memory'

*Instruction* Please use 'Adding Memory' to record this meeting and write down the information on the paper copy (see Figure 6.1 and 6.2). After you finish recording the information, please click 'FINISH' button on the computer. Then close the pop up message to complete this task.

#### Question

1. How difficult do you think the way of inputting information was? (very easy – easy – normal – difficult – very difficult).

Due to the digital paper prototype not supporting the inputting of data, the participants had to write down the information on a paper copy as shown in Figure 6.1 and 6.2. The paper copy used in the study is a screenshot of the two-short screen design (see Section 5.5.2).

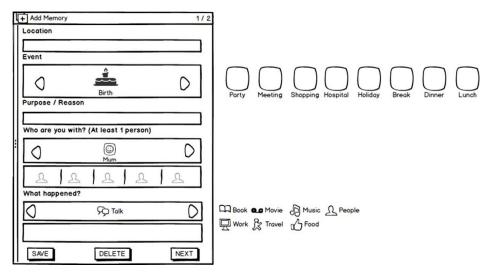


Figure 6.1: Paper copy of 'Adding Memory' for the first screen.

Figure 6.1 is the first screen for 'Location', 'Event' (Event Subject), 'Purpose/Reason', 'Who are you with?' (Involved People) and 'What happened?' (Activity). The paper copy cannot display the options in the way a digital paper prototype would; therefore, the options for the subject and the activity are listed next to them. For the person's options, MyMemory lists the options of the person who has entered and saved using 'Adding Memory'.

#### Chapter 6 Interface User Study for the Conceptual Design of MyMemory

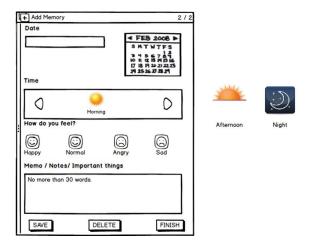


Figure 6.2: Paper copy of 'Adding Memory' for the second screen.

Figure 6.2 is the second screen for the date, time, emotion and brief note. The date offers two ways to enter: typing directly in the text field or selecting the data on the calendar. The options for time is listed next. Four emotion's icons display on the screen. The brief note is the text field that is limited to 30 words.

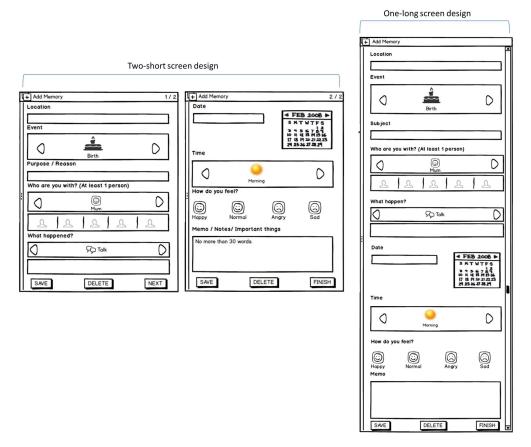
## Two-short Screens or One-long Screen Design

*Instruction* Please click 'LONG LIST' button to check one-long screen design. Click 'HOUSE' icon on left side then go back to the main page. Figure 6.3 shows the screenshots of the two-short screens design and the one-long screen design.

#### Questions

- 1. There are two types of displays (one-long screen design and twoshort screens design), which one do you prefer and why? and
- 2. Please specify the reason of your choice.

Task 1 is designed to investigate the usability of 'Adding Memory' and which types of interface design are accepted by the participants. The participants can review these two types of interface in the digital paper prototype.



**Figure 6.3:** Paper copy of 'Adding Memory' for two types of design. Left: Two-short screens design. Right: One-long screen design.

## Task 2 - FlashCard Training

Task 2 explores the effectiveness of 'FlashCard Training' of MyMemory. Two scenarios lead the participants through this study.

Scenario 1 – Before I Go to Sleep: Mark held a dinner party last Friday in his house. You went to the party and met Janet. Janet mentioned a book which related to a woman with amnesia due to traumatic brain injury. You know the book – Before I Go to Sleep and you bought it last month. At the end of the conversation, Janet and you are planning to watch Spider-Man next Friday at Chartwell cinema, and you will lend her the book.

Chapter 6 Interface User Study for the Conceptual Design of MyMemory

Scenario 2 – Mike Proposed to Nancy: You went to Waihi Beach with your friends. On the beach, Mike proposed to Nancy and Nancy asked you to be the bridesmaid/best man.

## Recording The Event Using Your Own Memory Strategy

#### **Ouestion**

1. For your own memory strategy, what kind of information do you need to record for both scenarios to help you remember.

## Usability of 'FlashCard Training'

Instruction You used 'Adding Memory' to record these two scenarios, then MyMemory shows the recorded memory as — Before I go to sleep, Mark's home, Janet want to borrow it and watching movies on next week and Mike proposed to Nancy, Waihi beach, I am the bridesmaid. Now please go to 'Training' -> 'FlashCard Training' -> Start Training to train two memories: Before I Go to Sleep and Mike Proposed to Nancy.

#### Questions

- What do you think about 'FlashCard Training'?
   (very useful useful normal slightly useful not at all), and
- 2. Any suggestions about 'FlashCard Training'?

Task 2 begins with requiring the participants to write down the information for two purposes. The first purpose is comparing the participants' records with MyMemory's records display. The second purpose is enhancing participants' memory about scenarios to execute this task. According to the results from Chapter 4, writing notes is a common strategy TBI survivors used. After participants completed the questions, they were asked to evaluate 'FlashCard Training' and to provide feedback.

## Task 3 – FlashCard Training Records

Task 3 used Scenario 2 – *Mike Proposed to Nancy* from Task 2 to execute the 'FlashCard Training Records' of MyMemory. Participants were asked to complete two questions.

## Interface Design of 'FlashCard Training Records'

Instruction 'FlashCard Training Records' shows all memories you have trained before. Please go to 'FlashCard Training Records' to find *Mike Proposed to Nancy* and do more training.

#### Question

How difficult do you think finishing Task 3 was?
 (very easy – easy – normal – difficult – very difficult).

## Usability of 'FlashCard Training Records'

#### **Questions**

- 1. What do you think about 'FlashCard Training Records'? (very useful useful normal slightly useful not at all), and
- 2. Any suggestions about 'FlashCard Training'?

Task 3 required the participants to find one event that they had already used for 'FlashCard Training'. Therefore, the participants can find it in 'FlashCard Training Records'. The purpose of this task investigates whether the training results could raise the participants' awareness about their autobiographical memory.

## Task 4 and 5 - Post-its and Screensaver

Task 4 and 5 are to test the usability of 'Post-its' and 'Screensaver'. Both tasks used the scenarios from Task 2. In the end, participants were asked to answer the question related to the useful of 'Post-its' and 'Screensaver'.

Chapter 6 Interface User Study for the Conceptual Design of MyMemory

## Usability of 'Post-its'

Instruction Please go to 'Training' -> Display Training -> Select Display Type -> 'Post-its' to set two memories: Before I Go to Sleep and Mike Proposed to Nancy. For 'Post-its' display, the memory information changes into a question and you will get the answer when you click it (it looks like the information on the right side).

#### **Questions**

- What do you think of 'Post-its'?
   (very useful useful normal slightly useful not at all), and
- 2. Any suggestions about 'Post-its'?

## Usability of 'Screensaver'

Instruction Please go to 'Training' -> Display Training -> Select Display Type -> 'Screensaver' to set two memories: 'Before I go to sleep' and 'Mike proposed to Nancy'. You can find three different types of 'Screensaver': banner, scrolling text and scrolling text box. You can click each one to check them.

#### **Questions**

- What do you think of 'Screensaver'?
   (very useful useful normal slightly useful not at all), and
- 2. Any suggestions about 'Screensaver'?

These two displays involve privacy because the events stay on the main screen constantly until the participants do the next activity. All participants thought that these designs show too much information on the main screen that may damage their privacy. Therefore, it would fixed and presented in the implementation of the MyMemory prototype (see Section 7.3.4).

## Task 6 - Voice Recording Training

Task 6 focuses on inspecting the icon and data display that the participants can recognize easily. It has two questions: Question 1 is asking for evaluation about 'Voice Recording' and Question 2 is asking the participants how often they will listen to the voice record.

## Interface Design and Usability of 'Voice Recording Training'

*Instruction* Please go to 'Training' -> Display Training -> Select Display Type -> 'Voice Recording Training'.

#### **Questions**

- How difficult is it for you to distinguish which memory has a voice note and which one does not?
   (very easy - easy - normal - difficult - very difficult),
- 2. What do you think of 'Voice Recording Training'?

  (very useful useful normal slightly useful not at all), and
- 3. When and where you will replay this voice record?

## Frequency of Playing Voice Records

#### Questions

- 1. If you use 'Voice Recording Training', then how many times will you need to listen for remembering? (1-3 times, more than five times, as many as need), and
- 2. Any suggestions about 'Voice Recording Training'?

In this task, the question asks the frequency of listening to the voice record for remembering. This question provides the data regarding the participants use of 'Voice Recording'.

Chapter 6 Interface User Study for the Conceptual Design of MyMemory

## Task 7 – My Memories

Task 7 is designed for studying the event data display and sorting function. It includes one scenario and questions. The main screen of 'My Memories' lists all event data with purpose/reason, event (subject) and location. The first part of this task is asking the participants to explain the event data on the 'My Memories' main screen. The second part of this task starts with the third scenario – *Easter Holiday Plan*, and asks the participant to use two sorting functions to find it.

Scenario 3 – Easter Holiday Plan: You celebrated your Dad's 60th birthday this March in his home. At that time, you and your Mum planned a 3 days trip on Lake Tekapo for this Easter holiday. You use this application to record it. Now you get an email from your mum, she mentioned the plan you discussed on dad's birthday and she wants to confirm the date for the flight and accommodation. Now you want to find the details about this memory.

## Usability of 'My Memories'

Instruction Please go to Main Page -> 'My Memories' to find a memory related to Easter Holiday Plan. There are tools: 'Sort by Time' and 'Sort by Event' to sort memories by different order. Please use them to find the memory of Easter Holiday Plan.

#### Questions

- What do you think of 'Sort by Time' and 'Sort by Event' when you looking for the memory?
   (very useful useful normal slightly useful not at all),
- 2. Which one do you think you need it mostly? ('Sort by Time', 'Sort by Event),
- 3. How difficult was finding the memory of *Easter Holiday Plan*? (very easy easy normal difficult very difficult),

4. How difficult is it for you to understand the information of *Easter Holiday Plan*?

```
(very easy - easy - normal - difficult - very difficult),
```

- 5. Can you explain the information on the screen?, and
- 6. Any suggestions about 'My Memories'?

## Task 8 - Settings

Task 8 explores the participant's requirements of 'Settings'. It includes asking the participants to back up their memories and observes how long this step takes and how to do it.

## Usability of 'Settings'

Instruction MyMemory would send an email which includes a week of memories once a week. Therefore, you need to set the email address in the application. Please go to Main Page -> 'Settings' to change the email address.

#### Question

How difficult do you find it?
 (very easy – easy – normal – difficult – very difficult)

## Preferences of Saving Memories

#### Questions

- 1. For saving your memories, which way do you prefer: MyMemory automatically sends an email, manually uploading memories to your desktop or others (specify it), and
- 2. Any suggestions about 'Settings'?

## Task 9 - Feedback of MyMemory

This part collects further feedback of participants about MyMemory's digital paper prototype. The questions relate to the convenience and usefulness of MyMemory for augmented autobiographical memory and which functions are most useful/liked or less useful/disliked. The openended question for asking suggestions about MyMemory ends this form.

## Questions

- How convenient is MyMemory to use?
   (very convenient convenient normal slightly convenient not at all).
- 2. How useful is MyMemory to support your memory? (very useful uesful normal slightly useful not at all).
- 3. Which functions do you think are most useful / do you like (select all that apply), why?
- 4. Which functions do you think are less useful / do you dislike, why?
- 5. Any suggestions about this prototype?
- 6. Follow up study: would you be willing for us to retain your contact details for related follow up studies?

## 6.3 Procedure

At the start of the study, the purpose was explained to the participants and they were informed of their rights (see Appendix B.3), as well as given time to ask questions and obtain their consent (see Appendix B.4). Then the procedure moved to the actual user study.

The participants were asked to use the digital paper prototype (see Section 5.5) to complete the tasks form described in Section 6.2.2 (see Appendix B.5). The participants used the researcher's computer to execute this prototype of the MyMemory application. They were assisted to execute this study. The study was audio recorded in its entirety.

# 6.4 Apparatus and Materials

The following apparatus and materials were required to carry out each study. The study environment was set up as shown in Figure 6.4, the apparatus and materials included:

- 1. Dictation machine
- 2. Laptop with the MyMemory digital paper prototype
- 3. Participant Information Sheet
- 4. Research Consent Form
- 5. Tasks Form
- 6. Digital Camera



Figure 6.4: Study environment.

# 6.5 Participants

Nine participants were recruited in this study: four participants with TBI and four participants without TBI. The one additional participant with multiple sclerosis (MS) was for the purpose of the study treated similar to the TBI participants (see MS participant's details in Section 4.5).

## 6.5.1 TBI-participants Group

Table 6.1 shows a summary of data for participants of the TBI-participants group. Five participants were assigned in the TBI-participants group. All of them had brain injury with memory impairments, four were females and one was male. Two participants were diagnosed with mild level TBI, two were moderate level with TBI and one participant has MS. Two of them were part-time tertiary students, one was part-time graduate student, one was not allowed to work and one was retired. The time to complete the study ranged from 45 to 95 minutes.

**Table 6.1:** TBI-participants demographics. (F: Full-time jobs of 40hrs/week. P: Part-time jobs of 20hrs/week.)

Tare time jobs of Zonis, week.					
	Gender	Time to complete	Severity	Current	
	Gender	(minutes)	level	job	
T1	F	85	[MS]	(P) Tertiary student (P) Gallery owner	
T2	F	75	Mild	Unable to work	
T3	M	95	Moderate	(P) Tertiary student	
T4	F	77	Moderate	(P) Graduate student Solo parent	
T5	F	45	Mild	Retirement	

## 6.5.2 Non-TBI-participants Group

Figure 6.2 presents a summary of data for participants of the Non-TBI-participants group. Four participants were assigned in the Non-TBI-participants group, one female and three males. Two were full-time graduate students, one was a university lecturer and one was a full-time tertiary student. NT1 and NT2 are the caregivers to T1 and T2. The time to

complete the study was between 32 to 77 minutes respectively.

**Table 6.2:** Non-TBI-participants demographics. (F: Full-time jobs of 40hrs/week. P: Part-time jobs of 20hrs/week.)

	•	3	• •
	Gender	Time to complete	Current
	Genuer	(minutes)	job
NT1	F	34	(F) University lecturer
NT2	M	55	(F) Tertiary student
NT3	M	32	(F) Graduate student
NT4	M	77	(F) Graduate student

## 6.6 Results

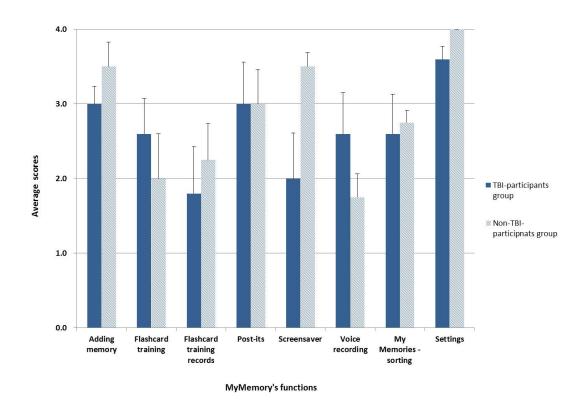
The study lasted between 32 and 95 minutes, which included the ethics consent and completing the nine tasks. The average for the nine participants was 57 minutes per participant. All studies were audio recorded.

## 6.6.1 MyMemory's Functions

This section presents the results of the evaluation of each function of MyMemory's prototype. The results are analysed following questions from Tasks 1 – 8.

Quantitative findings Quantitative findings are detailed by analysing the data from Tasks 1 – 8, as described in detail in Section 6.2.3. The question evaluates the usability or interface design for each function. Each question is scored from zero to four. There are five options for the answers from 'very difficult' or 'not at all' (scored by zero) to 'very easy' or 'very useful' (scored by four).

Figure 6.5 presents the average scores of each function with the standard error of the mean (SEM) by TBI-participants and Non-TBI-participants. As shown in Figure 6.5, both groups gave a high score to 'Settings', 'Adding Memory' obtaining the second highest score. Both groups gave the same scores to 'Post-its'. TBI-participants group scored 'FlashCard Training' and 'Voice Recording' higher than Non-TBI-participants group.

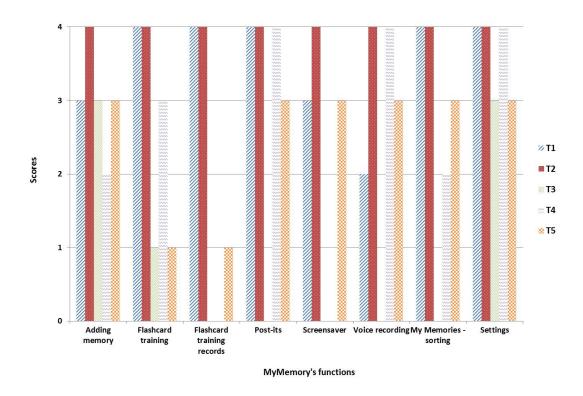


**Figure 6.5:** Average scores of each function with the standard deviation by TBI-participants and Non-TBI-participants groups. Data is presented as the mean of SEM. TBI-participants group n=5 and Non-TBI-participants group n=4.

The differences are 0.6 and 0.85. Non-TBI-participants group gave a high score to 'FlashCard Training Records', 'Screensaver' and 'My Memories' – Sorting. The significant difference is 1.5 score for Non-TBI-participants group higher than TBI-participants group to 'Screensaver'. The differences of the other two are 0.45 for 'FlashCard Training Records' and 0.15 for 'My Memories' – Sorting.

The score is between zero and four and the sample mean is two. Figure 6.5 presents the standard error of the mean (SEM) on each function's bar. According to the SEM, TBI-participants had different opinions of the usability and interface design of the functions. Particularly for 'Flash-Card Training', 'FlashCard Training Records', 'Post-its', 'Screensaver', 'Voice Recording' and 'My Memories' – Sorting. Compared with TBI-participants, Non-TBI-participants had different opinions only on 'Flash-

Card Training', 'FlashCard Training Records' and 'Post-its'. On 'Settings', Non-TBI-participants had no problem with the interface design of 'Settings'. The following sections detail and explain each participant with their results for each function.



**Figure 6.6:** Scores of MyMemory's function by TBI participants.

The results of TBI participants in Figure 6.6 indicates that the Setting gained 3.6, being the easiest to use function of MyMemory. Three participants (T1, T2 and T4) gave a full score to 'Settings' and the remainder scored three. 'Adding Memory' and 'Post-its' both obtained three being the second easiest to use, thus being useful functions of MyMemory. For the function of 'Adding Memory', T2 gave full score, the lowest score of two was given by T4 and the remainder gave three. Three participants gave full score to 'Post-its', T5 gave one and T3 zero. 'FlashCard Training', 'Voice Recording' and 'My Memories' – were scored 2.6 being the joint third most useful functions of MyMemory. Two participants (T1 and T2) gave a full score to 'FlashCard Training', T4 gave three and

the others gave one. For 'Voice Recording', two participants (T2 and T4) gave the full score, T5 gave three, T1 gave two and T3 zero. For sorting function of MyMemory, two participants (T1 and T2) gave full score, T5 gave three, T4 gave two and the others zero. 'Screensaver' gained two. T2 gave the full score, two participants (T1 and T5) gave three and two zero. 'FlashCard Training Records' (1.8) was the least useful function of MyMemory reported by the TBI-participants group. The score of 'FlashCard Training Records' was distributed thus; two (T1 and T2) for the full score, two (T3 and T4) zero and T5 one.

T2 was the only participant who gave a full score for each function in MyMemory. The reason was she has never used a memory aid to support her memory impairments since she had the brain injury. In this study, she found out her memory impairments could be improved when she used the suitable memory aid.

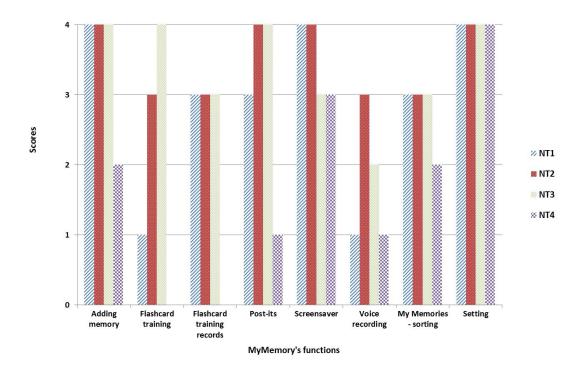


Figure 6.7: Scores of MyMemory's function by Non-TBI participants.

Figure 6.7 presents the results of the Non-TBI participants. All partic-

ipants gave full score to 'Settings' suggesting that it is the easiest to use function of MyMemory. 'Adding Memory' and 'Screensaver' both obtained three being the second easiest to use or useful function of MyMemory. Three participants gave full score to 'Adding Memory' and NT4 was the only participant who gave two. Two participants (NT1 and NT2) gave two to 'Screensaver' and the rest three. 'Post-its' obtained three being a useful function. NT2 and NT3 both gave full score, NT1 gave three and NT4 one. 'My Memories' – Sorting gained 2.75: three participants (NT1, NT2 and NT3) gave three and NT4 two. FlashCard training record obtained 2.25: three participants (NT1, NT2 and NT3) scored it three and NT4 zero. 'FlashCard Training' gained two: NT3 gave a full score, NT2 three, NT1 one and NT4 zero. 'Voice Recording' obtained 1.75 being the least easiest to use or useful function of MyMemory. NT2 gave three to 'Voice Recording', NT3 scored it two and the reminder one.

Qualitative Findings The following paragraphs report the participant's qualitative responses about the most and least useful/liked function of MyMemory.

Most useful/liked function Analysing the results from Task 9 – Feedback of MyMemory, the question is Which functions do you think are most useful? / Do you liked and why?. 'Settings' obtained the most votes from both groups. Except for 'Settings', each group reported two functions with the second highest votes for MyMemory.

TBI-participants group reported 'Adding Memory' and 'Post-its' as the most useful/liked function. Two common pieces of feedback reported by all participants about 'Adding Memory': 1) easier to organize inputting information, and 2) inputting information is the same as I record it on my own memory aid. All participants from the group were able to complete the task of 'Adding Memory' without instruction or assistance. Participants reported feedback about 'Post-its': "it's similar to keeping events I used to write down on the paper post-its note". All of them reported they can accept the 'Post-its' function without difficulties.

Non-TBI-participants group reported 'Adding Memory' and 'Screensaver' as the most useful/liked function. Easy inputting and saving information were the feedback of 'Adding Memory' from all participants of this group. All participants of this group preferred 'Screensaver' for displaying the information. The reason being that its information display is similar to the reminder application such as the widget of Evernote or Remember The Milk (see Figure 6.8).



Figure 6.8: Example of the widget of Remember The Milk on the main screen.

Interestingly, 'Post-its' were not the favourite function from the Non-TBI-participants group but all participants highly recommended the question-answer pattern for displaying the event data. The interactive design of 'Post-its' could enhance their memories.

Least useful/liked function 'FlashCard Training Records' was the least useful/liked function from the TBI-participants group, 'Voice Recording' for the Non-TBI-participants group.

Participants from the TBI-participants group gave the following feedback about 'FlashCard Training Records':

- "Checking the records is like an exam and I don't like exams" T1
- "If I remember it already, why should I bother to know the training I did" – T2
- "I personally would not need this application" T3

- "I am a game lover so making it is like a game" T4
- "FlashCard is not my thing" T5

Participants of Non-TBI-participants group reported that 'Voice Recording' is not a regular function they used on their mobile devices. Therefore, 'Voice Recording' of MyMemory was the least useful/liked function for them.

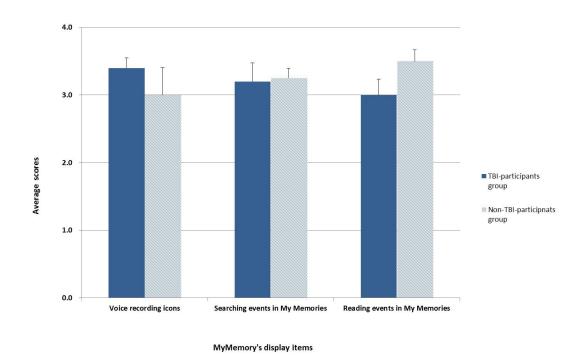
These two functions would not be implemented in the implementation of the MyMemory prototype.

## 6.6.2 MyMemory's Information Display

Task 6 and 7 examine how the participant would be able to search information quickly and easily through the interface of MyMemory. Three items were considered for the study: 1) voice recording icons, 2) searching events in 'My Memories' and 3) reading events in 'My Memories'. The icons of 'Voice Recording' examines the representation of the media playing and the events with voice records. Searching events in 'My Memories' requires the participant to find a particular event with the sorting function. Reading events in 'My Memories' asks the participant to explain the meaning of a particular event in 'My Memories'.

Each item corresponds to one question. Each question has five options for the answer ranging from 'very difficult' (scored by zero) to 'very easy' (scored by four). The questions were described in detail in Section 6.2.3.

As shown in Figure 6.9 both groups gave similar scores for these subjects. In general, all participants understood the way to display information in MyMemory. However, SEM showed that some of the TBI-participants reported they felt challenged when searching and reading the information in 'My Memories'. They needed more time to complete related tasks. Sorting the information order for searching is an unusual way in comparison to textual search. Once TBI-participants understood how to use sorting then all of them agreed that it is the better method for them for searching. Non-TBI-participants group had a different opinion on voice recording icons. Some of them reported they did not need this



**Figure 6.9:** Average scores of MyMemory's display items with the standard deviation by TBI-participants and Non-TBI-participants groups. Data is presented as the mean of SEM. TBI-participants group n=5 and Non-TBI-participants group n=4.

function therefore they scored it quite low. However, they agreed the interface design of voice recording icons was simple and easy for reading.

# 6.6.3 One-long Screen or Two-short Screen Design for Adding Memory

Question 2 in Task 1 is designed to explore which type of interface design is accepted by TBI participants. Participants reviewed two types of screen design then selected their favourite and gave reasons.

Table 6.3 summarises the results obtained from the study. There were significant differences between the two interfaces. Of the five participants in the TBI-participants group, four prefer the one-long screen to the two-short screens. In the Non-TBI-participants group, all participants favour the two short screens.

Participants of the TBI-participants group preferred one-long screen

**Table 6.3:** Results of two interfaces of the 'Adding Memory' by TBI-participants and Non-TBI-participants groups.

and item in participants groups.						
Group name	One-long screen	Two-short screen				
TBI-participants group	4	1				
Non-TBI-participants group	0	4				

design to two-short screens design, because of scrolling being easy for participants to check the data and move back and forth. NT2 was the only participant who gave a vote for two-short screens design. The feedback stated:

- "Seeing it all at once is what I want." T1
- "Scrolling takes more visual effort and I have visual scanning and tracking problems. Therefore I prefer the two short screen." T2
- "Better to complete the input without changing screens." T3
- "Depends on display. Would see two-short screens as more useful for the desktop application. One-long screen with the mobile/tablet is the ideal performance." – T4
- "Prefer it on one page (rather than going between screens) easier to see it all at once and scroll down." – T5

All participants of the Non-TBI-participants group agreed the two-short screens was their preferred design. The reason they reported was it was too much information to follow on one-long screen interface.

#### 6.6.4 Sort by Time or by Event on My Memories

TBI survivors have memory impairments thus text search is not a suitable solution for them. MyMemory provides a sorting approach instead of a text search. Participants completed Task 7 then described which sorting approaches they used to complete the task and gave reasons.

According to the results, Table 6.4 reported which sorting function could help the both groups. Participants can choose either function or neither of them. The results were very similar for both functions for both groups.

The votes from the TBI-participants group showed, two votes for 'Sort by Time' and three for 'Sort by Event'. Within these five votes, T1 and T5 chose both sorting functions. T3 voted for 'Sort by Event'. T2 and T4 chose neither of them. The votes from the Non-TBI-participants group showed two votes for 'Sort by Time' and two for 'Sort by Event'. NT1 and NT4 voted for 'Sort by Time'. NT2 and NT3 voted for 'Sort by Event'.

TBI participants all considered the sorting approach is better than the text search but for different reasons. T1, T3 and T5 all reported that they finally can do searching and exactly know what they are looking for. T2 and T4 agreed with the sorting approach but they both suggested 'Sort by People' or 'Sort by Location'. Non-TBI participants all reported that textual search is what they expected for searching. Therefore, they asked for textual search to be added into MyMemory.

**Table 6.4:** Results of two sorting functions of 'My Memories' by TBI-participants and Non-TBI-participants groups.

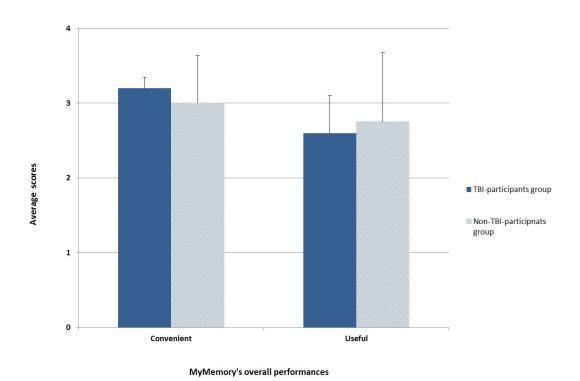
Group	Sort by Time	Sort by Event
TBI-participants group	2	3
Non-TBI-participants group	2	2

### 6.6.5 MyMemory's Overall Performance

Questions in Task 9 explore MyMemory's overall performance. Participants asked for the evaluation of how convenient using MyMemory is and how useful MyMemory is to support their memory. The last question is an open-ended question that asks the participant to give suggestions about MyMemory.

Figure 6.10 presents the summary of the scores for evaluating MyMemory for convenience (for using) and usefulness (for supporting your mem-

ory). TBI-participants group scored 3.2 for convenience, while Non-TBI-participants group gave three only. However, Non-TBI-participants group gave 2.75 to MyMemory's usefulness for their memories, and TBI-participants group gave 2.6.



**Figure 6.10:** Overall scores for the MyMemory by TBI-participants and Non-TBI-participants groups. Data are presented as the mean od SEM. TBI-participants group n=5 and Non-TBI-participants group n=4.

All TBI participants accepted MyMemory as an external memory storage for their memories. Moreover, T1 and T2 declared they believed MyMemory can replace their own current memory aids, such as their paper diary or writing on the hand. However, two suggestions were provided by TBI participants about MyMemory's interface design: more concise main screen display and more options of back-up/sharing functions. All TBI participants reported the main screen design may be good for controlling functions of MyMemory but not good for using. They preferred to review all event data once they open the application. All TBI participants agreed that 'FlashCard Training', 'Post-its' and 'Screen-

saver' are good for improving their memory. However, T3 and T5 reported that 'Adding Memory' is enough for their memory, they do need other functions.

More back-up/sharing functions is another suggestion that was not only provided by the TBI participants but also Non-TBI participants. Two Non-TBI participants (NT1 and NT2) are caregivers of TBI relatives. In the study, emailing the event data is the only option provided by MyMemory. They suggested that text messages should be included. Text messages are the general and common way for TBI survivors to back-up their memories and caregivers usually use them to remind their TBI relatives.

The summary of feedback from TBI-participants group matches the aim of MyMemory as designed – the external memory storage and memory training tool, that was mentioned in Section 5.2.2. Participants reported their feedback:

- "I believe it's just not a memory storage for me. These have progressive depth of information to organize and display so the 'Post-its' are even better then paper 'Post-its'." T1
- "So helpful condensing complex information, storing, training and retrieving memory will be amazing. Before I was living in a fog of not remembering – now there is the possibility of clarity and an improved tool for me." – T2
- "I personally wouldn't need this method. However, it provides a relatively simple method of memory recalling assistance that can be on hand at all time." – T3
- $\bullet$  "Overall, it is a good storage for my memory. But I don't like its performance too boring, try to make it more interesting just like the game." T4
- "All functions to aid memory are recorded and saved in logical meaningful ways. Colour coding may be helpful if your design can have it." T5

Non-TBI-participants group considered MyMemory as a reminder. Therefore, all suggested an alarm setting was required to be added to MyMemory. The training function could be removed because it was not useful.

- "It might be useful to be able to add an alarm or photo to the memory. For the caregiver viewpoint, syncing between two devices would be useful and necessary." – NT1
- "The application needs an alarm function." NT2
- "Adding an alarm function and taking off the training parts, I would love it more." – NT3
- "Attaching a photo to a memory could make a complete memory record." – NT4

#### 6.7 Discussion

This section reviews the findings from the study and compares them between the two groups, TBI-participants and Non-TBI-participants groups. This discussion supports the usability of the MyMemory for implementation described in Chapter 7.

## 6.7.1 Time for Completion of Study

The expected completion time for the study was 60 minutes. The actual average for completion for the TBI-participants group is 75.4 minutes and for Non-TBI-participants group is 38 minutes. All participants completed the study without extra assistance. The results showed that MyMemory, while having a clear interface, may not be intuitive enough for TBI-participants. Particularly for tasks related to searching and reading the information in 'My Memories'. Sorting the information order for searching is an unusual approach in comparison to textual search. TBI-participants took time to understand how to use sorting for searching. Once they understood it, they all agreed it is a better method for them.

#### 6.7.2 Core Functions of MyMemory

Core functions of MyMemory are 'Adding Memory' (feed single event data), 'Post-its' and 'Screensaver' (display selected event data) and 'Flash-Card Training' (display selected event data). These core functions mean MyMemory can record and display information for memory training. Most of the TBI-participants like MyMemory's interface design but it is a different story for the usability of MyMemory. The next sections discuss this for each function.

1. Adding Memory The average score of 'Adding Memory' has a difference of 0.5 between the two groups (TBI-participants group for three, Non-TBI-participants group for 3.5). Participants from TBI-participants group all reported the required information for 'Adding Memory' is concise and adequate for them. An explanation of this might be that it includes similar data they record for their memories using their own memory aids. However, the feedback from Non-TBI participants provided the opposite opinion of 'Adding Memory'. They required more data such as attaching a photo or color coding for organizing event records.

The most striking result to emerge from the data is for the two interfaces of 'Adding Memory'. According to the interview user study with TBI survivors with memory impairments, too much information displayed at once caused TBI survivors to suffer increased physical discomfort. Therefore, the two-short screens design was deemed more suitable for TBI participants. The results stated the contrary proposition for the TBI-participants group. Most TBI-participants reported they preferred the one-long screen design because it was easier for checking their input data. Only one TBI-participant reported the two-short screen design as the best choice for her. The reason being her visual scanning and tracking problem caused her difficultly in scrolling the screen and reading. Non-TBI participants have no preference on both designs. However, all Non-TBI participants reported the two-short screens design is suitable for them. Two-short screens design seems more organized and compact to display the data of 'Adding Memory'.

- 2. Post-its and Screensaver TBI-participants group gave a score of three to 'Post-its', the same score they gave to 'Adding Memory'. According to the interview user study in Section 4.6.3, 'Post-its' is the most common paper-based material TBI survivors used. Therefore, 'Post-its' obtained a high score in training tools from the TBI-participants group. However, the privacy issue was raised for 'Post-its' by the TBI-participants group. Understandably, the question-answer pattern on 'Post-its' is the cause for the privacy issue. Non-TBI-participants group scored 3.5 to the 'Screensaver', the same score they gave to 'Adding Memory'. Non-TBI participants gave a full score or three to 'Screensaver'. They preferred 'Screensaver' because it is similar to some applications they use on their phone already, such as the Evernote list or Google calendar.
- 3. FlashCard Training 'FlashCard Training' is the function with the lowest scores in both groups. Interestingly, all participants agreed that it is a useful tool to improve their memory. The data display in FlashCard is the major cause for giving a low score. T1 and T2 suggested the contents of the card change to be question-answer pattern. T4 expected more game elements within it, such as gaining points. T3 and T5 announced it could help other TBI survivors but not them. NT1 and NT2 believed it could help their TBI relatives if their relatives remember to use it. NT2, NT3 and NT4 all reported that 'FlashCard Training' is a good tool for learning new information, such as new languages, but they would not use it to train their autobiographical memory.

#### 6.7.3 Feedback for MyMemory

The feedback for MyMemory from the TBI-participants group suggests they consider MyMemory as an external memory storage. It satisfies the purpose of MyMemory designed for TBI survivors. However, a more concise main screen display and more back-up/sharing functions were required by TBI-participants. They asked for the main screen to display all event data rather than the control panel. A text message for back-up/sharing functions were not only suggested by TBI participants but also Non-TBI participants who are caregivers of TBI survivors.

For Non-TBI participants all reported that MyMemory is a reminder tool for them. Therefore, they required these functions to be added to MyMemory: an alarm setting, photo attaching and colour coding for categorizing the importance of events.

# 6.8 Summary

This chapter contributes further to answering the third research question identified in Section 1.3.3, i.e., "What kind of special requirements do TBI survivors have for the design of an augmented memory aid?" by interviewing TBI survivors to investigate requirements of their ideal memory aid. The answer was found from the interface user study, which aims to examine the usability of the conceptual design of MyMemory.

The interface user study uses the conceptual design of MyMemory in a digital paper prototype and participants completed tasks with this digital paper prototype. These findings supported the conceptual design of MyMemory for augmenting autobiographical memory. This conceptual design is based on the autobiographical memory theory and the results from the previous studies. 'Adding Memory' uses the concept of five factors of memory being the elements to record the event. These elements are enough for TBI survivors to trigger their memory. One-long screen design of 'Adding Memory' is accepted by most TBI survivors. The training tools are useful for TBI survivors' memory ability, especially 'Postits'. Overall, even though MyMemory is specialized for the TBI survivors these findings confirmed that it also worked for the average person's memory.

Findings of open-ended questions focused on participants describing their thoughts and experiences about MyMemory. The findings of the TBI-participants group confirms an external memory storage is a memory aid TBI survivors required for their memory. The concept of an external memory storage is important for TBI survivors that was reviewed in the related works in Section 3.2.2. Later this concept was confirmed by TBI survivors through the interview user study in Section 4.9. Findings shows that memory training tools could improve TBI survivors' memory.

MyMemory applies spaced retrieval in 'FlashCard Training' and 'Postits'. Most TBI participants believe that 'Post-its' could improve their memory while they use it. However, they were concerned the event data display with the question-answer pattern on 'Post-its' may cause a breach of personal privacy. Overall, all participants agreed that MyMemory is easy to use as an application for recording their memories.

In summary of this study, the conceptual design of MyMemory was confirmed by the TBI-participants group to be helpful for dealing with their memory impairments. However, they suggested three modifications for the implementation: concise main screen of MyMemory, altering the contents of 'FlashCard' with the question-answer pattern and using text message for back-up/sharing.

The next chapter will further discuss these suggestions and modifications before implementing MyMemory.

# Chapter 7

# Implementation of MyMemory

Chapter 5 described the conceptual design of MyMemory, our augmented autobiographical memory application for TBI survivors with memory impairments. Chapter 6 reported on the interface user study to test the usability of the conceptual design of MyMemory. This chapter now describes the implementation of the MyMemory digital prototype, focusing on the user interface (the final version) and the architecture of the system.

The chapter is structured as follows. Section 7.1 describes the architecture and data flow of MyMemory. Section 7.2 reports the system structure and the implementation details. It highlights the coding part related to SQLite for the database and SQL statements for selecting data. Section 7.3 explains the implemented interface design of MyMemory with a scenario. Section 7.4 discusses the implementation of the MyMemory prototype in relation to the insights from preceding chapters. The Chapter closes with a summary in Section 7.5.

# 7.1 Architecture and Data Flow of MyMemory

This section introduces the architecture of MyMemory. It includes eight steps of the data flow through MyMemory. Figure 7.1 shows the high level architecture of the prototype of MyMemory. The prototype is made up of three parts, the interface of adding memory, the database of saving events and the interface of displaying events.

#### Chapter 7 Implementation of MyMemory

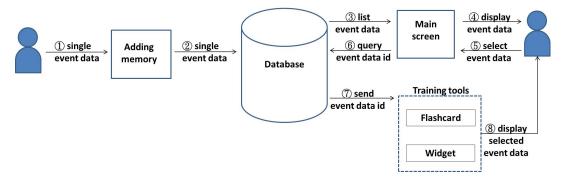


Figure 7.1: Implemented parts of the conceptual design

Step 1 & Step 2 – Feed single event data The user inserts single event data through Adding memory's interface and it is saved in the database. This includes the database automatically creating a unique id when the event data is saved.

Step 3 & Step 4 – Display all event data As soon as MyMemory is opened, the database retrieves all event data and lists them on the main screen. The user can read all event data on the main screen.

Step 5 & Step 6 – Query selected event data The user selects the event data on the main screen and makes a query to the database. The query finds the selected event data's id in the database.

Step 7 & Step 8 – Display selected event data MyMemory receives the event data's ids from the previous steps and sends them to the training tools. The training tools finds the respective event data according to the received ids, then displays them.

The implementation follows the data flow sketched above. The next section introduces the system structure and implementation details of MyMemory.

# 7.2 Implementation

This section of the implementation include details of the environment used for building MyMemory and the structure of MyMemory's code.

#### 7.2.1 Implementation Environment

MyMemory was written for Android using Eclipse. Android Development Toolkit (ADT) is a plug-in for the Eclipse IDE that extends the capabilities of Eclipse.

The structure of an Android application is fairly rigidly defined. Android projects in Eclipse have a pre-defined structure with code and resource organized into a number of folders. Table 7.1 describes the structure.

The "src" folder contains the file source code that implements the functionality of MyMemory. The "res" folder includes the resource files for MyMemory, such as the drawable file stores graphics used in MyMemory. The layout file contains XML files that define the layout of the widgets, buttons, text fields etc., in the screens of MyMemory. The values file contains various string values used throughout MyMemory, such as text strings and style definitions. The main use of this is the string.xml file, which can be used to store the text strings used in MyMemory's layouts, such as the labels on buttons. It is also convenient for the application when translating into other languages with just the addition of a single

**Table 7.1:** Summary of the structure of an Android projects.

Folder	Description
src/	This folder contains the Java source files.
gon/	Generated Java library,
gen/	this library is for Java internal use only.
	It can store resource files such as pictures,
rocl	XML files for defining layouts etc
res/	Within this folder there are additional folders
	such as Drawable, Layout, and Values.
res/drawable	It stores the various graphic files.
	This is the place for XML layout files.
	Layout files are XML files
res/layout	which define how various Android objects
	(such as textboxs, buttons, etc.).
	are organized on the screen.
res/values	XML files which store various string values
165/values	(titles, labels, etc.).

file.

#### 7.2.2 Memory Storage

The data for MyMemory was designed to be stored in a single SQL table. There were three reasons for this design choice. Firstly, the SQL table allows us to review and analyse data conveniently. Secondly, the structure of the SQL table is useful for managing the increasing data over time. Thirdly, storing data in a database has advantages for developing and improving MyMemory in the future.

The database was built using SQLite. SQLite is an open source database that supports standard relational database features like SQL syntax, transactions and prepared statements. There are three advantages for using SQLite as a database on MyMemory. Firstly, SQLite database provides queries and stores the data in a structured manner. Secondly, SQLite database can be queried and the data retrieval is much more robust than MySQL in the Android system. Thirdly, SQLite only has to load as much data as it needs, startup time and memory consumption are reduced <sup>1</sup>.

Following the architecture of MyMemory (see Section 7.1), Figure 7.2 displays the UML diagram for MyMemory. The 'event data' records the detail of the event and gives a unique id (event data id) for representing each event. The entity for 'main screen' reads an event data id and retrieves the detail from the database to display. The entity for 'selected event data' processes the query with the event data id and passes the result to the training tool. The entity for 'training tool' receives the results which are the event data id for the selected event data to generate the information with the memory-factor pattern (see Section 7.3.4) and display.

The entity of 'event data' aims to capture and save the event data. It is also the first step to process the event data in the database. There are three main classes to manage the 'event data' entity. The MyDBHelper class is designed to create and manage the database in MyMemory. Capturing of the event data and writing the record into the database was controlled by the ItemDAO class. The Item class was designed to set

<sup>&</sup>lt;sup>1</sup>SQLite website: http://www.sqlite.org

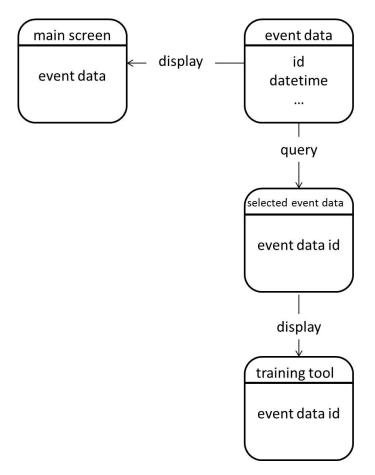


Figure 7.2: UML diagram of MyMemory.

the constructor with properties/characteristics of object (meaning Item-DAO).

The MyDBHelper class follows SQLite's rule to build the database. The getDatabase method is checking the database first. If the database exists then the next thing is writing the record into the database. Otherwise, it would create a new database using the onCreate method.

The main purpose of the ItemDAO class is to write the record. In the class, using the SQL statement creates one table with 15 columns for writing the record in the database. Figure 7.3 shows the entity of item.

There are 15 fields in this table. Each entity represents one column of the record. Here, some interesting columns in the table are explained. The 'id' is created automatically by the database and it's unique. The 'datetime' means the local time and date that is written on the row with

#### Chapter 7 Implementation of MyMemory

item Id: Integer datetime: Integer (NOT NULL) it\_date: Integer time: Text colour: Integer (NOT NULL) title: Text location: Text people: Text activity: Text content: Text(30) filename: Text latitude: Real longitude: Real lastmodify: Integer selected: Integer

Figure 7.3: ER diagram of the item table.

the id. It also will present the current date on the date field in add memory. The 'colour' is presenting the label colour and the default is assigned with the id. The 'datetime' and 'it\_date' are recording different dates and times for the record. The 'it\_date' is the date that was set up by the user in the interface of add memory. 'Selected' is showing whether the event is selected or not.

#### 7.2.3 Display Event Data

The entity of 'main screen' focuses on retrieving and displaying all recorded events on MyMemory's main screen, which was controlled by the getAll method in the ItemDAO class. The process is retrieving the data from the database and presenting it on MyMemory's main screen. The ItemDAO class uses the SELECT statement to fetch all data from the database to display them in descending order on the main screen. There is a Cursor object in the class. A Cursor represents the result of a query and basically points to one row of the query result. A Cursor has two functions. Firstly, it is that Android can buffer the query results efficiently, as it does not have to load all data into memory. Secondly, it is

retrieving the data, which was selected to display on the training tool. 'Selected to display' means 'selected event data', which is discussed in the next section.

Related to the 'main screen' entity are two new searching approaches, 'Sort by People' and 'Sort by Location', of the sortByLocation and sort-Bypeople methods in the ItemDAO class. The design concept of using a sorting approach to replace the textual searching approach was based on TBI survivors with memory impairments, as described in Section 5.5.3. These two methods were designed to rearrange all recorded events by location or people in the ascending order to display on the main screen.

#### 7.2.4 Selected Event Data

The entity of 'selected event data' and 'training tool' is designed to display the selected event data in the training tool. Two methods in the ItemDAO class operate these two entities: setItemSelected and getSelectedItmes methods. The setItemSelected method is marked 'true' on the selected filed of the selected event data. Then the getSelectedItmes method retrieves id from the database, passing these related data to the flashcard or widget displaying these selected event data.

#### 7.2.5 Log and Record Report

According to the results from the interview user study, each TBI survivor has their own memory strategies even though thy may use the same memory aids. Based on this result observing TBI-participant's activity usage in MyMemory, is an important part of this research. Therefore, the implementation of MyMermoy includes two functions that were designed to collect reports of the user's activity usage (the log report) and event data records (the record report).

The function of the log report details the activity usage of 1) execution date, 2) execution time, 3) execution function, and 4) execution content over a period of time. Figure 7.4 shows an example of the log report. This function used the Android Log class to log executions and record them to a txt file. Through the log report, we can review every activity

#### Chapter 7 Implementation of MyMemory



Figure 7.4: Screenshot example of the log report.

the user did including the deleted record.

1	ID	Date	Time	Title	Location	People	Activity	Content
2	35	8/11/2015	Lunch	BBQ	Home.	Gурзу 1	eating	Lovely lunch withfriends today.
3	30	7/11/2015	Morning	Accident	69 Thomps	Dad	talking	Dad was coming in for morning vi

**Figure 7.5:** Screenshot example of the record report.

The function of the record report is designed to collect all recorded events TBI-participants saved in MyMemory. The record report is written into a csv file. It contains the event with eight related items: 1) ID, 2) Date, 3) Time, 4) Title, 5) Location, 6) People, 7) Activity, and 8) Content. Figure 7.5 shows an example of the record report. Using this function allows the ContentProvider class to provide access to files in the application's cache.

Both functions were designed to produce and attach on the email when clicking 'Email Results' or 'Logcat Report' buttons, which located on the screen of 'About MyMemory'. Once the email is sent then the txt or csv files will be destroyed. The data of the user's activity usage and the recorded events were analysed to investigate the effectiveness of MyMemory to TBI-participants in the evaluating user study, see Section 8.6.6.

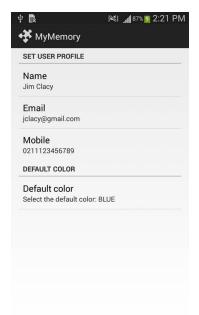
This section described the implementation of the code's structure and the user interface of MyMemory. It introduced the related classes and methods of the interaction on MyMemory.

#### 7.3 User Interface

This section introduces the user interface of the implementation of MyMemory's digital prototype. It is developed on an Android system and demonstrated on the Android mobile device. All screenshots come from the Samsung Galaxy S3 with Android version 4.3. The following sections discuss each element, and starting with this section uses one of the scenarios to outline the interaction of the user and the user interface. The scenario – *Easter Holiday Plan* was introduced in Section 5.1. The screenshots were produced using an artificial data set created specially for the walkthrough, which was made for this scenario.

#### 7.3.1 Settings

Three months ago, was the first time Jim used MyMemory. Jim followed the instructions to use MyMemory. He clicked the gear icon on the function bar to go into the settings screen. He completed the personal information (see Figure 7.6) and started using MyMemory.



**Figure 7.6:** Screenshot example of the setting.

The screen of the 'Settings' has two aspects: user profile and default colour. The user profile includes name, email and mobile. MyMemory

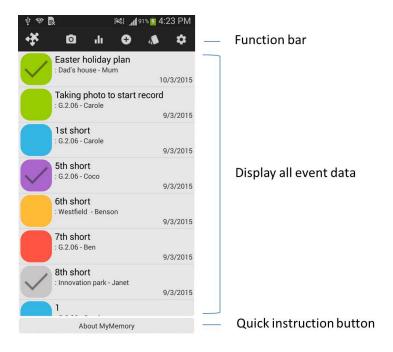
#### Chapter 7 Implementation of MyMemory

uses this information as the default, when the user sends the event data as an email or text message (see Section 7.3.3). The default colour is the default for the label colour.

#### 7.3.2 Main Screen

On Jim's dad 60th birthday, Jim, Melody and Jim's family had a celebration party at his dad's house. Jim's mum planned to go to Lake Tekapo during the Easter holiday. Everyone was so excited about this plan. Jim took charge of booking flight tickets. Before Jim left the dining room, he turned on MyMemory on his mobile to record this event.

Figure 7.7 illustrates the screenshot example of MyMemory's main screen. The main screen of MyMemory is composed of three parts. All event data are displayed on the middle area of the screen. The function bar is located on the top of the main screen and the quick instruction list at the bottom.



**Figure 7.7:** Screenshot example of the main screen.

The features of the application TBI survivors required (see Section 4.8.5) are a simple and clear information display. Therefore, MyMemory presents all event data on the main screen. The function panel from the prototype

had been changed to the function bar that is relocated on the top of the main screen. Starting at the left, is the MyMemory logo, which is an icon representing a puzzle. The camera icon is used for taking a photo to add new event data. The list icon is for sorting all event data 'Sort by Person' or 'Sort by Location'. The add icon is for adding new event data by the text input. The cards icon is for starting the 'FlashCard Training'. The gear icon is for going to the 'Settings' screen.

All event data is listed in the middle of the main screen sorted by time with the most recent time event first. Each event data is divided into three parts, see Figure 7.8. The part on the left presents the label colour that is assigned for the event data. When the event data is selected, the label is marked as shown in Figure 7.8. The middle section includes the title at the top, followed by the location and people. On the right is the date of the event.



**Figure 7.8:** Screenshot example of event data.

#### 7.3.3 Adding Memory

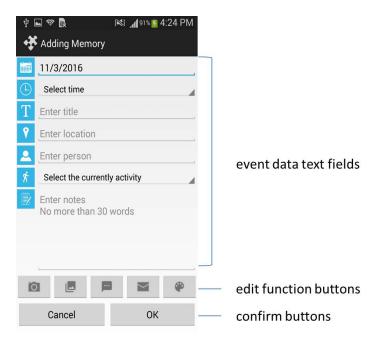
Jim clicked the 'Adding Memory' icon on the function bar then 'Adding Memory' screen was opened. He filled the related data and clicked 'OK' button for saving. Jim records the details as:

- **Date** 20/08/2013
- **Time** Evening
- Title Easter Holiday Plan
- Location Dad's house
- People Mum
- **Activity** talking

• **Notes** 3 days trip to Lake Tekapo. Booking flights\*6 to Christchurch.

He closed MyMemory and went to the living room joining the family for his dad's birthday cake.

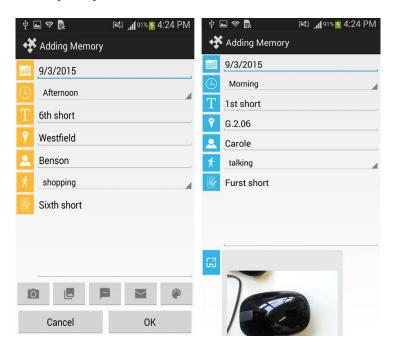
The screen for 'Adding Memory' includes three parts. The first part is the event data text fields that are based on the effectiveness factors of the memory. Each factor is presented by an icon and the related text field is behind. A set of edit function buttons are below the text fields. The confirm buttons are at the bottom of the screen. Figure 7.9 shows the screenshot example of 'Adding Memory'.



**Figure 7.9:** Screenshot example of 'Adding Memory'.

There are design concepts of 'Adding Memory' interface based on what was learnt from the study of the prototype. For one-screen with the simple display on 'Adding Memory' screen, using the related icons with the hint text in the field replaced the text prompt for each item. Avoiding colour coding on words may cause concentration difficulties for some TBI survivors. The colour coding applies to the icon's background only, see the example in Figure 7.10. The first column is the date field, the default is the current date. The second column is the time field that provides five options: morning, lunch, afternoon dinner and evening. The

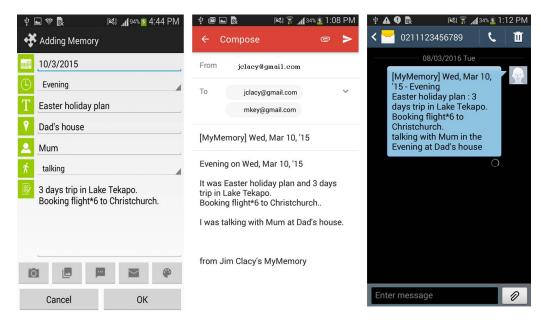
third to fifth columns are asking for inputting of the related event data: title, location and people. The sixth column offers nine selections for the current activity: talking, eating, working, studying, watching, reading, shopping, holidaying and exercising. The seventh column is a text field with 30 words limited to take a note for the event. If the event had an attached photo, the eighth column would be shown. Otherwise the screen of adding memory only has seven columns.



**Figure 7.10:** Screenshot examples of the differences of the label colour. Left: Colour coding with yellow. Right: Colour coding with blue and with a photo attached.

On the way home, Melody asked Jim, "How many tickets do we need". "Six, I remembered Mum said Alex will go with his girl friend, but let me check it", Jim said. He turned on MyMemory and clicked the event named "Easter holiday plan" on the screen. The screen showed the detail of the event, see left in Figure 7.11. "Yes, I am right. We need six flights", Jim was really happy about his memory. "Well, I think we need a big accommodation. Honey, could you send me an email about it, thanks", Melody said. "Sure, give me a second", Jim clicked the email icon button on the screen and the screen presented the composed email, see middle of Figure 7.11. Jim added Melody's email address from the phone's contacts

and sent it. Several seconds later, Melody's mobile phone received the mail. She opened and read it. "That's great. I will check the accommodation on Monday. I cannot wait to meet everyone there", Melody said. "Me too" Jim said.



**Figure 7.11:** Screenshot example of the email and text message. Left: Example of 'Adding Memory'. Middle: Example of the email. Right: Example of the text message.

Figure 7.11 shows the event display. A set of edit function buttons works only on the current event record shown. Starting at the left, the buttons are the camera, gallery, text message, email and palette. The buttons of the camera and gallery are for taking or attaching a photo to the event data after entering details of the event. The camera icon in here does the same job as the camera in the function bar to take a photo to attach to the event data. The only difference between them is the one in the function bar is enabled to open the 'Adding Memory' screen. The buttons of the text message and email are for wrapping the event data in a message and email.

Figure 7.11 shows how the event data from 'Adding Memory' (left) is transferred to the email (middle) and text message (right). The email and text message are designed for TBI survivors backing up their memory or sharing memories with their caregivers. In the email, MyMemory

processes the data to be a description of the event that is similar to the verbal description the caregivers used. In the text message, MyMemory processes the data to be a note similar to that which TBI survivors wrote on the paper material such as the diary or post-its. The palette button is providing the colours for changing the label colour.

#### 7.3.4 Training Tools

The training tools of MyMemory are based on the spaced retrieval technique and executed using the flashcards or a widget. There is a limit of five events for the training tools. The theory derived from Section 2.2.4 is that the human memory span is five to nine items for short-term memory. MyMemory is specialized for the TBI survivors with memory impairments therefore it sets five as the maximum number for the memory span.

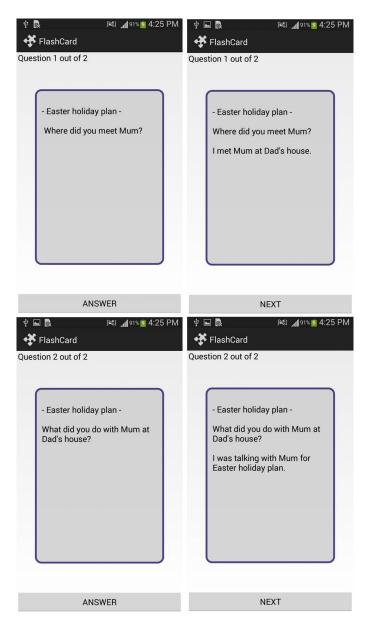
#### FlashCard

The next morning, Jim had his breakfast with Melody at his own home. He also turned on MyMemory and found Easter Holiday Plan on the top of the event list. He ticked it and clicked the 'FlashCard' icon on the function bar. Then Jim played the 'FlashCard' with Easter Holiday Plan, see Figure 7.12.

After breakfast, they went to the supermarket for the weekly grocery shopping. They ran into Alex and his girlfriend – Kelly. Alex mentioned the Easter holiday plan and Jim told him "I remember you and Kelly will join us". Alex was pretty surprised about Jim's memory, he said "Wow! You remember it so I do not worry about tickets, do I?". Melody smiled and said "Jim got it, just worry about what would we do there?". Kelly said she can arrange horse riding for everyone. Jim and Melody both thought it is a good idea. After that, they said goodbye to each other and continued their grocery shopping.

The concept of 'FlashCard' uses a memory-factor pattern to create the question and answer. The elements of the pattern include People, Location, Activity and Title from the event data to produce two questions with answers. They are:

#### Chapter 7 Implementation of MyMemory



**Figure 7.12:** Screenshot example of 'FlashCard'. From left to right: First question card, First answer card, Second question card and Second answer card.

- Question 1: Where did you meet People?
   Answer 1: I met People at Location.
- Question 2: What did you do with People at Location?
   Answer 2: I was Activity with People for Title.

Therefore, 'FlashCard' uses this pattern to produce these questions

#### and answers:

Question 1: Where did you meet Mum?
 Answer 1: I met Mum at Dad's house.

Question 2: What did you do with Mum at Dad's house?
 Answer 2: I was talking with Mum for Easter Holiday Plan.

According to the memory-factor pattern maintained above, each event data is processed with two questions and answers. The question card shows the event's title followed by question one. Once the 'ANSWER' button is clicked, the answer card is presented. The answer card repeats the title, the question and lastly the answer is displayed.

#### Widget

On Sunday night, Jim turned on his phone and read MyMemory's widget Easter Holiday Plan on the mobile's home screen, see Figure 7.14. He turned on his calendar and checked tomorrow's scheduler. He is free after the morning meeting so he can deal with the flight booking. Then he turned off the mobile and went to bed.

On Monday, Jim finished the meeting and went back to his office. He turned on his phone then saw MyMemory's widget – Easter Holiday Plan on the phone. He sent an email to his travel agent for booking six flight tickets to Christchurch on Easter Friday. He got the agent's phone call and confirmed the information about the flight on the way back to the office. Jim felt happy because he can remember the information he needs without checking again. After five minutes, he received the e-tickets from the agent and forwarded them to his family before he left the office to go back home. He got a text message from his mum: "I cannot wait to meet you at the airport!".

The concept of 'Widget' is derived from the post-its in the conceptual design. From the interface user study there emerged concerns about the privacy issue of 'Post-its' displayed on the home screen. The solution is to use the factors of memory instead of the question-answer display. Widget is one function of the Android system and it is an essential aspect

#### Chapter 7 Implementation of MyMemory

of home screen customization. Therefore, the widget meets the concept of 'Post-its' – repetition. MyMemory uses the widget to implement these requirements, Figure 7.13 shows an example of 'Widget'.



Figure 7.13: Screenshot example of 'Widget'.

'Widget' is a 4\*2 banner design on the home screen, see Figure 7.14. The banner includes three parts. The MyMemory and its logo are at the top, followed by the event data which includes the title, location and people. Figure 7.13 presents the event data that is the event related to Easter Holiday Plan (Title) with Mum (People) at Dad's house (Location). These three factors are the most common elements that TBI survivors recorded for their own memory on the physical post-its. In other words, the widget is the digital version of the post-its on the main screen of the mobile device, and clicking the widget can show the next event data.



Figure 7.14: Screenshot example of 'Widget' on the home screen.

#### 7.4 Discussion

This section discusses the implementation of the MyMemory prototype with regards to the conceptual design from Chapter 5 and what was learnt from the study of the interface in Chapter 6.

#### 7.4.1 Functions

This chapter described the implementation of the MyMemory prototype on the Android system. It also detailed the final version of the conceptual design on the interface.

It further explains how MyMemory fulfils the requirements of TBI survivors for their memory impairments. The requirements are:

- An external memory storage for TBI survivors that saves their memories.
- TBI survivors' memory only requires adequate data for triggering.
- Simple and clear information display reduces TBI survivors difficulty with concentrating.
- The spaced retrieval technique improves TBI surviviors' memory ability

The first two requirements focus on the 'Adding Memory' function of MyMemory and Section 7.3.3 explains the detail. The main screen of MyMemory satisfies the third requirement, see Section 7.3.2. Training tools are based on the spaced retrieval that fulfils the fourth requirement, see Section 7.3.4. The implementation of the MyMemory prototype follows these requirements and the architecture and data flow discussed earlier.

#### 7.4.2 User Interface

The final version of the interface design is using the main screen to present all the event data in the middle and to change the function panel into the function bar at the top. Thus the user can review all events

#### Chapter 7 Implementation of MyMemory

when they turn on MyMemory. The screen of 'Adding Memory' uses the icon presentation instead of text prompts. One-long screen design is accepted by most TBI survivors as discovered from the interface user study in Chapter 6. The training tools are 'FlashCard' and 'Widget' and both of them now have a different their information display from the prototype. 'FlashCard' uses the memory-factor pattern to describe the event. The pattern follows the results from the interview user study, including factors of memory and the sentences the caregiver used to remind or trigger their TBI relatives' memory. 'Widget' uses factors of memory to protect the personal information appearing on the mobile's home screen.

# 7.5 Summary

This chapter contributes to answer the fifth research question identified in Section 1.3.4, "Can the training make a difference?".

It introduced details of the implementation of MyMemory, the conceptual design of which was described in Chapter 5. The implementation also detailed the final version of the conceptual design on the interface. This prototype was used in an evaluation study, as reported in Chapter 8.

# Chapter 8

# Evaluating The Effectiveness of MyMemory

The previous three chapters described the conceptual design, the interface user study of the conceptual design and a prototypical implementation of MyMemory. The goal of this implementation, following the objective of the thesis, is to develop a memory aid to improve the autobiographical memory of TBI survivors. To determine whether the prototype reaches this goal, MyMemory was evaluated in a user study.

The fifth research question in Section 1.3.5 asks "Can memory training using a mobile system make a difference for TBI survivors?". This chapter contributes to answering this question by evaluating the effectiveness of MyMemory based on a user study. The study received ethical approval from Psychology Research and Ethics Committee, School of Psychology, University of Waikato in 2015 (see Appendix C.1). The study participants completed tasks using the digital prototype of MyMemory.

The structure of the chapter is as follows. Section 8.1 explains the purpose of the study and its importance for our research. Sections 8.2 to 8.4 report the method (recruitment and design for the study), procedure and materials of the study. Section 8.5 analyses the participants in the study. They are the participants with TBI (referred to as TBI-participants) and the participants who support their relatives with TBI (named Caregiver-participants). Section 8.6 reports results about the participants access to their own memory aids and how MyMemory affected their mental state, memory ability and their caregiver's burden. Section 8.7 relates the outcomes of both phases which are important for the goals of the study. The

chapter concludes with a summary in Section 8.8.

# 8.1 Goal of the Study

This study evaluates the effectiveness of MyMemory for improving autobiographical memory for people with TBI. In particular it aims:

- 1. To investigate the usefulness of MyMemory in supporting TBI-participants with their memory impairments.
- 2. To investigate the use of MyMemory in improving the quality of life of TBI-participants.
- To assess the possible decrease in the amount of assistance required from Caregiver-participants after the TBI-participants use MyMemory.

The overall aim of this research is to develop better memory aids to assist TBI survivors, with a particular focus on autobiographical memory. The aim of this study verifies that MyMemory is a memory system designed specially for TBI survivors to train their memory which will improve their ability to remember.

#### 8.2 Method

The study method involved two stages: recruitment and design. Recruitment included enlisting participants and arranging meeting times with them. The design refers to the psychology study design used. The following sections explain both elements in detail.

The methodology described here applies to each questionnaire used in the study (see Appendix C). Most of them use a scale to rate the result, which we calculated after each phase of ABAB study. For the open questions or interview, we followed the approach published by Levine et al. (2002). This method of analysing interviews the same as described in Section 4.2.

#### 8.2.1 Recruitment

In order to achieve the aims of the study, there are five criteria for participants. Participants need to

- 1. be over 16 years old.
- 2. have a brain/head injury and memory problems.
- 3. may or may not have someone who helps them in their day-to-day life.
- 4. own an Android mobile device (smartphone or tablet).
- 5. live within 50km from the University of Waikato.

Participants are also required to be living in the local, thus allowing the face to face interviews for this study. Participants were recruited via posters (see Appendix A.2), which were distributed via appropriate organizations (e.g., focus on potential, Waikato head injury society) and the University of Waikato. Participants from the previous study were contacted via email.

After contacting the researcher (via email as specified on the poster), participants received an information sheet via email. When participants presented themselves at the agreed time and place, the researcher answered any questions regarding the nature of the study and gave a consent form for participants to sign.

## 8.2.2 Design

The study design for each participant was that of an ABAB design (Svoboda and Richards, 2009; Stapleton et al., 2007; Ferguson et al., 2015), with 'A' denoting the baseline phase – complete tasks with their own memory aids and 'B' denoting the active intervention phase – complete tasks with MyMemory. Comparing the results of the A and B phases allows exploration of the differences in the participant's outcomes with and without MyMemory. Each phase lasted two weeks; the researcher met participants at the beginning and the end of each phase.

The interview environment was set up as shown in Figure 8.1, the TBI-participant and the Caregiver-participant attended every meeting together (see Figure 8.1-1). The apparatus and materials included the TBI-participant with their own memory aid and smartphone, the Caregiver-participant with the memory log booklet and researcher with related material (described in Section 8.3) and a dictation machine (see Figure 8.1-2). Essential apparatus and materials for every meeting were the TBI-participant's smartphone, the Caregiver-participant's memory log booklet and the Assigned Task Sheet provided by the researcher (see Figure 8.1-3).



Figure 8.1: Interview environment.

#### 8.3 Procedure

Participants were asked to complete a questionnaire for 1) assessing their memory functions, 2) estimating the effectiveness of using MyMemory and 3) evaluating the amount of assistance provided by caregivers. The details of the questionnaire are described in Section 8.4.

According to the ABAB design, the study replicates the baseline phase and the intervention phase twice. The baseline phase gathers information about the participant's memory ability with their own memory aids. The intervention phase assesses the effect of participant's memory ability with MyMemory. Each phase lasted two weeks; TBI-participants were required to complete four tasks: two assigned-tasks from the Assigned Task Sheet (see Appendix C.9) and two self-assigned tasks from their daily life. The study included a meeting at the beginning and end of each phase; there were five meetings in total. Each meeting took around 60 minutes; participants and the researcher arranged a mutually convenient time and place before the meeting. Figure 8.2 briefly outlines the procedure of the study.

This study included five meetings, Meeting #1 (M1) was the preparation for the study and meetings #2 (M2) and #4 (M4) covered the baseline phase (named A1 and A2). Meetings #3 (M3) and #5 (M5) were during the intervention phase (named B1 and B2).

The baseline phase consisted of:

- 1. meeting at the beginning of the phase (i.e., in meeting M1), the researcher and participants chose two assigned-tasks from the assigned-task sheet,
- 2. participants completion of two assigned-tasks and two self-assigned tasks with their own memory aids during week one and week two,
- 3. the researcher and participants had a short interview at the end of the phase (i.e., in meeting M2) for discussing their progress, in completing the required questionnaires.

The intervention phase included:

- 1. at the beginning of the phase (i.e., in meeting M2), the researcher installed the MyMemory prototype on the TBI-participants' phone and demonstrated,
- 2. the researcher and participants chose two assigned-tasks from the assigned-task sheet,
- 3. the participants accomplished two assigned-tasks and two self-assigned tasks with MyMemory during week three and week four,

# Chapter 8 Evaluating the Effectiveness of MyMemory

Week	Set-up	W1	W2	W3	W4	W5	W6	W7	
Meeting	M1		M2		M3		M4		
Phase	Introduction & Preparation	Baseline phase - A1	nase - A1	Intervention phase - B1	phase - B1	Baseline p	ne phase - A2	Intervention phase - B2	pha
	Information sheet - TBI /Caregiver version	WHO Well-Being Index (TBI)		WHO Well-Being Index (TBI)	dex (TBI)	WHO Well-Being In	ng Index (TBI)	WHO Well-Being Index (TBI)	dex (
	Ethics consent - TBI/Caregiver	Support burden inventory		Support burden inventory	entory	Support burden inventory		Support burden inventory	ento
		(Caregiver)		(Caregiver)		(Caregiver)	1	(Caregiver)	
	Demographic questionnaire -	Memory function Scale	ale-	Memory function s	cale -TBI/Caregiver	Memory function scale -TBI/Caregiver Memory function Scale -		Memory function scale -	ale .
	TBI/Caregiver version	TBI/Caregiver version	Š	version		TBI/Caregiver version	n	TBI/Caregiver version	on
Materials	Strategies of PDA/Smartphone Use	Autobiographical memory		Autobiographical memory	emory	Autobiographical memory		Autobiographical memory	emo
required	(TBI)	questionnaire (TBI)		questionnaire (TBI)		questionnaire (TBI)		questionnaire (TBI)	
	Assigned-task sheet (TBI)	Assigned-task sheet (TBI)		MyMemory evlauation form (TBI)	ion form (TBI)	Assigned-task sheet (TBI)		MyMemory evlauation form (TBI)	ion f
	Memory logbooklet (Caregiver)	Memory logbooklet (Caregiver)	(Caregiver)	Assigned-task sheet (TBI)	t (TBI)	Memory logbooklet (Caregiver)		Assigned-task sheet (TBI)	t (TB
				Memory logbooklet (Caregiver)	t (Caregiver)			Memory logbooklet (Caregiver)	t (Car
Memory aid required	N/A	Their own memory aid or strategies	aid or strategies	МуМетогу	mory	Their own memory aid or strategies	aid or strategies	МуМетогу	mory

Figure 8.2: Outline of MyMemory's evaluation study.

4. at the end of the phase (i.e., in meeting M3), the researcher and participants had a short meeting for discussing their progress, and participants had to complete the required questionnaires.

Then, the study reproduced the baseline phase from week 5 (W5) to week 6 (W6), the following two weeks the intervention phase was repeated. After completing the second intervention phase, this study was concluded.

Each meeting is described in more detail below. M1 is the preliminary meeting of the study; the main agenda includes the researcher giving an explanation of the study to the participants and going through the consent process with the participants; the participants completed the Demographic Questionnaire and the Strategies of PDA/Smartphone Use Questionnaire. During the second part of this meeting, the participants chose two tasks from the assigned-task sheet.

Meeting M2, involved discussion of the participant's progress with the tasks they chose using their normal memory aids and completion of the WHO Well-being Index (WHO-5), Support Burden Inventory, Memory Functioning Scale — TBI version and Caregiver version and Autobiographical Memory Questionnaire. The next step was installation of the MyMemory prototype into the participant's mobile device and they were given a brief demonstration of its use. Once again they chose two tasks from the Assigned Task Sheet to complete within the next two weeks.

During meeting M3, the participant's progress with the tasks they chose using MyMemory and also downloading records from their mobile devices was discussed. Participants were required to complete the WHO-5, Support Burden Inventory, Autobiographical Memory Questionnaire, Memory Functioning Scale — TBI and Caregiver version and MyMemory Evaluation Questionnaire.

Meeting M4 followed the same procedure as M2, and M5 repeated the same process as M3.

Participants were allowed to continue using MyMemory after finishing the study. They were contacted one month after finishing the study with a brief email or short phone call to investigate the state of MyMemory use. This will be valuable when exploring the long-term impact of MyMemory for TBI-participants as part of future work.

#### 8.4 Materials

This section lists all questionnaires and justifies their use in the study. The Assigned-task Sheet is a list of tasks which were any sort of activity requiring autobiographical memory (e.g., meeting a person). The Memory Log Booklet example demonstrates the booklet for Caregiver-participants to record their observations of the TBI-participants' behaviours when accomplishing the tasks.

#### Demographic Questionnaire — TBI/Caregiver version

The demographic questionnaire asks for age, gender, education and marital status, their head injury history or the assistance history for their TBI relatives. This questionnaire explores general information about participants and helps with understanding more information, supporting people with TBI and their caregivers. TBI-participants were required to complete the demographic questionnaire — TBI version in M1. At the same time Caregiver-participants were required to complete the caregiver version. Participants only needed to complete this once in M1 (see Appendix C.6 and C.7).

#### Strategies of PDA/Smartphone Use Questionnaire

This questionnaire investigates the experience of using a smartphone and helps us to understand its value in the life of the participants (Svoboda et al., 2010). The questionnaire consists of three parts: experience of smartphone use, smartphone use for remembering information from the past and smartphone use for remembering to do things in the future.

The questions of the experience of smartphone use include – when did you first use the smartphone or how would you rate your confidence in using the smartphone?

Six activities is related to use the smartphone for remembering information from the past and remembering to do things in the future with a scale rating from 0 (never) to 4 (always) – for example, how often you

used the smartphone for remembering names of people?

The details of this questionnaire are shown in Appendix C.8. TBI-participants have to complete it once in M1.

#### Assigned-task Sheet

This sheet lists 15 tasks two of which the researcher and participants chose and recorded on the sheet – for example, 'Adding [item name] to your grocery list for your next grocery shopping' or 'Planning to visit [location name]'.

The aim of this task sheet is to ensure a minimum task quantity for participants to complete in each phase. This sheet was used in every meeting for assigning tasks to TBI-participants, except for M1 (see Appendix C.9).

#### WHO Well-being Index (WHO-5)

This questionnaire focuses on the detection of depression in people (Heun, Bonsignore, Barkow and Jessen, 2001). It is used to assess the quality of life of TBI-participants. It helps with monitoring TBI-participants mood changes during ABAB single case design study. Therefore, TBI-participants will complete it at every meeting, except for M1.

The WHO Well-being Index includes five questions and each question is required to be answered using a six level scale (0 (at no time) to 5 (all of the time)) about how the participant felt over the last two weeks. The questions ask for estimates of the participant's well-being over the last two weeks – for example, 'I have felt cheerful and in good spirits' or 'I wake up feeling fresh and rested'.

The full version is given in Appendix C.10. High scores indicated that participants felt happy and positive. Maximum score is 25.

#### Caregiver Burden Inventory

In this study, we also investigate the

Caregiver-participants burden when they assist TBI-participants in their memory impairments (Novak and Guest, 1989). Caregiver-participants were required to complete it at every meeting, except for M1. It helps

with monitoring the Caregiver-participants burden changes between the baseline and intervention phase (see Appendix C.11).

Caregiver Burden Inventory investigates five factors of the burden on the caregiver using 24 questions. These are time-dependence burden, developmental burden, physical burden, social burden and emotional burden.

The questions of time-dependence burden study the burden due to restrictions on the caregiver's time. Because persons with TBI may require the extra assistances to remain the activities of daily living, caregivers devote time and energy to helping them with these tasks. This examination caution and feeling of responsibility places stress on the caregiver. Items like, 'I have to watch my care receiver constantly' or 'I have to help my care receiver with many basic functions' reflect their feeling of burden.

The developmental burden questions explore caregivers' feeling in their development with respect to their peers. Most caregivers were the parent, spouse, children or sibling of TBI survivors. This close relationship might increase the caregiver's responsibility and affect their individual social life. The questions inspect the caregiver's feeling being off duty and back to their individual life. Items like, 'I feel that I missing out on life' or 'I expected that things would be different at this point in my life', reflect this feeling of burden.

The questions of the physical burden investigate caregivers' feeling of chronic fatigue and damage to physical health. Items like, 'I am not getting enough sleep' or 'My health has suffered', reflect caregiver's feelings of physical burden.

The social burden questions focus on caregivers' feelings of role conflict with other family members for how to manage the TBI survivor-receiver's needs. It also might limit the time and energy for their jobs. Items like, 'I don't get long with other family member as well as I used to' or 'I don't do as good as job at work as I used to' reflect caregiver's feelings of social burden.

The questions of emotional burden ask for caregiver's negative feelings about their TBI survivor-receivers, including TBI survivors' unpre-

dictable and odd behaviour. Items like, 'I feel embarrassed over my care receiver's behaviour' or 'I resent my care receiver' reflect these feelings of emotional burden.

Each question is required to be answered using a five level scale (0 (never) to 4 (nearly always)). Participants with a high score had a heavy burden with their relatives relying on them a lot. Maximum score is 96.

#### Memory Functioning Scale -- TBI/Caregiver version

This questionnaire focuses on investigating the participant's memory function in their daily life (Hardy, Oyebode and Clare, 2006). There is a similar questionnaire in the caregiver version in order to compare the outcomes from the viewpoint of TBI-participants and Caregiver-participants. The impact of TBI-participants memory ability can then be estimated with and without MyMemory. Therefore, all participants were required to complete this at every meeting, except for M1.

The questions are based on a series of everyday situations where a person might need to use his/her memory to manage in that situation – 'You have made an appointment and need to remember to go along' or 'You have promised to do something later in the day and need to remember to to it a the right time'.

The complete questionnaires of TBI and Caregiver version correspondingly exhibit in Appendix C.12 and C.13.

Each question supports using a five level scale for answers (0 (never) to 4 (nearly always)). A higher score indicates the participant has a good memory ability. This questionnaire includes 13 questions and the maximum score is 52.

#### Autobiographical Memory Questionnaire

This questionnaire aims to evaluate the TBI-participants' autobiographical memory function. Before completing this questionnaire, the researcher and participants chose one task the participant completed during the previous two-weeks. The details of this task was used in the interview and the questionnaire.

In order to retrieve more memories of TBI-participants, they were asked

to first describe the task (Fitzgerald and Broadbridge, 2013). After the interview, TBI-participants completed an autobiographical memory questionnaire. These two steps enable understanding of TBI-participants autobiographical memory function changes between the baseline and intervention phase. TBI-participants completed it at every meeting, except the M1.

There are 18 questions and each question is required to be answered using an eight level scale (0 (not at all) to 7 (as much as any memory/as clearly as if it were happening right now)), except question 15. Question 15 asks the participants to rate their emotions during the event, the scale from -3 (as negative as any event I have experienced), -1 (mildly negative), 1 (neutral) to 3 (as positive as any event I have experienced). The questions include – 'As I remember the event, I feel as though I am reliving the original event' or 'As I remember the event, I can hear it in my mind'. So are designed to fund out how well they have remembered, Appendix C.14 lists the full version of this questionnaire. Maximum score is 122 in this questionnaire.

#### MyMemory Evaluation Questionnaire

The goal of this questionnaire is evaluating the effectiveness and impact of MyMemory for TBI-participants. TBI-participants completed it after every intervention phase at M3 and M5 (see Appendix C.15). This questionnaire was designed to collect feedback and suggestions after TBI-participants use MyMemory.

The questionnaire is designed to be answered using a five level scale (0 (not at all helpful) to 4 (very helpful)) with one open-ended question for asking for participant's suggestions. There are two parts to the questionnaire: rating for each function on MyMemory and overall evaluation of MyMemory.

#### Memory log booklet example

Caregiver-participants were asked to record their reflections on their TBI relatives performing tasks in the booklet (see Appendix C.16). The filled-in booklet provides information to help the researcher analyse the

information provided by TBI-participants during the post-tasks discussion.

# 8.5 Participants

The participants were selected based on responses they provided, as described in Section 8.2.1. Exclusion also occurred when the potential participant lost contact after the email for arranging time and location, and for those under the age of 16. Following this process, two participants of the initial responders were excluded from the study, one due to health problems and one who lost contact.

Six participants were recruited: three TBI-participants and two Caregiver-participants. The one additional participant with multiple sclerosis (MS) was for the purpose of the study treated similar to the TBI participants (see MS participant's details on Section 4.5).

#### 8.5.1 TBI-participant

Tables 8.1 and 8.2 show a summary of TBI-participants' demographics. All are female and had brain injury with memory impairments. The age range was 41 to 57 years old and the average age was 48.25 years old. The range of years of post injury were 7 to 28 and the average was 14.75 years. All the participants were diagnosed with moderate severity level of TBI. T2 and T4 had part-time jobs, T1 had a voluntary job for 10 hours per week and T3 was diagnosed unable to work. T1 and T2 rely on their caregiver to remind them and both of them were used to recording their schedule in a paper diary. T3 and T4 relied on their mobile device's calendar with the alarm to remind them of their schedule. Writing down their memories is a common way for all TBI-participants to remember.

# 8.5.2 Caregiver-participant

Figure 8.3 presents a summary of Caregiver-participants' demographics. Both were males and the relatives of TBI survivor (C1:Husband and C2:Son). The ages of Caregiver-participants were 20 and 61 years old and the years being caregiver were 4 and 16 years. Both of them help

Chapter 8 Evaluating the Effectiveness of MyMemory

Moderate	28	Sporting accident 28	Son (2)	Married Son (2)	Female (P) Administrator	Female	42	T4 42
Moderate	æ	Sporting accident 8	Daughter (24) Daughter (22)	Divorced	Female Unable to work	Female		T3 53
Moderate	7	[NS]	Son (20)	Single	(P) Tertiary student Gallery Owner	Female	41	T2 41
Moderate	16	Vehicle accident 16	Son (23)	Married Son (23)	N/A	T1 57 Female N/A	57	T1
Severity level	Years post injury	Cause of TBI	Children (Age)	Marital Childrer status (Age)	Vocation	Age Gender Vocation	Age	

**Table 8.1:** TBI-participants demographics – 1. (F: Full-time jobs of 40hrs/week. P: Part-time jobs of 20hrs/week.)

Mobile device's calendar or alarm Mobile device's calendar or alarm Mobile device's calendar or alarm Google calendar on the desktop Writing on the hand Writing on the hand Caregiver reminder Caregiver reminder Memory strategies Outlook for work Monthly planner Monthly planner Monthly planner Scraps of paper Post-it notes Post-it notes Paper diary Paper diary Paper diary Facebook Facebook or aids **Table 8.2:** TBI-participants demographics – 2. Living with husband and son Female Husband (C1) Living with husband Living situation Living with son Living alone Caregiver Female Son (C2) N/A Female N/A Gender Female Age 42 57 53 41 T4T2T3 $\Pi$ 

their TBI-relatives in the health and medical area, work and household chores. Verbal reminder was the most common strategy they used to help their relatives remember things.

# 8.6 Analysis

This section describes the results which were analysed from the participants completed materials in each phase. In addition, the event records were downloaded from MyMemory which was installed on the participant's smartphone, and which record the events of the study.

#### 8.6.1 TBI-participant's smartphone experience

Table 8.4 summarizes TBI-participant's experience of using smartphones.

All TBI-participants were relatively new to using smartphones. All phones were Samsung's mobiles with Android 4.X version. T2 and T4 had over one year's experience with a smartphone and T1 and T3 only several months. All of them reported that they used the smartphone with difficulty. The reason is that they were familiar with using a computer, an experience which helped them but going a phone was different. So they declared having low confidence in smartphone use in the questionnaire. Most of them could understand and use MyMemory without any assistance after a one-time demonstration. However some complex functions were required to be presented more than three times, such as for editing the contact details. The Strategies of PDA/Smartphone Use Questionnaire (see details on Secion 8.4) lists 12 activities related to using the smartphone for remembering information from the past and doing them in the future. The results are displayed in Figures 8.3 and 8.4.

Six activities on the form related to participant use of a smartphone for remembering information from the past: 1) remembering names of people, 2) recognizing people's face, 3) recording and accessing information about a person, 4) remembering that a particular event happened in the past week, 5) figuring out when/where something happened in the past, and 6) remembering important information that they were told. Figure 8.3 shows TBI-participants use of a smartphone for remembering

Ţ	rble 8.	3: Caregiv	er-participants demogra	phics. (F: Full-	time jobs of 40hrs/wee	<b>Table 8.3:</b> Caregiver-participants demographics. (F: Full-time jobs of 40hrs/week. P: Part-time jobs of 20hrs/week.)
	\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \	Condor	Aro Condor Vocation	Years being	Tack accietance	Acciserate constant
	Aye	Genner	VOCALIOII	caregiver	iask assistante	Assistance strategies
					Health/medical	
5	77	7.010	(D) Motor consistent	16	Social life	Verbal reminder
3	10	Male	(r) Motor engineer	10	Work business	Post the memo on the fridge door
					Household chores	
						Verbal reminder
					Health/medical	Text message
C2	20	Male	(F) Tertiary student	4	Work	Phone calling
					Household chores	Email
						Writing on the Post-it for them

0.3

1.5

		3		-
			If you have	
			ever used	How confident do
			smartphone	you use the
	Mobile	Years using	before, then how	smartphone?
	brand	smartphone	often did you	("not confident" (0)
			use it?	to
			("N/A or never" (0)	"very confident" (4))
			to "always" (4) )	
	Samsung J5	0.1	0	0
T2	Samsung I5	1	0	1

0

4

0

3

**Table 8.4:** Summary of TBI-participants of the smartphone experience.

things from the past.

Samsung J2

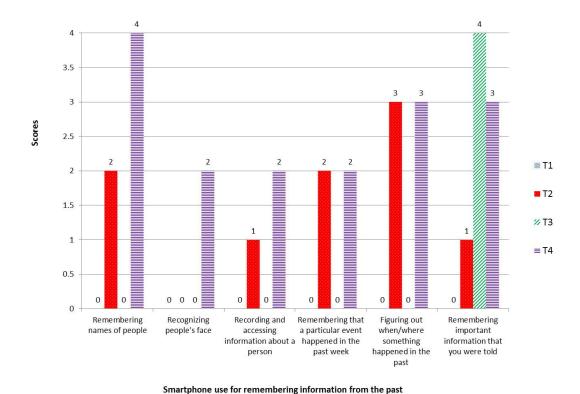
Samsung J5

T3

T4

T4 was the person with 1.5 years experience in using a smartphone and the only participant who reported all six activities. 'Remembering names of people' was the activity she always used the smartphone for helping her remember. 'Figuring out when/where something happened in the past' and 'Remembering important information that you were told' were activities where she often used the smartphone to assist her memory. T2 had one year's experience in using smartphone but she never used her smartphone for helping her to 'Recognize people's faces'. 'Figuring out when/where something happened in the past' was the thing T2 often did on the smartphone for her memory. T1 and T4 had experience with the smartphone only for a couple of months. T3 had over four month's experiences with the smartphone and she only used the smartphone for 'remembering important information that you were told'. T1 had the least experience in using smartphone (two months) and she never used the smartphone for 'remembering things from the past'.

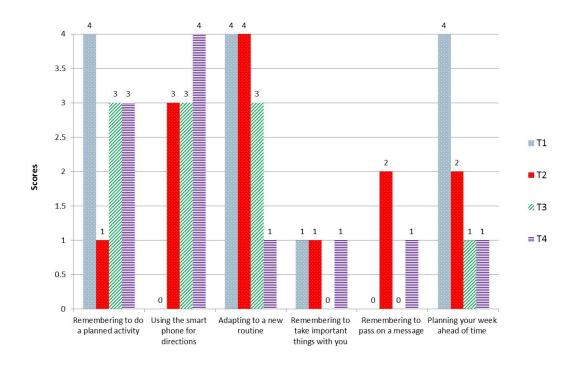
The form lists another six activities to ask the participant about using smartphone for remembering to do things in the future: 1) remembering to do a planned activity, 2) using the smartphone for directions, 3) adapting to a new routine, 4) remembering to take important things with you, 5) remembering to pass on a message, and 6) planning your week ahead of time. Figure 8.4 shows how TBI-participants used the smartphone for



**Figure 8.3:** TBI-participants use of smartphones for remembering information from the past. Frequency ratings were given from 0 (never) to 4 (always).

remembering to do things in the future.

All TBI-participants reported they used the smartphone when doing these three things: 'Remembering to do a planned activity', 'Adapting to a new routine' and 'Planning our week ahead of time'. T1 and T3 were new to the smartphone but they strongly relied on it for doing these three things. However, T1 did not use the smartphone for directions and remembering to pass on a message. T3 did not use the smartphone for 'Remembering to take important things' and 'Remembering to pass on a message'. T2 and T4 had over one year's experience in using the smartphone, and both of them used it for doing all six things. Dependency on the smartphone for their memories differed, T2 used the smartphone to help adapt to a new routine and T4 for directions.



Smartphone use for remembering to do things in the future

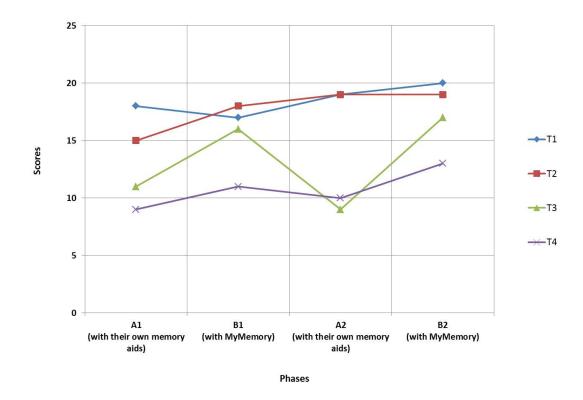
**Figure 8.4:** TBI-participants use of smartphones for remembering to do things in the future. Frequency ratings were given from 0 (never) to 4 (always).

# 8.6.2 TBI-participants Well-Being Index and Caregiver-participants Burden Inventory

TBI-participants were required to use their own memory aids during the baseline phase (A1 and A2) and MyMemory in the intervention phase (B1 and B2) to finish four tasks. After each phase, all participants were asked to complete the form that explored their well-being. TBI-participants were additionally required to complete the WHO Well-being Index form (see details on Section 8.4) to explore their well-being change. Caregiver-participants were asked to fill in the Support Burden Inventory form (see details on Section 8.4) to investigate any change in their burden.

Figure 8.5 shows changes in the TBI-participant's well-being in every phase. In this WHO Well-being Index, a higher score indicates the participant felt more positive and happier. There are five questions to measure

the participant's well-being index and each question is measured from 0 (at no time) to 5 (all of the time), the maximum score is 25.



**Figure 8.5:** TBI-participants' well-being index in each phase. Well-being index ratings were given 0 (at no time) to 5 (all of the time). Well-being index lists five questions and its maximum score is 25.

Overall, all TBI-participants reported their well-being was improved when they used MyMemory. T1 had low scores on B1 (17) but improved in A2 (19) and B2 (20). She reported she was new to her Android mobile phone, therefore she felt nervous and under pressure when she first used MyMemory in B1. T2 had similar outcomes in B1 (18), A2 (19) and B2 (19). T2 reported that MyMemory had already changed her memory behaviour because she now using the five factors of memory to store and recall events without MyMemory (see Section 4.6.4 and 5.5.2). T2 further mentioned her sleep improved since she used MyMemory because she knew she could find memories when she needed. Therefore, her well-being index in A2 was similar to B1 and B2. T3 had significant changes between the baseline and intervention phases. T3 also reported

her memory behaviour changed after using MyMemory. She mentioned in the MyMemory Evaluation Questionnaire (see details on Section 8.4): "I cannot live without MyMemory". Her results appeared to be consistent with her words. The highest score of T3 was in the phase with MyMemory (B1 was 16 and B2 was 17) and the lowest score in the phase without MyMemory (A2 was nine). T4 had a similar outcome to T3 but the change was not so dramatic. T4 had high scores in B1 (11) and B2 (13) and A1 (9) and A2 (10) had low scores.

**Table 8.5:** Results of TBI-participants' well-being index in each phase. Avg.: Average. Comp.: Comparison.

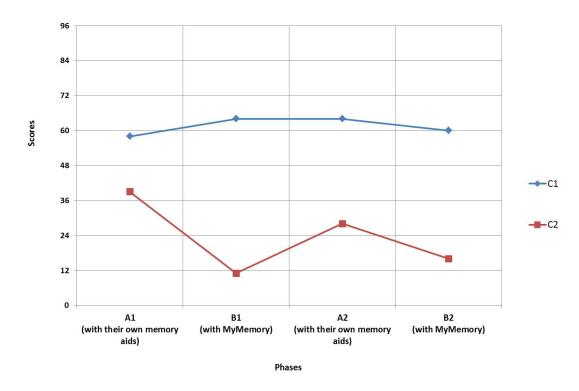
	A1 (with their own memory aids)	B1 (with MyMemory)	A2 (with their own memory aids)	B2 (with MyMemory)	
T1	18	17	19	20	
T2	15	18	19	19	
Т3	11	16	9	17	
T4	9	11	10	13	
Avg.	13.3	15.5	14.3	17.3	
Comp.	N/A	16.5% (A1)	N/A	30% (A1) 20.9% (A2)	

Table 8.5 shows the average results of the TBI-participants well-being in each phase as well as a comparison between the different phases. The average results of phases (B1 = 15.5 and B2 = 17.3) with MyMemory were higher than with their own memory aids (A1 = 13.3 and A2 = 14.3). These results revealed that TBI-participants' well-being were improved when they used MyMemory. In addition, the average result of the B2 phase was higher than B1. It might be that once they were familiar with MyMemory then their well-being was improved more. Table 8.5 also shows the compared improvements were all positive, which were 16.5% (B1 compared with A1), 30% (B2 compared with A1) and 20.9% (B2 compared with A2). These results revealed TBI-participants well-being was improved when they used MyMemory.

Two Caregiver-participants in the study supported TBI-participants: C1 to T1 (husband to wife) and C2 to T2 (son to mother). They all were re-

quired to complete the Caregiver Burden Inventory (CBI) (see details on Section 8.4) at each phase. Participants gave high scores on the CBI. This emphasised the heavy burden they felt having TBI relatives so reliant on them. Caregiver-participants' burden inventory has 24 questions and each question is scored from 0 (never) to 4 (nearly always), its maximum scores is 96.

Figure 8.6 presents the Caregiver-participants' burden inventory in each phase. Two Caregiver-participants suffered the different levels of the burden from supporting their TBI relatives at the beginning of the study. Through entire study, their burden showed a different tendency to change along with their TBI relatives using MyMemory.



**Figure 8.6:** Caregiver-participants' burden in each phase. Burden ratings were given 0 (never) to 4 (nearly always). Caregiver-participants' burden inventory consists of 24 questions, its maximum score is 96.

C1 provided daily comprehensive assistance to T1 and C1 described that he did not feel any differences when his wife started to use MyMemory (B1 phase). Nevertheless, he found some improvements in his wife's

memory in the fifth week (the first week after the B1 phase). C1 described his observation that "she can remember something when she used MyMemory to record the memory but not in detail". "It was a slight change but can be noticed when the person lives with you 24/7", C1 said.

Compared with C1, C2 had significant change on his burden inventory. Even though C2 was not providing help to T2 continually, he still found his mother's memory improving with MyMemory. C2 reported that "my mother can remember her words after she used MyMemory even though she mixed up the date but she did remember".

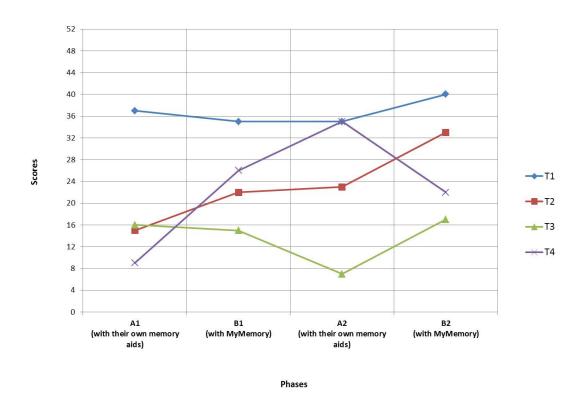
**Table 8.6:** Results of Caregiver-participants' burden in each phase. Avg.: Average. Comp.: Comparison.

Comp.	N/A	-22.6% (A1)	N/A	-21.6% (A1) -17.4% (A2)	
Avg.	48.5	37.5	46	38	
C2	39	11	28	16	
C1	58	64	64	60	
	A1 (with their own memory aids)	B1 (with MyMemory)	A2 (with their own memory aids)	B2 (with MyMemory)	

Table 8.6 shows the average results of Caregiver-participants' burden in each phase as well as comparison between the different phases. The results of B1 and B2 phases (B1 = 37.5 and B2 = 38) were when their TBI relatives were using MyMemory which were lower than A1 and A2 phases (A1 = 48.5 and A2 = 38) when they were using their own memory aids. Comparisons of the burden were all negative (i.e., their burden was reduced). The largest difference was -22.6% which was B1 compared with A1. It means the Caregiver-participants found a significant difference of their burden when their TBI relatives first used MyMemory. -21.6% was their reduction in burden in B2 phase compared with A1 and -17.4% was the reduction in B2 phase compared with A2. Overall, the results showed that Caregiver-participants' burden was reduced when their TBI relatives used MyMemory.

#### 8.6.3 Memory Ability

The memory functioning scale (see details on Section 8.4) explores the participants' memory ability. There are two versions, one for TBI-participants to inspect themselves and the other for Caregiver-participants to observe their TBI relatives' memory ability. Each version has 13 questions and each question rating was given from 0 (never) to 4 (always), and thus its maximum score is 52. Figures 8.7 and 8.8 show the outcomes of all participants in each phase.



**Figure 8.7:** TBI-participants' memory functioning scale in each phase. Memory function rating were given 0 (never) to 4 (always). This memory function scale includes 13 questions, its maximum score is 52.

Figure 8.8 displays the results of the Caregiver-participants observation of their relatives. The outcomes of the baseline and intervention phases concluded that Caregiver-participants observed their TBI relatives' memory ability improved using MyMemory in B2.

Figure 8.7 presents the TBI-participants' memory functioning changes

in each phase. Most TBI-participants' memory functions improved when they used MyMemory in the end of the study, except for T4. T1, T2 and T3 had similar outcomes in the memory functioning scale in this study. Overall the outcomes showed their memory abilities were improved when they used MyMemory. Their results with MyMemory (in the B1 and B2 phases) were higher than with their own memory aids (in the A1 and A2 phases). Their outcomes in A2 were lower than other phases and their B2 outcomes were highest. Compared with the outcome of A1 and B2, T1's scores increased by three, T2 had 18 and T3 had 13. T4 was the only participant with a decreasing result in B2.

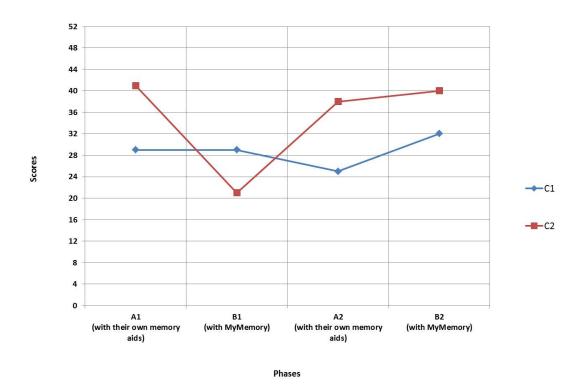
Nine months ago, T4 started a new journey of her life, which was living with her two year old son. This change brought some positive influences to her life, such as getting enough sleep due to following her son's 10 hours sleep routine. On the other hand, the negative impact was her schedule was filled with coming events and things to-do. These influences led to her memory function being unstable and different from other TBI-participants in this study. The assumption was that she was under extreme pressure taking care of her two year old son, but still an overall improvement.

**Table 8.7:** Results of TBI-participants' memory functioning scale in each phase. Avg.: Average. Comp.: Comparison.

	A1 (with their own memory aids)	B1 (with MyMemory)	A2 (with their own memory aids)	B2 (with MyMemory)	
T1	37	35	35	40	
T2	15	22	23	33	
T3	16	15	7	17	
T4	9	26	35	22	
Avg.	19.3	24.5	25	28	
Comp.	N/A	26.9% (A1)	N/A	45% (A1) 12% (A2)	

Table 8.7 shows average results of TBI-participants' memory functioning scale in each phase. There were increased results in B1 and B2 phases (B1 = 24.5 and B2 = 28) when they used MyMemory compared

to A1 and A2 phases (A1 = 19.3 and A2 = 25) when they used their own memory aids. Comparisons of the results were all positive. There was a significant positive result (45%) which was B2 compared with A1. The improvement when they first used MyMemory which was 26.9%. A comparison of the result for the B2 phase compared with A2 phase was lower which may be TBI-participants' memory behaviours were changed to effect their memory function after they first used MyMemory. Overall, TBI-participants memory functioning scale were increased when they used MyMemory.



**Figure 8.8:** Caregiver-participants' observed memory functioning scale for their TBI relatives in each phase. Memory function ratings were given from 0 (never) to 4 (always). This memory function scale includes 13 questions, its maximum score is 52.

Figure 8.8 presents the Caregiver-participant's observed their TBI relatives' memory functioning scale in each phase. C1 gave 29 in A1 and B1 which indicates he did not observe any differences when his wife used her own memory aid and first time accessed MyMemory. However,

C1 found his wife's memory ability slightly decreased (25) after using MyMemory in B1 but increased when she used her own memory aid in A2. To his knowledge, the presumable explanation of the decrease in B1 was that his wife needed time to learn using MyMemory. The results of the B2 phase proved his assumption was right because he gave 32 for his wife's memory ability when she re-used MyMemory. Besides, it was the best score of his wife's memory ability in the study.

C2 observed his mother's memory ability dramatically changing during the study. C2 gave 41 when his mother was using her own memory aids (A1 phase) but significantly dropped to 21 when she first used MyMemory (B1 phase). He gave an account from his view to explain the dramatic decline was learning new thing. His mother required time and repeated demonstrations to learn to use MyMemory. This might explain why he observed his mother's memory ability varied in B1. He scored that his mother's memory ability increased (38 in A2) when she returned to use her own memory aid. Comparing with the results of B1, he scored his mother's memory ability as 40 for her second time using MyMemory (B2 phase). The score of B2 was almost twice as higher as B1.

**Table 8.8:** Results of Caregiver-participants' observed memory functioning scale for their TBI relatives in each phase. Avg.: Average. Comp.: Comparison.

	A1 (with their own memory aids)	B1 (with MyMemory)	A2 (with their own memory aids)	B2 (with MyMemory)	
C1	29	29	25	32	
C2	41	21	38	40	
Avg.	35	25	31.5	36	
Comp.	N/A	-28.5% (A1)	N/A	2.9% (A1) 14.3% (A2)	

Table 8.8 shows the average results of Caregiver-participants observed memory functioning scale for their TBI relatives in each phase. A comparison of the results for B1 and A1 showed a reduction. Caregiver-participants reported that they did not find their TBI relatives' memory

functions improving when their TBI relatives first used MyMemory. After their TBI relative used MyMemory in B1, the results increased by 2.9% (B2 compared with A1) and 14.3% (B2 compared with A2). Cargiverparticipants gave the possible explanation that their TBI relatives required more time to accept MyMemory. At the end of study, both Caregiverparticipants observed their TBI relatives' memory function were improved when they used MyMemory. This matches the results from the TBI-participants themselves.

# 8.6.4 Autobiographical Memory

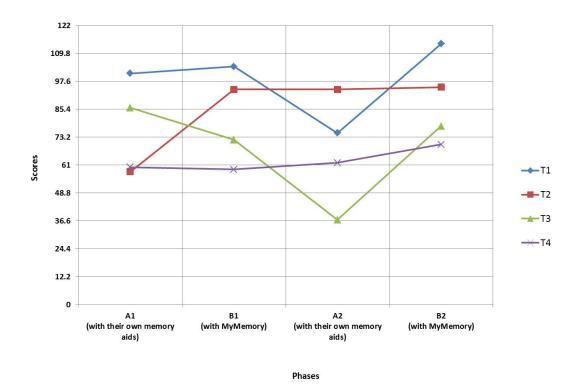
Table 8.9 lists the events with scores for every TBI-participant in each phase. The scores were measured using the autobiographical memory questionnaire (see details on Section 8.4). It includes 18 questions and the measurements range from 1 (not at all) to 7 (as much as any memory or as clearly as if it were happening right now). Except Question #15, where memory score ratings were given -3 (as negative as any event I have experienced), -1 (mildly negative), +1 (neutral) to +3 (as positive as any event I have experienced). Therefore, the maximum score of this questionnaire is 122.

Most events were planned at the previous meeting and were recorded on the Assigned Task Sheet. According to the selections, most events involved familiar people such as family or friends, except for two which did not. These two events were recorded by T3 – Meeting with Doctor (72) and T4 – Attending a Lecture (59). Furthermore, the results might indicate that memories involving familiar people are those that TBI-participants do to remember.

Figure 8.9 displays the TBI-participants' autobiographical memory score to the selected event mentioned in Table 8.9. Overall, all participants' highest scores were during B2, higher than A1 and A2. T1 and T3 had their lowest score in A2 (T1 = 75 and T3 = 37) and their highest score in B2 (T1 = 114 and T3 = 78). T2 had her lowest score in A1 (58) but had similar results (94) in the other three phases. T4 had slight progress in her autobiographical memory. Her lowest score was in B1 (59) which increased to 70 in B2 which was her highest score in the study. The

Chapter 8 Evaluating the Effectiveness of MyMemory

Tabl	Table 8.9: Summary of TBI-participants' results of event and scores on Autobiographical memory questionnaire (AMQ)	ants' results of event and score	es on Autobiographical memory	questionnaire (AMQ).
	A1	B1	A2	B2
	Event (AMQ score)	Event (AMQ score)	Event (AMQ score)	Event (AMQ score)
1	Travaling with family (101)	Calling friends (104)	Visiting Hamilton lake	BBQ with friends
1	11 Havening with failing (101) Caning Hends (104)	Caiiiiig ii ieiius (104)	with family (75)	at home (114)
<del>]</del>	Watching the movie	Meeting with friends (01) Birthday with family (01)	Rirthday with family (91)	Lunch with family
1	with family (58)	TATOCOTTIS MICH TITLEM (7.4)	Dir maay widi rammy (3x)	at restaurant (95)
J J	Weekend away	Mooting with doctor (72)	Doing mum's	Tax refund on-line
1	with friends (86)	Meening with doctor (72)	tax refund (37)	with mum (78)
Į.	Swimming with family (60)	Attending a locture (50)	Birthday with friends (67)	Lunch with friend
±1	14 Swilling with failing (80) Attending a rectare (39)	Attending a recture (39)	Bit tilday with Hielius (0z)	(70)



**Figure 8.9:** TBI-participants' autobiographical memory scores in each phase. The autobiographical memory questionnaire lists 18 questions in total and memory score ratings were given 1 (not at all) to 7 (as much as any memory or as clearly as if it were happening right now). Maximum score is 122.

overall results indicated that TBI-participants' autobiographical memory improved when they used MyMemory (B1 and B2 phases). In addition, the results might interpret the progress was ongoing when they accessed MyMemory again, because their results in the B2 phase were the highest scores of the study.

Table 8.10 presents the results of TBI-participants' autobiographical memory score in each phase as well as the average and comparison between phases. The average result of B1 and B2 phase (B1 = 82.3 and B2 = 89.3) were higher than A1 and A2 (A1 = 76.3 and A2 = 67) phase. It shows TBI-participants' autobiographical memory were improved when they used MyMemory. Comparisons of the results are all positive which supports this. A significant comparison was 33.2% which was B2 com-

	phase. Avg Ave	erage. Comp C	omparison.	
	A1 (with their own memory aids)	B1 (with MyMemory)	A2 (with their own memory aids)	B2 (with MyMemory)
T1	101	104	75	114
T2	58	94	94	95
Т3	86	72	37	78
T4	60	59	62	70

82.3

7.8% (A1)

67

N/A

89.3

33.2% (A2)

17% (A1)

**Table 8.10:** Results of TBI-participants' autobiographical memory score in each phase. Avg.: Average. Comp.: Comparison.

pared with A2. 7.8% was B1 compared with A1 and 17% was B2 compared with A1. The possible reason for the significant comparison result (33.2%) was TBI-participants need time to learn and accept the use of MyMemory. Once they learn and know more about MyMemory, they improve more. Overall in this study, participants reported that MyMemory did improve TBI-participants' autobiographical memory ability.

## 8.6.5 MyMemory Evaluation

76.3

N/A

Avg.

Comp.

All TBI-participants used a Samsung smartphone with Android 4.X. TBI-participants were required to complete this evaluation form (see details on Section 8.4) when they finished the intervention phases (B1 and B2). Therefore, each column includes two results for B1 and B2 in Table 8.11.

#### The way to add new event records

Table 8.11 shows how TBI-participants reported their experiences to add new event record. TBI-participants were required to evaluate the usability of each method for adding a event record. MyMemory provides two ways to add a new event record: staring with 'Camera' (photo capture) or starting with 'New Memory' (text input). Each way is scored from zero (not at all helpful) to four (very helpful).

All participants reported that 'starting with new memory' was a very

**Table 8.11:** What do you think the way to add new event record, by starting with 'Camera' and 'New Memory' in B1 and B2 phases. Feedback ratings were given 0 (not as all helpful) to 4 (very helpful), – not applicable.

	Start	ing with	Start	ing with	
	ca	mera	New	Memory	
	B1	B2	B1	B2	
T1	1	2	4	4	
T2	-	-	4	4	
Т3	_	4	4	4	
T4	4	4	3	4	

helpful design. According to the feedback they gave, it was the first choice for them to add a new event record. However, TBI-participants had the completely different suggestions for 'starting with camera' to add a new memory. T2 was a person who never used 'starting with camera' during the study and T3 did not use it in B1. T1 directly commented 'starting with camera' was a useless design. T3 was the only person who gave full scores to it in both phases. Most of her event records were attached the photo, which describes in Section 8.6.6.

This results suggest that TBI-participants preferred recording their memory starting at the text input rather than the photo capture.

#### Features of Memory

Table 8.12 illustrates the TBI-participants' feedback about the Memory function. It includes event data display (reviewing detail), attaching photos (taking photo and browsing gallery), sharing/back-up functions (sending text and email) and classifying data (changing label color). Participants were required to evaluate the six features. The score ranges from zero (not at all helpful) to four (very helpful).

All participants liked the method of presenting the event data when they first used MyMemory. T1 and T3 gave full scores (4) for reviewing details in Memory, T2 and T4 only gave 3. T2 concurred with the concept of Memory design but asked for more opinions for the activities, such as meetings. T4 disliked the time field. She required an exact time display

			were g	jiven	0 (not	as all	l helpfu	l) to 4	(very	helpf	ful), – 1	not ap	plicable.
		Revi	ewing	Tak	king	Bro	wsing	Sen	ding	Sen	ding	Cha	nging
		de	tails	ph	oto	ga	llery	te	ext	en	nail	labe	l color
		B1	B2	B1	B2	B1	B2	B1	B2	B1	B2	B1	B2
T	71	4	4	1	2	_	3	_	4	_	3	3	4
Τ	72	3	3	-	_	3	3	3	4	_	_	4	4
Т	73	4	4	4	4	4	4	4	4	3	4	4	4
Т	٦4	3	3	4	4	4	4	4	4	4	4	4	4

**Table 8.12:** What do you think these features of Memory. Feedback ratings were given 0 (not as all helpful) to 4 (very helpful), – not applicable.

such as 10.00am not 'morning'.

Regarding attaching photos of the event, results varied between individuals. T2 never used either of the attaching photo functions of MyMemory. She declared that photos are not essential for recalling her memory. T1 described she was a person who did not rely on photos for triggering her memory. According to their individual memory strategies, both of them were used to recording their memory on physical materials (paper diary or wall calendar) or their hand. Therefore, they had not developed the habit of using photos. It was one possible cause of why they did not use or dislike the feature related to attaching photos in MyMemory. In addition, both of them had revealed they were uncomfortable taking photos in public places in the interview. We might assume this was another cause of their results. In contrast, T3 and T4 were used to taking photos for recording their memories. They gave full scores (4) for taking photo and browsing gallery.

Sending text and email were designed for sharing/backup of the event data. T1 declared she did not use either in B1, because she was new to the smartphone. After becoming more familiar with her smartphone, she gave a high score for both. She considered that 'sending text' was very useful when she tried to share her memory with family and friends. T2 was unused to 'sending email' on MyMemory because she seldom sent email from her smartphone. All participants supported the memory-factor pattern to describe events in MyMemory (see Section7.3.4). T2 and T3 reported that when they read the text from MyMemory, their memory was triggered immediately.

Changing label color was the feature that gained almost full scores from every participant in both phases. All participants used label color to classify the event. Moreover, without adding description to the color, all participants could interpret each color.

#### Memory training tools

Memory training tools include 'FlashCard' and 'Widget'. Participants were asked to evaluate the usability of each tool. Each tool is scored from zero (not at all helpful) to four (very helpful). According to the interface user study for usability test, all TBI-participants considered the flashcard was a very useful tool for training their memory (see Section 6.6). However, there were different results when TBI-participants used them on the smartphone. Table 8.13 lists TBI-participants feedback about memory training tools.

**Table 8.13:** What do you think about Memory training tools, 'FlashCard' and 'Widget' in B1 and B2 phases. Feedback ratings were given 0 (not as all helpful) to 4 (very helpful), – not applicable.

	FlashCard		Widget	
	B1	B2	B1	B2
T1	3	4	4	4
T2	-	3	3	4
T3	3	4	4	4
T4	2	2	4	4

For 'FlashCard', T1 and T3 gave 3 and 4 in B1 and B2 but both reported they hardly used it. T2 did not use it in B1 but she tried it in B2 and gave it a three. She speculated it might be useful for some people but not for her. For her, she considered 'FlashCard' as a tool for learning new things not for training memory. T4 gave 2 for both phases. She reported it could be helpful, if she could remember to use it. All of them commented that accessing 'FlashCard' was the cause for the low usage. 'FlashCard' was located within MyMemory, the user has to turn on MyMemory then click the flashcard icon on the top of the function bar to access.

However, the outcomes for 'Widget' were different. All participants supported and gave full scores to it. They liked the data display of the

widget which was enough to trigger their memory but without revealing too much information of the event. Therefore, they did not worry about the privacy issue even though the widget is located on the main screen of the smartphone. Another possible cause of such differences are that the widget, is a digital version of post-its, similar to the post-its people used already.

#### Assistant functions

Assistant functions involve the searching function ('Sort by Person' and 'Sort by Location'), default setting ('Settings') and brief instructions ('About MyMemory'). Participants scored each function from zero (not at all helpful) to four (very helpful). Table 8.14 shows TBI-participants' feedback about four assistant functions, including 'Sort by Person', 'Sort by Location', 'Settings' and 'About MyMemory'.

'Sort by Person' and 'Sort by Location' were designed to replace specified text search in MyMemory. Both T1 and T2 did not use the two functions during B1. They did in B2 and gave low scores to them. Consistently high scores were given by T3 and T4. The presumable interpretation of differences was some TBI survivors find it difficult to adapt to change. Another potential cause was that their amount of recorded event data was not sufficient to fully explore the feature.

'Settings' was designed for saving the participant's email, mobile phone and default label color. Once the participant completed these settings, these results were used for text messages or emails, or the label of a new

**Table 8.14:** What do you think about the Assistant functions in B1 and B2 phases. Feedback ratings were given 0 (not as all helpful) to 4 (very helpful), – not applicable.

	Sort by		Sort by		Settings		About	
	Person		Location				MyMemory	
	B1	B2	B1	B2	B1	B2	B1	B2
T1	_	2	_	2	3	4	4	4
T2	-	-	-	4	2	2	-	2
T3	4	4	3	4	4	4	2	4
T4	3	4	3	4	3	4	4	4

memory. Most participants considered it was a good design for them, especially for some TBI survivors who had trouble to remember their personal information. They gave three or full scores to it in both phases, except for T2. According to her experience of smartphone use, she did not send emails from her smartphone or share her memory with family. Therefore, she did not think 'Settings' was a useful design in MyMemory.

'About MyMemory' was designed as a brief instruction of MyMemory. Even though none of the participants used it, they all thought it is essential for MyMemory. Some participants considered it might help people who have trouble remembering new instructions, 'About MyMemory' was a solution for them. In this study, they gave high scores for it.

### Overall evaluation of MyMemory

Overall evaluation of MyMemory asks the participants' to self-report how MyMemory improves their memory and quality of their life. Participants were required to evaluate each item from zero (strongly disagree) to four (strongly agree). Table 8.15 lists TBI participants feedback about how MyMemory affects their memory and life after they used.

For improving memory ability, all participants gave a three or a full score for both phases. T4 made a comment for the training tool that requested more 'game' features involved. It might be increasing her interest in using the memory training tools.

For changing memory behaviour, all participants gave low scores for B1. A reasonable cause suggested by the previous user studies, is that TBI survivors have troubles to learn new things and adapt to change. For TBI survivors, it involves the expenditure of time and effort to adapt to MyMemory. After two weeks experience, TBI-participants adapted to MyMemory and found the memory-factor pattern of data display suitable for them. Therefore, all participants gave a higher score for B2 than B1.

For helping to organize life, all participants strongly disagreed. The explicit reason was that MyMemory did not include an alarm function for reminding. Therefore, all of them gave lowest scores even zero in B1. After two weeks experience, T1, T2 and T4 understood reviewing recorded event data in MyMemory could assist them to organize a similar

Chapter 8 Evaluating the Effectiveness of MyMemory

Table 8.15: Rate how much you agree or disagree with the six statements about how MyMemory affects your memory and T1 T2 T3 memory ability Improving life in B1 and B2 phases. Ratings were given from 0 (strongly disagree) to 4 (strongly agree). 4 memory behavior 2 4 2 Changing В2 organize life 0 2 2 Helping to 2 4 0 8 memory ability  $\omega$   $\omega$   $\omega$   $\omega$ Training their memory aid in  $\omega$ May replace further В2 Recommend to other people 4

activity. For example, they could find the recorded event data for this week's meeting in MyMemory, and then know the tasks they need to accomplishing during the next two weeks. Therefore, they gave scores for B2 higher than B1. T3 gave a zero for both phases. She declared an alarm as essential to organize her life and MyMemory does not provide the alarm function so cannot help her.

For training memory ability, all participants supported and gave a three or full scores for both phases. However, they only reported using the 'Widget' training in the study not the 'FlashCard'. Most participants gave a concise explanation that convenience of accessing the tool contributed to this difference. 'FlashCard' is located under MyMemory, the user has to turn on MyMemory then clicks the flashcard icon on the function bar. 'Widget' is located on the main screen of the smartphone, the user can directly use it without extra steps.

All participants considered MyMemory might replace their own memory aids in the future. The effectiveness of factors of memory for storing and retrieving the memory, the combination of the memory-factor pattern for displaying event data to train and trigger memory. All of them felt there had a positive effect on their memory ability when they used MyMemory.

## 8.6.6 MyMemory's Records

This section relates to TBI-participants activities and records with MyMemory which were downloaded from participant phone. Due to confidentiality issues, the details of all event records and related information cannot be presented here; however, all results were used to analyse data.

Table 8.16 presents the analysed data related to the number of event records for each participant.

The first column of the table is the total number of event records TBI-participants used MyMemory to record for four weeks (the B1 and B2 phases). T2 and T3 had 29 event records respectively. T4 had eight and T1 had five. The average record number was 17.75. The maximum number of event records for a day is shown in the second column of the table. T2 had five records, T3 had three, T1 had two and T4 had one

		gories.					
	Total	Maximum	Attached the photo	Without full details	Sent	Sent	Self
					by	by	involved
					email	text	only
T1	5	2	2	12	1	1	2
T2	29	5	0	19	0	0	3
Т3	29	3	23	19	13	0	7
T4	8	1	0	7	2	0	2

**Table 8.16:** Number of event records by the participant and different categories.

only. These two figures might suppose TBI-participants do not need to remember everything they experienced. They only need to remember the things with significance for them.

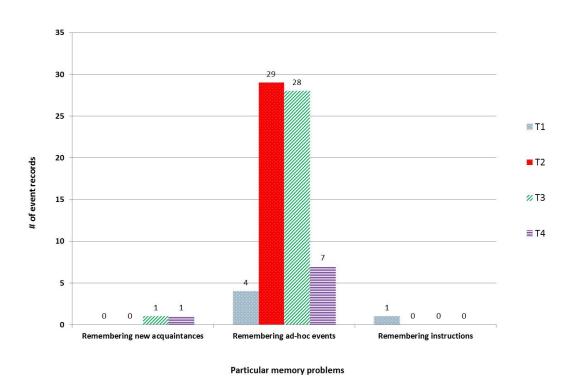
The third column presents the number of event records that had an attached photo. T3 used MyMemory for recording 29 event records in total, and 23 event records were attached with a photo. T1 had five records in total and two were attached with a photo. However, T2 (29) and T4 (4) were the people who did not attach a photo to their event records. These results might assume the photo needs was important for some TBI survivors' memory but not necessary for supporting each TBI survivor's memory.

For adding memory, MyMemory was designed with seven columns for the user to fill in the related information about the event (see Section 7.3.3). Table 8.16 also displays the number of event records without the full event details. T1 and T3 filled in all event records they entered in MyMemory. T2 had seven records without the full details and T4 had two.

Table 8.16 also shows the number of event records sent via emails and text messages. T3 had 13 event records that were sent to herself by email. T4 sent two event records to herself and T1 sent one. T1 and T4 sent one event record via the text message to their mobile device, T3 never sent any. T2 was the only participant in the study who never sent any event record through email or text message. These figures suggest sharing memory with others or backing up memory might be the personal requirement rather than something for all TBI people. It was similar to the photo requirement as presented previously.

The final column of Table 8.16 presents the number of records about events that only involved TBI-participant themselves. T3 had seven event records involving only herself, T2 had three, and T1 and T4 had two each respectively. These results suggest the memories TBI-participants want to remember do not only involve other people, but also can be for therm selves only.

Figure 8.10 shows each participant's event record categorized by three types of memory problems. The results from the interview user study showed three particular memory problems which most distress TBI survivors (see Section 4.6.2), these are 'remembering new acquaintances', 'remembering ad-hoc events' and 'remembering instructions'.



**Figure 8.10:** TBI-participants' event records, by three particular memory problems.

Most event records related to 'Remembering Ad-hoc Events'. T2 had 29 event records in total and all of them belonged to 'Remembering Adhoc Events'. T3 had 28 event records related to 'Remembering Adhoc

Events' and one was 'Remembering New Acquaintances'. T4 had seven event records related to 'Remembering Ad-hoc Events' and one was 'Remembering New Acquaintances'. T1 had four records which belonged to 'Remembering Ad-hoc Events' and one related to 'Remembering Instructions'. This results assumed that the most important memory for TBI survivors remembering in real life is 'Remembering Ad-hoc Events'. The ad-hoc events normally implicate particular purpose and more than one person was included, e.g., meeting with someone. These events usually contributed to people's autobiographical memory. However, these events general involved a lot of 'new' information within, which was a challenge for TBI survivors' memories. Consequently, this study showed that TBI-participants required assistances to remember them.

Table 8.17 shows TBI-participants' number of uses for training tools, sorting functions and editing. Editing is designed to enable the user to edit an existing event record. These numbers come from the log report which was a function designed to collect the user's activity (see Section 7.2.5).

<b>Table 8.17:</b> Nun	nber of uses group	ed into the participant	and function.
------------------------	--------------------	-------------------------	---------------

	Elachoond	Widget	Sort by	Sort by	Editing existed records
	Flasiicaru		people	location	records
T1	21	19	0	0	0
T2	0	6	0	0	1
T3	15	39	6	1	3
T4	0	5	0	0	2

For the flashcard, T1 had used it 21 times and T3 15 times. T2 and T4 never used it. For the widget, all TBI-participants had used it. T3 used the widget 39 times, T1 had 19, T2 six and T4 five.

Most TBI-participants never used the sorting functions, except for T3. The log report indicated that she used 'sort by people' six times and 'sort by location' once.

The editing function was a function TBI-participants did not use so often. According to the log report for the editing function, T3 used it three times, T4 two, T2 once and T1 never used it.

### 8.7 Discussion

The main goal of this study, introduced in Section 8.1, is to determine whether MyMemory, and the approach taken in this thesis to augment autobiographical memory, actually helps TBI survivors to improve their memory ability. Another goal was to determine if MyMemory could improve the quality of life of TBI survivors and people around them. The goals were subdivided into three aims. This section relates the findings to the goals by giving explanations to each of the aims.

### 8.7.1 TBI-participant's Improvements

TBI-participants reported improvements when they used MyMemory. The improvements included their well-being, memory function and autobiographical memory during the study.

#### Well-being

As described in Section 8.6.2, TBI-participants reported positive changes in their well-being. Overall, the results without MyMemory (phases A1 and A2) were lower than with MyMemory (phases B1 and B2). Additionally, the results when they first used MyMemory were lower than the second time. One possible explanation considers that TBI-participants required time to learn MyMemory and adapt to the changes of using MyMemory as their memory aid. This explanation was supported by two Caregiver-participants' observations as well.

Compared with the results when not using MyMemory (phases A1 and A2), most TBI-participants presented their well-being in A2 were higher than A1. According to participants reports, they felt more confidence about their memory abilities after first using MyMemory (B1 phase), and this positive influence continued until the next phase (A2 phase: without MyMemory). Some of them further reported their quality of sleeping was better and found their fatigue decreased after they used MyMemory.

It is surprising to find that some TBI-participants relied on MyMemory in the such a short time (a phase is two weeks). They described they felt anxious when they were asked to stop and use their own memory aids. This negative emotion also reflected on their well-being scores in A2. Even so most participants presented well-being scores in A2 which were higher than A1.

Overall, the findings described in Section 8.6.2 show that TBI participants were happier after they has used MyMemory. We might interpret that the positive influences was produced after they used MyMemory, which were accumulated and affected TBI-participants, even though they were not using MyMemory.

#### Memory ability

The findings reported in Section 8.6.3 show that

MyMemory affects TBI-participants' memory functioning capacities during the study. MyMemory allowed participants to record event data and train their memory with the flashcard and the widget. Together, this contributes to an indication that MyMemory is a memory aid for TBI survivors in training their memory abilities.

Overall, the results of participants without MyMemory (phases A1 and A2) were lower than with MyMemory (phases B1 and B2). Additionally, most participants reported their memory function improved after using MyMemory, the results of the B2 phase were highest in the study.

Compared with two phases for participants using MyMemory, most participants found their memory functioning in the B2 phase better than in B1 phase. It suggested the effect of MyMemory in improving the memory functioning required TBI survivors to use it long term. As opposed to their well-being, the improvement of the memory ability stopped when they returned to their own memory aids. T1 and T2 showed their memory ability remained the same level since they first used MyMemory (B1 phase) to return to their own memory aid (A2 phase). However, T3 was a person for whom memory function rapidly declined without MyMemory.

Some participants even copied the concept of factors of memory after they first used MyMemory and used it to record memory with their own memory aids. T2 and T3 described that they found such changes regarding to their memory behaviours in A2. That was one possible cause that their results in the A2 phase were higher than the A1 phase. However, T4 was a person who did not get the highest result in the B2 phase (second time with MyMemory), but rather in the A2 phase (with her own memory aid). The possible interpretation was that the changes is her personal use of taking care of her child caused stress and changed her memory needs. According to her interview, she relied on the reminder to track her and her son's schedules. These changes were reflected in the results of her memory functioning, the highest results was with her own memory aid (in A2), not with MyMemory. She said, "I do believe MyMemory could improve my memory ability, but now I need a reminder with an alarm to track my busy schedule."

#### Autobiographical memory

Participants used MyMemory to record event data and review the recorded event data. As described in Section 8.6.4, participants reported their autobiographical memory was improved when they used MyMemory.

Overall, the results of all participants with MyMemory (phases of B1 and B2) were higher than without MyMemory (phases A1 and A2). In addition, the results of participants in the B2 phase (second time with MyMemory) were highest in the study. Most participants reported that their autobiographical memory was improved when they first used MyMemory; however, the effects of MyMemory ceased when participants returned to their own memory aid. These results are similar to the results of TBI-participants' memory functioning. Its improvements would be stopped when TBI-participants did not use MyMemory.

That is to say long-term use of MyMemory is a necessary condition for improving TBI-participants' autobiographical memory. It differed from the progress of well-being of TBI-participants, what the effects accumulated and affected the next phase. The improvements of the autobiographical memory were similar to the memory ability as described previously, which ceased when TBI-participants stopped using MyMemory.

### 8.7.2 Caregiver-participant's Observations

Caregiver-participants reported their observations about their relative's use of MyMemory. The observations contain self-reports of their burden

#### Chapter 8 Evaluating the Effectiveness of MyMemory

amelioration and their observation about the improvements of the memory functioning for their TBI relatives.

### Reduction of Caregiver-participants burden

One aim of MyMemory is in reducing the caregiver's burdens. The results of Caregiver-participants reported their burden actually decreased when TBI-participants used MyMemory. There were two Caregiver-participants in the study and each of them are involved in different roles with their TBI relatives. One is the husband for supporting his wife on a daily basis (C1), and the other is the son who helps his mother with limited things (C2), such as reminding her to pay a bill before the due date.

Both of them reported their burden lessened when their TBI relatives used MyMemory (phases B1 and B2). However, there were varying degrees of results provided by Caregiver-participants. C1 provided 24/7 support for a daily comprehensive assistance for his wife; for him its difficult to detect his wife's changes in their daily life. Occasionally, he found his wife remembered to feed the cat or discussed with him about her last phone call. These changes were observed after she used MyMemory. Contrary to C1, C2 supported his mother with things for a limited amount of time. It was easy to note his mother's improvement, e.g., his mother remembered to pay a bill without his reminder. Therefore, we supposed that the role of two Caregiver-participants in the relationship might be the explanation of the results varying in the study.

Overall, Caregiver-participants found their burdens lessened when their TBI relatives used MyMemory but increased when not using MyMemory. The results seemed compatible with TBI-participants' progress of the memory ability and autobiographical memory. When TBI-participants stopped using MyMemory that resulted in their memory ability and autobiographical memory also stopping or declining, Caregiver-participants' burden increased as well.

#### Observation of TBI-participants memory ability

The results were reported by Caregiver-participants regarding their observations of the memory ability of their relatives with TBI, as described

in Section 8.6.3. Overall, Caregiver-participants detected when their TBI relatives used

MyMemory, it improved their memory ability. However, these improvements were not obviously observed by Caregiver-participants when TBI-participants used MyMemory for the first time.

One partial explanation given by both Caregiver-participants when asked about this was that "my wife's [my mother's] memory improved if she had more time [remembered] to use it" – they speculated that their TBI relatives required time to learn new things, such as learning to use MyMemory. It seems compatible with the findings from the interview user study. Section 4.6.2 described three particular problems which caused TBI survivors distress, and 'remembering instructions' is one of problems.

Overall results of Caregiver-participants reported the memory functioning of their TBI relatives was improved when they used MyMemory. When they returned to their own memory aids the improvements stopped or even regressed. One possible explanation is TBI survivors could not cope with the alternation between using MyMemory and their own memory aids.

## 8.7.3 MyMemory and TBI-participant's Memory Needs

This section relates to TBI-participants activities and records with MyMemory. These results might explain what kind of memories TBI-participants want to use MyMemory recording and retrieving.

#### Photo needs

The results of the photo needs of TBI-participants were determined using two approaches. One is the feedback to ask TBI-participants whether they preferred to add a new memory starting with camera or starting with new memory (text input), as described in Section 8.6.5. The other is reviewing the event records and the log report, which were downloaded from MyMemory of each TBI-participant (see Section 8.6.6).

Starting a memory input with text scored higher than with camera. Also, most TBI-participants did not attach a photo to their event records. Some of them never even used any function related to taking photos in MyMemory (i.e., starting with the camera on the function bar or taking a photo or browsing the photo gallery in Memory function).

These results suggest that photo inclusion is a personal preference for TBI survivors, not essential for their memory. Some TBI participants gave an explicit account of their reactions to taking the photo when they used MyMemory. For example, T2 reported she felt embarrassed taking some photos, such as taking a picture of a new acquaintance for an event record. Nevertheless, T3 found her memory could be rapidly retrieved by reading the event with a textual description and a photo in MyMemory. She was the only participant who attached a photo to each event record in the study.

#### Organisation needs

The organisation needs include backup/sharing and categorising memories. These were designed for sending text messages or emails, and changing label color. The results were collected from the feedback evaluation from TBI-participants during the phase B1 and B2, and the event records and log reports downloaded from MyMemory.

TBI-participants gave a high score for both functions. However, reviewing the number of event records we found TBI-participants sent by emails more than by text messages. T3 was the participant mostly sending event records as emails for backing up her own memory or sharing her memory with others.

Changing label color is a function that MyMemory provides to categorize event records the user has saved in MyMemory. All TBI-participants gave a full score (4) to this when they used MyMemory in the second time. All of them used the color to categorize event records and they remember the color that represents the category. MyMemory offers six colors for the label changing, in average each TBI-participant used at least four colours. During the interview, all TBI-participants precise described each color representing of the category they used in MyMemory. Some TBI-participants reported that the color label is better than a folder for organizing (e.g., using a folder to organize documents on a computer). These results might interpret that the color coding is another factor for

supporting TBI survivors memory.

Training tools: FlashCard and Widget

The training tools include 'FlashCard' and 'Widget' for training and improving the user's memory ability. In the feedback TBI-participants gave, both tools had a high score (see Section 8.6.5). 'Widget' got a full score from all TBI-participants in the B2 phase. All of them reported the widget as a tool that can improve their memory. According to the usage from the log reports, all TBI-participants had used the widget, the maximum number of times was reached 39 by T3. However, there were differences for the flashcard. The outcomes of log reports revealed two TBI-participants had used it (T1 and T3) and two never used it. Some participants made the concise explanation of the different usage and feedback. 'Widget' is located on the main screen, the user can access it after they turn on their cell phone. However, 'FlashCard' is located within MyMemory, the user has to access MyMemory to use it. It is convenient for them to check; however, not to access.

#### Searching approaches: Sort by Person and Sort by Location

'Sort by Person' and 'Sort by Location' were designed to replace text searching in MyMemory. Most TBI-participants did not know how to use these new searching approaches when they first used MyMemory. However, after the explanation and demonstration, TBI-participants understood that how these two sorting functions worked and how they could help them search efficiently. According to the usage from log reports, most TBI-participants did not actually use these two sorting functions. During the interview, we asked all TBI-participants about the low usage of these new searching approaches. All of them reported that their event records were not big enough for them to need to do a search. It might interpreted the low usage for these two sorting functions in the study.

### TBI-participants' event records

According to the interview user study, the results explored the three particular memory problems TBI survivors most distressing: 'Remem-

bering New Acquaintances', 'Remembering Ad-hoc Events' and 'Remembering Instructions'. In this study, most records of all participants in MyMemory related to 'Remembering Ad-hoc Events'. T3 and T4 had one record each related to 'Remembering New Acquaintances' respectively and T1 had one record related to 'Remembering Instructions'. Total event records were 71 for four TBI-participants over eight weeks (for B1 and B2 phases). The maximum number of event records were five for one day. These numbers suggest the TBI-participants might not record every event they experienced.

Each event recorded usually involved the participant themselves and sometimes other people. However, some records showed the event only related to themselves, T1 had two out of five, T2 had three out of 29, T3 had seven out of 29 and T4 had two out of eight. It revealed that TBI-participants not only recorded events which involved other people but also they recorded events that happened when they were alone. Most of these records concerned personal achievements with important meaning for themselves. For example, T3 had a record about clearing her room, which was the first time she cleared her lounge since she had TBI. She said "I don't need to tell other people about it but I want to remember it".

#### Recording and editing needs

Analysis of event records and log reports showed that most TBI-participants entered event records with full details in MyMemory. T1 and T3 completed all their records with full details. Nonetheless, T2 had seven records (out of 29) without full details and T4 had two records (out of eight). Furthermore, checking the usage for each TBI-participant's log report, T1 was the only participant who had never edited event records since she recorded them in MyMemory. Others had experience of editing their records more than once. T2 had used the edit function once, T4 twice, and T3 three times.

These figures might suggest that MyMemory includes the correct amount of detail elements for TBI-participants to record the event data. These elements were based on the five factors of memory, which was explored

from the interview user study. Therefore, TBI-participants were able to complete the event data in one step. Some of participants found the factors of memory became a part of their memory strategies after they used MyMemory.

## 8.7.4 Limitation of the Study

Limitations of the study includes the length of time and the number of participants. This study was designed, so that TBI-participants changed their memory aids every fortnight for investigating the effectiveness of MyMemory on their memory abilities, giving an overall study time of eight weeks for this study. It is a challenge for TBI survivors to accept this alteration, causing pressure on some TBI-participants.

The target number of participants for this study was five TBI-participants and five Caregiver-participants, and the researcher met both in person every fortnight. However, there are many uncontrollable factors which made this target number unachievable. Our ethical approval only allows to recruit the participant in public places excluding the hospital and clinics, which caused difficulties for the recruitment. This study not only needed to recruit TBI-participants but also had difficulty finding TBI-participants with a caregiver, to participate in the study. In addition, every meeting for the study required a face to face interview, which limits participants to those living within 50km from the University of Waikato. Combinations of these reasons result in the shortage of the numbers of participants in this study, which indirectly effects the results.

# 8.8 Summary

This chapter aimed to answer research question five: "Can the training make a difference?". Using the implementation of MyMemory prototype, an evaluation study was executed to determine the effectiveness of MyMemory. The study was designed using an ABAB design and also observing TBI-participants' mental and memory functioning changes. This study also invited two Caregiver-participants, they provided their observations about their TBI relatives changes.

#### Chapter 8 Evaluating the Effectiveness of MyMemory

The answer for the fifth research question is – yes, the training makes a difference in TBI survivors and for the people around them. The results of this evaluation study present differences, which are the result of TBI-participants using MyMemory. One hypothesis of this research was that the memory ability of TBI survivors can be trained. Overall results show that MyMemory is a memory aid for training TBI survivors' memory ability and can also improve the quality of life of TBI survivors and the people around them. TBI-participants all consider that the training tool of MyMemory, the flashcard and widget, are able to improve their memory ability. The results of the memory functioning scale indicate a difference in their memory ability when accessing their own memory aids and MyMemory. The results with MyMemory are on average higher than when using their own memory aids. Their well-being also improved along with their memory ability and the burden on Caregiver-participants was reduced.

# Chapter 9

# Summary and Conclusions

This thesis proposed a new approach to augmenting autobiographical memory for TBI survivors that is grounded in both cognitive psychology and computer science research. The new approach integrated findings from the computer science research which we summarize as follows: that a mobile device is the most suitable equipment to meet the requirements of a memory aid for TBI survivors. This based on the fact that mobiles have a small size screen which shows a restricted amount of information and the portable size allows it to be carried around.

The objective of this thesis was to explore the effect of memory impairments in the life of TBI survivors, and to design and develop an augmented memory aid to help reduce these effects. From the first interview user study we identified the factors of memory and from reviewing the related work understood that a mobile device is the most suitable equipment. The combination of these two concepts suggest storing, retrieving and training are keys to helping TBI survivors remember past experiences and thus to achieve the objective of this thesis. Our research confirms the hypothesis, it was that:

a digital system designed specifically for TBI survivors to train their memory will improve their ability to remember.

This chapter is structured as follows. Section 9.1 answers the five research questions and Section 9.2 outlines the contributions of this thesis to the area of augmented autobiographical memory for TBI survivors. Section 9.3 discusses the limitations of the research, and Section 9.4

gives ideas for future work, including enhancements to the implemented prototype and propositions for future studies. Finally, Section 9.5 concludes this chapter and the thesis.

## 9.1 Answers to the Research Questions

This section details our answers to the five research questions presented in Chapter 1.

# 9.1.1 What kind of memories do TBI survivors remember or forget?

Most TBI survivors can remember repeated events, such as everyday tasks. They find it hard to remember ad-hoc events, for example, a task assigned during a conversation with someone.

The memory impairments of TBI survivors may vary due to different damaged areas of the brain and other symptoms. Therefore, clarifying which memories TBI survivors remember was the first question in this research. We began by reviewing literature (as described in Chapter 2) and analysing related work (as detailed in Chapter 3), and by interviewing TBI survivors. From the literature it was known that autobiographical memory impairments often result in social problems for TBI survivors.

Chapter 2 reported that autobiographical memory consists of episodes recollected from an individual's life. It is based on a combination of personal experiences and specific objects, people and events experienced at particular time and places (episodic), and general knowledge and facts about the world (semantic) memory. It is complex and because it is personal to an individual it is hard to measure accurately by a thirty party. In studies of TBI survivors, there is a lack of detailed and accurate information about the memory problems experienced by those with TBI.

The aim of the interview user study was to 1) explore which memories TBI survivors want to remember, 2) discover what kind of information is the most efficient trigger for TBI survivors' memories, and 3) investigate the memory strategies/aids TBI survivors used.

The results reported in Chapter 4 to answer this question. The re-

sults of the study indicated three particular memory problems of TBI survivors: Remembering New Acquaintances, Remembering Ad-hoc Events and Remembering Instructions. From the analysis of the results of the study we also identified five factors of memory that are effective cues to trigger TBI survivors' memories: Location, Date/Time, People, Emotion and Activity. In addition, we identified three requirements of a memory system that TBI survivors required: Simple, Discreet and Customisable.

# 9.1.2 How can a mobile system help TBI survivors remember?

Chapter 3 and 4 show that TBI survivors need an external memory storage for supporting their memories. We found from the interview user study they often use physical paper material (e.g., a diary) for this purpose. However, they cannot always remember to use these physical materials or they may lose them. A mobile device is suitable equipment to support TBI survivors, which can act as a memory storage and be easily carried around. The nature of a mobile device (e.g., small screen size) limits the amount of information that can be displayed which is good for supporting TBI survivors with concentration difficulties and headaches caused by dealing with large amounts of information at once.

Existing psychology research has provided influential insights into the use of mobile systems to help memory impairments. A mobile device limits the information display which avoids difficulties in concentration when TBI survivors use it. Moreover, the results of the interview user study indicated that TBI survivors need an external portable memory storage to support their memories. Combining these two factors indicate, a mobile device is the appropriate equipment for an external memory storage of TBI survivors, as detailed in Chapter 3.

Our interview study (as described in Chapter 4) was supporting by caregivers is a common memory strategy for TBI survivors. However, most TBI survivors live alone or need to support other people, such as taking care of children. For these TBI survivors, their memory strategies include two concepts discovered from the interview user study: Processes by Hand and Repetition. In the interview user study, TBI-participants

reported that writing things down (or typing them) are essential for their memory. Once they wrote or typed information they can remember something, but not the details. Repetition is the only method which can help them remember more detail. The repetition has to be executed in different time periods called Spaced Repetition in the psychology research.

# 9.1.3 What kind of special requirements do TBI survivors have for the design of an augmented memory aid?

Chapter 4 and 5 explored that most TBI survivors do not want other people to discover their memory impairments; they would rather pretend to have a short memory lapse. TBI survivors require a simple interface design and information display. Every TBI survivor has their own strategies and expects a memory aid to support their strategies.

The results from the interview user study (as detailed in Chapter 4) highlighted three features of the memory aid TBI survivors required: Simple, Discreet and Customisable. Simple is a requirement for the interface design and the method of displaying information. Difficulty with concentration and visual problems cause TBI survivors problems when reading too much information at once. Therefore, they require a memory aid to have a simple interface design and information display. Discreet is a requirement for TBI survivors who expect no one to know when they use a memory aid to record their memory. Customisable is required to support every TBI survivors individual memory strategies by allowing them to personalise aspects of the system.

# 9.1.4 What kind of information display will TBI survivors accept?

A simple and clear information display is a requirement for TBI survivors for the memory system design. TBI survivors require the right amount and type of information for both capturing and displaying memories.

The conceptual design (as described in Chapter 5) follows the requirements of TBI survivors expectations of the memory aid. It includes three core features: 'Adding Memory', 'My Memories' and 'Training'. The in-

terface design of 'Adding Memory' is based on the five factors of memory that allow TBI survivors to efficiently record their memories. 'My Memories' is designed for information display with the question-answer pattern of data display. 'Training' includes the flashcard and post-its both of which are designed for the repetition to display records.

In Chapter 6, the interface user study was structured to test the usability and interface design of the conceptual design. The results confirmed the conceptual design meets TBI survivors requirement to support their autobiographical memory. TBI survivors found the questionanswer pattern of data display was helpful to retrieve their memories. However, they worried this method of displaying data caused a threat to privacy. This privacy requirement for information display was solved and presented in the implementation of the MyMemory prototype.

# 9.1.5 Can memory training using a mobile system make a difference for TBI survivors?

Training not only improves TBI survivors' memory ability, but also improves their quality of life and reduces burdens for caregivers.

The aim of the final study was evaluating the effectiveness of the implementation of the MyMemory prototype in improving TBI survivors memory in Chapter 8. The study applied the ABAB technique for observing the participant's differences with and without the use of the memory aid. In this study, participants were required to use alternately their own memory aid and MyMemory twice. The results showed using MyMemory prototype can train TBI survivors memory.

The overall results of the study showed that MyMemory can improve the psychological condition and memory functions of TBI survivors. Furthermore some TBI-participants reported their memory pattern and behaviour changed after using MyMemory. Two Caregiver-participants declared their TBI relatives had improved their memory ability and well-being after using MyMemory. For Caregiver-participants, they reported their burden was reduced when their TBI relatives used MyMemory.

### 9.2 Contributions

This section summarises the contributions made by this thesis to research into augmenting autobiographical memory for TBI survivors.

# 9.2.1 Requirements for an augmented autobiographical memory in TBI

Our examination of research in the field of Cognitive psychology contributes a thorough understanding of the problem of TBI survivors' autobiographical memory. This is important because research related to problems in the past have focused on TBI survivors' prospective memory for the completion of everyday tasks and neglected their autobiographical memory for supporting the quality of life. The examination yielded three key points for the design of an augmented autobiographical memory system. Two of the key points indicated when designing such a system, are Rehearsal and Spaced Retrieval. The third key point is the development of the Memory Box Concept to explain differences between Alzheimer's disease patients and TBI survivors.

# 9.2.2 Analysis of related work for both Computer Science and Psychology

The analysis of existing computer science approaches enabled us to explore the strengths of augmented autobiographical memory system. The approaches selected for analysis are either designed for assisting AD patients and TBI survivors' memory in daily life or are designed for related types of information and incorporate context, semantic information and associations as the cue for triggering memory. Most approaches for AD patients focus on recording all personal experiences for later reviewing or teaching patients to regain their independence. The approach for TBI survivors aimed at supporting the completion of everyday tasks. The other analysed systems that incorporate context, semantic information and associations are designed for a contextual cue memory system that is already in digital form – the Digital Parrot. As a result, these systems do not meet TBI survivors needs for their memory impairments but outline

three factors for designing a system for TBI survivors: a mobile device as the suitable platform, the spaced retrieval concept and the contextual cue memory system.

# 9.2.3 Special requirements for TBI survivors with memory impairments

The interview user study explored how memory impairments affect TBI survivors and people around them. The study contributed three aspects to requirements of TBI survivors with memory impairments. The first aspect was identifying five factors of memory that are most useful to trigger TBI survivors' memory. The second aspect was outlining problems that are most problematic for TBI survivors in their lives. The third aspect was related to requirements that are specialized in the memory system for supporting TBI survivors' memory.

# 9.2.4 Conceptual design for an augmented autobiographical memory system for TBI survivors

The conceptual design of a system for supporting autobiographical memory applies the analysis of related approaches and the understanding of TBI survivors' requirements to derive a new solution. The design uses five factors of memory to capture the event data and the question-answer pattern for displaying information. Its purpose is rehearsing TBI survivors' memory. The design also employs a new searching approach based on sorting: Sorting by People and Sorting by Location, which is instead of the textual searching approach. The design includes the use of flashcards as one of the training tools. In early childhood education, the flashcards are a useful tool to teach children because they have a short attention span. TBI survivors have difficulty concentrating, similar to children. Therefore, flashcards are introduced as a tool for training TBI survivors' memory.

### 9.2.5 Prototype implementation of the design

The implementation of the conceptual design in the MyMemory prototype, further clarifies the design by introducing charges for capturing event data and displaying information. The focus in this implementation is on training, following the focus of the research presented in this thesis. The MyMemory prototype allows the design and its implementation to be evaluated.

# 9.2.6 An evaluation of the effectiveness of an augmented autobiographical memory system in a user study

The evaluation contributes in three ways. The first contribution is identifying how TBI survivors' memory ability can be trained by the tailored memory system. This includes how to apply the psychology design method to observe differences of TBI survivors and their caregivers with MyMemory.

The second contribution is the design of the capture and display of event data accepted by TBI survivors to improve their autobiographical memory. The design of capturing event data is based on the five factors of memory and the event data display is designed using the memory-factor pattern in the memory training tools.

The third contribution is improving TBI survivors' memory ability, which also can improve their quality of life. The results were confirmed to be accurate by TBI survivors well-being index showing improvement and their caregivers burden reducing when TBI survivors used MyMemory.

#### 9.3 Limitations

This section discusses the choices made during the research presented in this thesis, and resulting limitations.

## 9.3.1 Design Choices

The design choices were mainly determined by feedback from the participants and so was limited by the number of participants we could recruit.

The design focused on support for TBI survivors with memory impairments. The ethics consent approval required to include such participants in our study was a significant factor in our ability to recruit participants so to the progress of the research. A hospital or out patient clinic is a reasonable place to recruit TBI participants, however the ethics consent approval for such studies requires six months to process. Due to the schedule of the research we instead applied for ethical consent approval from the Psychology School of the University of Waikato. Ethical consent approval from the Psychology school takes three weeks to process but it only allowed us to recruit participants from public places or organizations for supporting TBI survivors and not from hospitals, clinics etc. In addition, most TBI survivors do not take an active part in social activity and do not tell others of their situation. All of these restrictions made the recruitment of participants more difficult.

### 9.3.2 Implementation Choices

The implementation of the MyMemory prototype is based on the Android system. Android is an operating system for mobile devices and its structure is similar to Java, which allows us to develop the application using the Eclipse IDE. There are other operating systems for mobile devices, e.g., iOS and Window systems. However, we could not develop for every platform in the limited time. Development requirements for these alternative operation systems are more than the Android system. These were reasons for choosing to implement the prototype of MyMemory on the Android system. However, some TBI survivors could not participate in the evaluating user study as their mobile devices used iOS or Window system.

#### 9.3.3 Evaluation Choices

The evaluating user study described in Chapter 8 investigates differences of TBI survivors with and without MyMemory over an eight week period. It required two weeks of TBI survivors alternating with their own memory aids and MyMemory. This study is not truly longitudinal because TBI

survivors require more time to accept the alteration in their life. All TBI-participants commented that their improvement could be boosted if they had more time using MyMemory.

Similar to the design choices, the same restriction for the recruitment of TBI-participants is another limitation. Close observation can provide additional results related to differences of TBI-participants with and without MyMemory. For this, caregivers are the best choice. Therefore, this study further required to recruit Caregiver-participants. After the first round of recruitment for this study, we found most moderate TBI survivors usually live alone and do not have caregivers. This meant we instead included two additional TBI-participants without caregiver support to participate in this study.

## 9.4 Future work

There are a number of promising avenues to be pursued to address limitations and extend this work further. This section describes directions of how this research can be extended.

# 9.4.1 Following up on observations made in the evaluating user study

We recommend extending the time frame for the study. Even though the results from the study confirm the effectiveness of MyMemory for improving TBI survivors' memory and quality of life, some TBI-participants reported that their memory ability could be raised if they were allowed to use MyMemory for an extended period.

Following observations in the evaluating user study, a next step would be investigation of whether the effectiveness of MyMemory for TBI-participants' improvement is permanent or temporary. Regular usage of MyMemory might cause improvement. Improvements may also be seen in TBI survivors' physical condition, such as the changes of sleeping patterns, headache and reduction of fatigue. A long term study of using MyMemory could provide more accurate results of TBI survivors' improvements. It will also allow us to identify any effects of familiarisa-

tion, although these should have been largely prevented due to the ABAB study design.

### 9.4.2 Conducting further user studies

We recommend a large cohort for evaluating the MyMemory prototype. In our evaluating user study, we had six participants (four TBI-participants and two Caregiver-participants). If the evaluating user study had a larger cohort of participants, the results would be more significant. If more TBI-participants participate to evaluate the MYMemory prototype, the results would cover more different memory impairments cased by TBI and more be subjective.

More Caregiver-participants would be beneficial for the evaluating user study. Their observations can provide and explain the progress of TBI-participants in the study. We found that the observation of Caregiver-participants provided more accurate information to measure and assess TBI-participants using different memory aids in the meeting every fortnight.

### 9.4.3 Support for iOS system or other wearable devices

We recommend two directions for implementing different versions of the MyMemory prototype. One would be to develop a different version for mobile devices. The implementation of the MyMemory prototype was only done for the Android operation system. iOS is another main operating system in the mobile device market. Therefore, developing the iOS version of MyMemory is one direction for future work.

Another focuses on an implementation for wearable devices, such as smartwatches. Due to advances in technology, wearable devices have gained popularity. Developing a version of the MyMemory prototype for a wearable device is therefore another direction to consider. However, wearable devices have a smaller screen to display information, which produce different requirements from using mobile devices. An extra user study perhaps is needed to explore TBI survivors' requirements for wearable devices.

## 9.5 Conclusion

The key contribution of this research is developing and testing the concept of a memory system to support TBI survivors' autobiographical memory. The data of how memory impairments affect TBI survivors' daily life and memory strategies/aids TBI survivors had, was found in the interview user study. Following the insights gained in our interview user study, a conceptual design was created and examined through an interface user study. The results of the interface user study contributed to developing the implementation of the MyMemory prototype for mobile devices with the Android system. An evaluation user study was designed to test the effectiveness of the implementation of MyMemory, particularly in observing differences of TBI survivors memory ability and their quality of life. The results of our studies show that an augmented autobiographical memory system can benefit TBI survivors with memory impairments.

This research is an initial step towards the realization of developing an augmented autobiographical memory system for TBI survivors. A number of steps for extending this research have been suggested.

# Appendix A

# Material for Interview User Study

This appendix contains material given to the participants in the study that the interview user study, described in Chapter 4:

A1 the approval letter form the from the Psychology Research and Ethics Committee, School of Psychology, University of Waikato, dated 12 July 2012;

- A2 the Poster for the public to recruit the participants;
- A3 the Newletter and News, which adverts the study information;
- A4 the Participant Information Sheet, which outlines the study goals and procedure as well as the participant's right;
- A5 the Participant Consent Form, which each participant signed at the beginning of their session;
- A6 the Interview Form, which contains instructions and the questionnaire.

#### Appendix A Material for Interview User Study

# A.1 Approval Letter

School of Psychology The University of Waikato Private Bag 3105 Hamilton 3240, New Zealand

Phone 64-7-856 2889 Facsimile 64-7-858 5132 www.waikato.ac.nz/psychology



12 June 2012

Carole Chang FCSM

Dear Carole

Ethics Approval Application – # 12:37
Title: An Augmented Memory System for Brain Injury

Thank you for your ethics application which has been fully considered and approved by the Psychology Research and Ethics Committee.

Please note that approval is for three years. If this project has not been completed within three years from the date of this letter, you must request reapproval.

If any modifications are required to your application, e.g., nature, content, location, procedures or personnel these will need to be submitted to the Convenor of the Committee.

I wish you success with your research.

Yours sincerely

Nicola Starkey

Convenor

Psychology Research and Ethics Committee

School of Psychology University of Waikato

### A.2 Poster in 2012

# Hów do you remember?



#### Help us to develop better memory aids

Traumatic Brain Injury (TBI) can lead to long-lasting memory and concentration problems. We would like to find out more about what memory problems you have and what types of things help you to remember so that we can try to develop better memory aids.



#### We would like to talk to you, if you:

- Had a brain injury (head injury), and have memory problems OR
- You are a caregiver for a person with brain injury (head injury) who has memory problems

What is involved? You would be required to meet the researcher to take part in an interview (45-60 mins) at a mutually convenient time and place.

**Participation** is voluntary, all personal information will be kept confidential, and results will not be linked to individuals. This study has approval from the School of Psychology Ethics Committee, University of Waikato.

How do I find out more? Contact the researcher Carole Chang (PhD student), Computer Science Department, University of Waikato. email: <a href="mailto:sc200@students.waikato.ac.nz">sc200@students.waikato.ac.nz</a> This study is part of Carole Chang's PhD, supervised by Dr Annika Hinze, Computer Science Department and Dr Nicola Starkey, School of Psychology, University of Waikato.

### A.3 Poster in 2014

2014 April



# **Brain (Head) Injury Research**

Help us to develop better memory aids for Brain Injury

#### If you:

Had a brain (head) injury (including brain tumor surgery), and have memory problems.

You are a caregiver for a person with brain (head) injury who has memory problems.

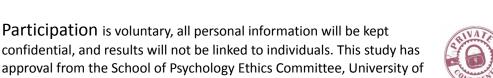
We would like to talk to you.

#### What is involved?



Waikato.

You would be required to meet the researcher to take part in an interview (45-60 mins) at a mutually convenient time and place.





#### How do I find out more?



Contact the researcher

Carole Chang (PhD student), Computer Science Department, University of Waikato. email: sc200@students.waikato.ac.nz

This study is part of Carole Chang's PhD, supervised by Dr. Annika Hinze, Computer Science Department and Dr. Nicola Starkey, School of Psychology, University of Waikato.

sc200@students.waikato.ac.nz Carole Chang Brain Injury Research Carole Chang 3rain Injury Research Brain Injury Research 3rain Injury Research rain Injury Research :200@students.waikato.ac.nz rain Injury Research :200@students.waikato.ac.nz

### A.4 THINK! Newsletter

THINK! QUARTERLY NEWSLETTER | Issue 28 THE UNIVERSITY OF WAIKATO **HOW DO YOU REMEMBER?** Help us to develop better memory aids. Traumatic Brain Injury (TBI) can lead to long-lasting memory and concentration problems. We would like to find out more about what memory problems you have and what types of things help you ABERSHIP FEES to remember so that we can try to develop better memory aids. **DUE ON 1ST APRIL 2014** Approved changes to membership fees from 1st April 2014. The new categories are as follow: Membership categories and benefits Member | Benefits Level Membership category fee Students, \$10 Field Officer support and beneficiaries, advocacy services We would like to talk to you, if seniors Support groups you: Receive Newsletter Notifications to Had a brain injury (head events/seminars injury), and have memory Individuals, \$50 As for level one problems OR waaed You are a caregiver for a 3 Community \$80 As for Level one person with brain injury (head Groups injury) who has memory problems Professional 2 Receive Newsletter \$80 or less · One complimentary What is involved? You would employees advertisement in be required to meet the newsletter researcher to take part in an Reduced cost for interview (45-60 mins) at a advertisements mutually convenient time and Notifications to place events/seminars Certificate of Participation is voluntary, all membership personal information will be Receive an annual report kept confidential, and results will not be linked to individuals. This Professions 3-\$250 As for level 4 study has approval from the 10 employees School of Psychology Ethics Professionals \$350 As for level 4 Committee, University of Waikato. 11-20 How do I find out more? Contact employees the researcher Carole Chang (PhD student), Computer Science \$450 Professionals As for level 4 Department, University of Waikato 21+ by email: sc200@waikato.ac.nz. employees

## A.5 News

COMMUNITY Hamilton News 11 Friday Dume 120s 2014 **Get THINKing** Living with a head injury Hannah (name changed to protect identity) has been living with a head injury for injury for seven years and still finds everyday a challenge.

Hannah was swimming in a shared lane with four other swimmers when she stopped part way through a length and failed to step aside to clear the way for oncoming swimmers.

"I collected the full impact of a backstroker to the back of my head and neck. I was dazed and confused. I felt sick to my stomach."

She got home and went straight to bed. For six months she suffered from chronic fatigue and severe vertigo and would often crawl around the house.

"I couldn't hold a thought, nor have conversations."

She says she would forget what someone was saying white they were still talking. "I had about one useful wound the tower was selepting."

Seven years later she is doing much better with help from THINK!

"I stated going to THINK!

"It stated going to THINK!

"I stated going to THINK! about head injury issues **David Nicoll** A new head injury Wintec student journalist occurs every 15 June is Head Injury Awareness month and The Head Injury Network for Kiwis (THINK) is working hard to raise awareness of head injury. THINK is a nationwide, charitable organisation that provides support and information to people who are head injured, their families/ whanau and carers throughout the exentry. minutes in New Zealand and it is imperative that we get the message out that head injury impacts on the who are head injured, their families/
whanau and carers throughout the
country.

"A new head injury occurs every
15 minutes in New Zealand and it is
imperative that we get the message
out that head injury impacts on the
person, their family and the
community,' says THINK manager
Ella Scheepers.
The estimated cost on the health
system is \$100m a year, but it is
expected that figure will firse.
Brain injuries, including stoke
and traumatic brain injury, is the
leading cause of disability and death
in New Zealand.

"Head injury is referred to as the
"silent epidemic", as the effects go
largely unseen and can have long
term consequences."

Planned activities include a
'Living with a Brain Injury Seminar
with neuropsychologist Dr Ron Dick
June 25 from 1-2:30pm at The Link, person, their family and the community Ella Scheepers THINK manager St Andrews Church Community
Centre, Hamilton. The cost is \$20
and it is open to allied health
professionals and service providers.
Businesses, community groups
and schools are invited to participate
in the annual 'Hats on Friday' event
on Friday, June 27 to raise
awareness of head injury. "People
wear a fun hat of their choice and
donate a gold coin towards much
needed resources." I had about one useful hour a day where I could get something done, the rest of the life."
An accombination of resting and a food plan meant that Hannah could drive herself to seminars and get to appointments and family gatherings.
She has been included in a PhD study about computerised time I was sleeping how my memory doesn't work and gives me hope for rehabilitation." memory aids for people with traumatic injury being conducted by Carole Chang. "It has made me understand ■ More information is available or the website www.thinknz.org.nz or phone 839 1191.

## A.6 Participant Information Sheet

An Augmented Memory System for Brain Injury



#### How do you remember?

#### **Participant Information Sheet**

#### Introductions

I am Carole Chang, a PhD student at the University of Waikato. My research focuses on developing a computerized memory aid for people with traumatic brain injury (TBI). This study aims to find out more about the memory impairments post-TBI. It includes 1) investigating which aspects of memory impairment TBIs and/or their caregivers find the most distressing and disruptive, 2) exploring what types of memory aids or strategies TBIs and their caregivers currently use and 3) finding out what types of information are most helpful in assisting TBIs to retrieve memories.

#### An invitation

The aim of this study is to find out more about memory problems to help us develop better memory aids. We are particularly interested in what types of memory aids/strategies people use and what types of information they record. You are being invited to take in this research study because:

- 1) You had a brain injury (head injury), and have memory problems OR
- 2) You are a caregiver for a person with brain injury (head injury) who has memory problems.

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you do agree to take part, you are free to with draw from the study at any time, without having to give a reason. To help you make you decision please read this information sheet. You may take as much time as you like to consider whether or not to take part.

#### What are the aims of this study?

We hope this study will lead to the development of better memory aids for people with TBI.

#### Who can take part in the study?

We need two groups of people to take part in this study. You can participate in this study if:

- a) You had a brain injury (head injury) with memory problems, and you are over 16 years of age.
- b) You are a caregiver or a close family member for a person with TBI with memory problems.



#### How many people will be in the study?

We estimate about 20-30 people will be involved in this study.

#### What happens if I do decide to take part?

You would be required to take part in an interview that takes 45-60 minutes.

#### How will the study affect me?

Taking part in this study will take some of your time and require you to answer a series of questions. There are no known risks caused by this study.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, you will be given an opportunity to discuss your memory problems. The results obtained from your participation may help others and improve the development of better memory aids in the future.

#### Confidentiality

The study files and all other information that you provide will remain strictly confidential, unless there is an immediate risk of serious harm to yourselves or others. No material that could personally identify you will be used in any reports on this study. Upon completion of the study your records will be stored for at least 5 years in a secure place at the University of Waikato. All electronic records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

#### Your rights

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact the convenor of the Research and Ethics Committee (via Joy Fellows, phone 83804466, in the School of Psychology).

#### Finally

This study has received Ethical Approval from the Ethics Committee, Psychology School, University of Waikato.

If you would like some more information about the study please feel free to contact the principle investigator:

Carole Chang, PhD student, Department of Computer Science, FCMS, University of Waikato, Hamilton, email: <a href="mailto:sc200@students.waikato.ac.nz">sc200@students.waikato.ac.nz</a>

#### A.6 Participant Information Sheet



An Augmented Memory System for Brain Injury

#### Supervisors:

Dr. Annika Hinze, Senior Lecture, Department of Computer Science, University of Waikato, Hamilton, on 07 838 4052 ext 4050 or email: <a href="mailto:hinze@cs.waikato.ac.nz">hinze@cs.waikato.ac.nz</a>
Dr. Nicola Starkey, Senior Lecture, School of Psychology, University of Waikato, Hamilton, on 07 8562889 ext 6472 or email: <a href="mailto:nstarkey@waikato.ac.nz">nstarkey@waikato.ac.nz</a>

Please keep this brochure for your information.

Thank you for reading about this study.

## A.7 Participant Consent Form

.



An Augmented Memory System for Brain Injury

#### How do you remember?

#### PARTICIPANT CONSENT FORM

- 1. I have read/had explained to me, and understand, the Information Sheet for participants taking part in the study. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- 2. I understand that taking part in this study is voluntary (my choice). I realize the study involves an interview with experience.
- 3. I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.
- 4. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- 5. I have had time to consider whether to take part.
- 6. I know who to contact of I have any questions about the study.
- 7. I agree to my responses to be audio recorded and photographs of my memory aids/strategies being used.
- I give approval for you to contact my caregiver or a close family member to ask them to take part in this study.

  Yes/No

If yes, complete the details below.	
Name:	
Relationship to you:	
Phone Number:	



in the case record file.

I am indicating my approval (or otherwise) for the following:

I wish to receive a copy of the results. I understand that there may be a significant delay		
between data collection and the publication of the study results.	es / No	
I hereby consent to take part in this research.		
Signature (or representative)		
Date:		
Name of witness		
Signature of witness		
Note: This conv of the consent form to be retained by participant and a conv to be placed		

Approved by the Ethics Committee, Psychology School,
University of Waikato

# A.8 Interview Form

,



PhD research : An Augmented Memory System for Brain Injury

# How do you remember?

### Questionnaire

Participant Initial:	
Questionnaire Number:	
Interview Number:	



Research will ask questions.

Ensure participant has read information sheet and signed the consent form.

1. General Questions		
1.1 Gender: O Female	O Male	
1.2 Age:		
1.3 Ethical Origin (tick on	e only)	
O NZ European	O NZ Maori	O Australian
O Fijian	O Cook Island Maori	O Asian
O Other: please specify	/	
1.4 You are a		
☐ TBI survivor severity	of original injury: O Mild C	) Moderate
☐ Patient with memory	y problem	
☐ Support: O Parent O Child OSibling O Spouse/Partner O Caregiver		
O Other: please specify		
1.5 When you did your problem start? When they did their problem start?		
(approximately date)		
D D M M Y	YYY	

# $Appendix\ A\ Material\ for\ Interview\ User\ Study$



An Augmented Memory System for Brain Injury

1.6 If you/they have TBI, what is the cause? If not, please go to <b>Question 1.7</b>		
O Motor vehicle accident	O Interpersonal violence	e O Industrial accident
O Sporting accident	OBicycle accident	
O Other: please specify		
1.7 What are current symptoms	do you /they have? (tick a	II that apply)
O Memory impairment	O Epilepsy	O Major depressive disorder
O Generalized anxiety disorder	O Fibromyalgia	O Exhaustion
O Other: please specify		
1.8 What was your/their main w	ork situation before the in	jury? (tick one only)
O Full-time paid work	O Part-time paid work	O Student
O Unemployed	O Beneficiary	O Homemaker
O Other: please specify		
1.9 What is the highest level of e	ducation that you/they at	tained? (tick one only)
O Primary School	O High	School
O Polytechnic/College	O Univ	versity

Please turn to the next page to Section 2.



2. Living an	d Work Arrangements		
2.1 What ar	e your/their living arrangen	nonts? (tick one only)	
			O Living with postures
O Alone	O Living with family	O Living with others	O Living with partner
2.2 What ty	pe of accommodation do y	ou/they live in? (tick one or	nly)
O Own, F	amily or Friends home	O Rented A	Accommodation
O Inpatie	nt, Rest Home, Retirement	Village	
O Other:	please specify		
2.3 Have yo	ou/they returned to the pre	-injury/previous job?	
☐ Yes, ho	w many hours a week do y	ou/they work? (tick one onl	<b>y</b> )
O Full 1	Time (35+ hours per week)		
O 20-3	4 hours per week		
O < 20	hours per week		
Go to C	Question 2.6		
□ No			
2.4 Have yo	ou/they changed jobs since	the injury/memory problem	s?
☐ Yes. If y	ou/they have changed job	s since the injury / the memo	ory problem, how many
ho	ours a week do you/they wo	ork	
O Fu	ll Time (35+ hours per weel	k)	
O 20	-34 hours per week		
0 < 2	20 hours per week		
□ No			

4

# $Appendix \ A \ Material \ for \ Interview \ User \ Study$



An Augmented Memory System for Brain Injury

2.5 If you/they have changed jobs since the injury what is your/their new occupation?
If yes, please specify
2.6 Since injury or the start at the memory problem, do you/they use any memory aids/strategies?
☐ Yes, please specify,
□ No
2.7 Do you find the memory aids /strategies to be helpful?
☐ Yes
□ No, please specify,
2.8 Are you/they satisfied with your memory aids/strategies?
□ Yes
☐ No, how could it be improved? Please specify,

Please turn to the next page to Section 3.



#### 3. Situation Support Questions and Information

#### Imagine you have a:

.1 A doctor's appointment in	a week time.	
Before that appointment them of the appointme	Before that appointment, what information would you/they usually record to remind them of the appointment?	
O Time and Date	O Places	O People who are going
O Other: please specify		
During the appointmen     the doctor gives you. (e.     Please specify,		you can remember the information
	if you want to remember w w do you do this? (e.g., look	what happened the appointment or back at note, ask person)

# $Appendix\ A\ Material\ for\ Interview\ User\ Study$



An Augmented Memory System for Brain Injury

	2 A lunch date with friends in a week time.		
	1) Before that date, what information would you/they usually record to remind them of the appointment?		hey usually record to remind them of
(	O Time and Date	O Places	O People who are going
(	O Other: please specify		
	2) During the lunch what do yo	u do to ensure you	can remember the conversation you
	had with friends. (e.g., note Please specify,		
-			
-			
-			
-			
	3) After the appointment, if you	u want to remembe	r what happened the date or
	what was discussed, how do	you do this? (e.g., lo	ook back at note, ask person)
F	Please specify,		
-			
-			
-			
-			



Are you currently working or volunteering? If yes, please answer  ${\bf Question~3.3.}$ 

An appointment with clie	nts in a week time.	
1) Before that date, what information would you/they usually record to remind them o		
the appointment?		
O Time and Date	O Places	O People who are going
O Other: please specify		
2) During the appointme you discussed. (e.g., n	•	re you can remember the information
Please specify,		
3) After the appointmen	t. if you want to remembe	r what happened the date or
• • • • • • • • • • • • • • • • • • • •	•	ook back at note, ask person)
Please specify,		

Please turn to the next page to Section 4.

# $Appendix\ A\ Material\ for\ Interview\ User\ Study$



An Augmented Memory System for Brain Injury

4. Additional Information
4.1 Is there anything else you would like to tell us about your memory problem?
Please specify,



4.2 What types of thing do you think would help your memory?		
Please specify,		

Please turn to the next page to Section 5.



An Augmented Memory System

5. Related follow up study  Would you be willing for us to retain your contact details for related follow up studies?
☐ Yes
Name:
Phone Number:
Address:
Email:
□No
Where did you find the information of this research study?
☐ THINK! Facebook
☐ THINK! Newsletter
☐ The university noticeboard
☐ The university Newsletter
□ Other

Thank you for your co-operation in completing this study.

# Appendix B

# Material for Interface User Study

This appendix contains material given to the participants in the study that the usability study, described in Chapter 6:

*B1* the approval letter form the from the Human Research Ethics Committee of the School of Computing and Mathematical Sciences at the University of Waikato, dated 10 September 2013;

*B2* the Invitation email, which introduces the researcher, the research and the information of this study.

*B3* the Participant Information Sheet, which outlines the study goals and procedure as well as the participant's right;

*B4* the Research Consent Form, which each participant signed at the beginning of their session;

*B5* the Tasks Form, which contains instructions, the study tasks and the feedback survey.

## **B.1** Approval Letter

Computing and Mathematical Sciences Rorohiko me ngā Pūtaiao Pāngarau The University of Waikato Private Bag 3105 Hamilton New Zealand

Phone +64 7 838 4021 www.scms.waikato.ac.nz



10 September 2013

Carole Chang
C/- Department of Computer Science
THE UNIVERSITY OF WAIKATO

**Dear Carole** 

#### Request for approval to conduct a research project involving human participants

I have considered your request to carry out a study for your PhD research project An Augmented Memory System for Traumatic Brain Survivors.

You will be asking people to use the software application Korimako on your personal computer while being audio recorded, and photographed.

I note that all information gathered will be used for statistical analysis only and no names or identifying characteristics will be in any reports. Any people in pictures will be anonymized by blurring out faces and any identifiable markings on clothing will also be blurred out. No names will be collected from any of the participants.

The interview recordings and photographs and all related data is to be stored in the FCMS data archive for 5 years and will be destroyed after that period. Data will be kept secure in Annika Hinze's office during the study.

The procedure described in your request is acceptable.

The research participants' information sheet, consent form and sample gathering questionnaire sheet all meet the requirements of the University's human research ethics policies and procedures.

I therefore approve your application to perform the research project.

Yours sincerely,

Lyn Hunt

Human Research Ethics Committee Faculty of Computing and Mathematical Sciences

#### **B.2** Invitation Email

,

Hi NAME,

I am Carole Chang from the Waikato University who has been studying for developing better memory aids for TBI people. We had met up for an interview last year and your feedback then is so appreciated.

Now the interface prototype for my application has been finished. With your feedback I will gain a much more insightful understanding of where it can be improved.

This time the user study is to use the application completing the task form. I will assist you to execute the prototype on the computer. The study will be audio recorded and photographed (the device and your hands only) all the way through. It should take no longer than one hour.

If you are interested in participating, please send me an email with a mutually convenient time and place. I will be more than happy to answer any questions you have before, during and after the user study.

Best regards,

Carole Chang

# **B.3 Participant Information Sheet**

#### **Participant Information Sheet**



#### **Ethics Committee, Faculty of Computing and Mathematical Sciences**

#### **Project Title**

An Augmented Memory System for Traumatic Brain Injury Survivors.

#### Purpose

This research is conducted as partial requirement for *Carole (Su-Ping) Chang of the PhD research*. This project requires the researcher to choose a topic and conduct research on the topic through using surveys or interviews or a combination of the two techniques.

#### What is this research project about?

This research is to investigate 1) how Traumatic Brain Injury (TBI) survivors record their personal information, 2) what types of equipment do they use, 3) what types of information do they need to remember. This research extends the concepts of the Digital Parrot (Andrea Schweer's PhD thesis) which is based on using the contextual cues to recall people's memories. With these results, I will re-build a memory system; it is based on Android system on the smart phones or tablets for using.

#### What will you have to do and how long will it take?

You will be asked to execute the prototype to finish task form. I will assist you to execute the prototype of the Korimako mobile application on my personal computer. The study will be audio recorded and photographed all the way through. This should take no longer than one hour.

You will be asked to give consent prior to the interview, and maybe asked to also give consent at a later stage.

#### What will happen to the information collected?

The information collected will be used by the researcher to write a PhD report. It is possible that articles and presentations may be the outcome of the research. Only the researcher will be privy to the notes, documents, audio recordings, photographs, participants' images and the paper written. Afterwards, notes, documents will be destroyed and audio recordings, photographs and images erased. The researcher will keep transcriptions of the recordings and a copy of the paper but will treat them with the strictest confidentiality. The audio recordings, photographs and your image will carry only a number, all identity portion of any images will be blurred. No participants will be named in the publications and every effort will be made to disquise your identity.

#### **Declaration to participants**

If you take part in the study, you have the right to:

- Refuse to answer any particular question and to withdraw from the study before or analysis has commenced on the data.
- Ask any further questions about the study that occurs to you during your participation.
- Be given access to a summary of findings from the study when it is concluded.

#### Who's responsible?

If you have any questions or concerns about the project, either now or in the future, please feel free to contact either:

Researcher:
Carole Chang
G2.06, Department of Computer Science,
The University of Waikato
Phone: (07) 8384466 ext 6011
Email: sc200@waikato.ac.nz

Supervisors: Dr Annika Hinze G2.26, Department of Computer Science, The University of Waikato Phone: (07) 8384052

Email: hinze@cs.waikato.ac.nz

Dr Judy Bowen G1.07, Department of Computer Science, The University of Waikato Phone: (07) 8384547 Email: jbowen @cs.waikato.ac.nz

K1.10, Department of Psychology, The University of Waikato Phone: (07) 8384466 ext 6472 Email: nstarkey@waikato.ac.nz

Dr Nicola Starkey

#### **B.4** Research Consent Form

#### Research Consent Form



#### **Ethics Committee, School of Computing and Mathematical Sciences**

An Augmented Memory System for Traumatic Brain Injury Survivors.

#### **Consent Form for Participants**

I have read the Participant Information Sheet for this study and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I also understand that I am free to withdraw from the study before, or to decline to answer any particular questions in the study. I understand I can withdraw any information I have provided up until the researcher has commenced analysis on my data. I agree to provide information to the researchers under the conditions of confidentiality set out on the Participant Information Sheet.

- I agree / do not agree (please circle one) to participate in this study under the conditions set out in the Participant Information Sheet.
- I agree / do not agree (please circle one) to my responses to be tape recorded.
- I agree / do not agree (please circle one) to my images being used.

Signed:	
Name:	
Date:	

Researcher's Name and contact information: Carole Chang G2.06, Department of Computer Science, The University of Waikato

Phone: (07) 8384466 ext 6011 Email: sc200@waikato.ac.nz

Supervisor's Name and contact information:

Dr Annika Hinze Dr Judy Bowen

G2.26, Department of G1.07, Department of Computer Science. Computer Science.

The University of Waikato The University of Waikato

Phone: (07) 8384052 Phone: (07) 8384547

Email: hinze@cs.waikato.ac.nz Email: jbowen@cs.waikato.ac.nz Dr Nicola Starkey K1.10, Department of

Psychology,

The University of Waikato Phone: (07) 8384466 ext 6472 Email: nstarkey@waikato.ac.nz

# B.5 Tasks Form

,



U	Iser	Stu	dv -	MvM	lemor	v
_	JULI	Deur	u y	1.1 A 1.1	CILIOI	y

MyMemory is the mobile application with the training purpose of helping TBI patients with their deficit memory which can save memories for inquiry later as well. It has four functions: Adding Memory, Training, My Memories and Setting. The prototype presents MyMemory's framework and you can execute functions on it. You will be gave tasks to finish. Please feel free to ask questions and give feedbacks.

-----

Date:

ID:

Age:

Gender:

S\_Time:

E\_Time:

Carole Chang 2013/9/1

MyMemory Prototype Evaluation March 2014 Carole Chang TASK 1 Please use Adding Memory to record this meeting and write down the information on paper After you finish input the infoarmation, please clicking Finish. Then clicking the pop up message then you accomplish this task. How difficult do you think about the way of information input? Difficult Very Difficult Very Easy Easy Normal Please click Long List checks this display and click HOUSE icon on left side then go back Main page. There are two types of displays, which one do you prefer and why? One long page with scrolling Two pages Reason:

# $Appendix \ B \ Material \ for \ Interface \ User \ Study$

MyMemory Prototype Evaluation	Carole Chang	March 2014
TASK 2		
There are scenarios of two memori Before I go to sleep:	es:	
Mark hold the dinner party on the Janet. Janet mentioned a book whi	·	• •
injury. You know the book that nam	nes "Before I go to sleep"	and you bought it on last month.
In the end of the conversiation, Jan Friday in Chartwell cinema, and you		o watch "Spider-Man" on next
- For your own memory strate memory which can help you		ntion you need to record for this
Mike Proposed to Nacy:		
You went to Waihi Beach with your asked you to be the bridesmaid/bri		like proposed to Nacy and Nacy
- For your own memory strate memory which can help you		ition you need to record for this

MyMemory Prototype Evaluation

Carole Chang

March 2014

You used the **Adding Memoy** to record these two memories then now the application shows the recorded memory is like –

"Before I go to sleep, Mark's home, Janet want to borrow it and watching movies on next week" and "Mike proposed to Nacy, Waihi beach, I am the bridesmaid."

Now please go to **Training** -> **Flash Card Training** -> **Start Training** to train two memories: <u>Before I go to sleep</u> and <u>Mike proposed to Nacy</u>.

- How	do you think abou	ut this training fund	tion?	
0	<del></del> O	<del></del> O	<del></del>	O
Very Useful	Useful	Normal	Slightly Useful	Not at all
Any suggestion	ons about <b>Flash C</b>	ard Training?		

# $Appendix \ B \ Material \ for \ Interface \ User \ Study$

MyMemory Proto	otype Evaluation	Carole Ch	ang	March 2014
TASK 3				
Flash Card Tra	ining Records sho	ows all memories	you had trained b	pefore.
Please go to <b>Fl</b> about it.	lash Card Training	<b>, Records</b> to find <u>/</u>	Mike proposed to	<i>Nacy</i> and do more traing
- How di	ifficult do you thir	nk of finishing Tasl	c 3?	
0	<u> </u>	<del></del> O	<u> </u>	O
Very Easy	Easy	Normal	Difficult	Very Difficult
- How do	o you think about Useful	Flash Card Traini  Normal	ng Records?  Slightly Useful	Not at all
Any suggestion	ns about <b>Flash Ca</b>	rd Training Record	ds?	
				<del></del>

MyMemory Prototype Evaluation

Carole Chang

March 2014

#### TASK 4

Please go to **Training** -> **Display Training** -> **Select Display Type** -> **Post-its** to set two memories: <u>Before I go to sleep</u> and <u>Mike proposed to Nacy</u>.

For **Post-its** displaying, the memory information change into a question and you will get the answer when you click it (it looks like the information on th right side).

- How	do you think of <b>Po</b>	ost-its?		
Very Useful	Useful	Normal	Slightly Useful	Not at all
Any suggestion	ons about <b>Post-it</b> s	s?		

# $Appendix \ B \ Material \ for \ Interface \ User \ Study$

MyMemory Pro	totype Evaluation	Carole C	hang	March 20	14
TASK 5					
_	Training -> Display	_		Screensaver to set two	
	the three different click each one to c		aver: Banner, Scro	lling text and Scrolling tex	αt
- How	do you think of <b>Scr</b>	eensaver?		O	
Very Useful	Useful	Normal	Slightly Useful	Not at all	
Any suggestion	ons about <b>Screens</b>	aver?			

MyMemory Prototype Evaluation Carole Chang March 2014 TASK 6 Please go to Training -> Display Training -> Select Display Type -> Voice Recording Training. - How difficult you distinguish which memory with voice note and which one is not? Difficult Very Difficult Very Easy Easy Normal - How do you think of Voice Recording Training? Useful Normal Slightly Not at all Very Useful Useful - When and where you will replay this voice recording? If you use the voice recoding function, then - How many times you will need to listen for remembering? 1-3 times More than 5times As many as need Any suggestions about Recording?

#### Appendix B Material for Interface User Study

MyMemory Prototype Evaluation

Carole Chang

March 2014

#### TASK 7

#### Easter Holiday plan:

You celebrated your Dad's 60<sup>th</sup> birthday on this March in his home. At that time, you and your Mum planned 3 days trip on Lake Tekapo for this Easter holiday. You use this application recording it. Now you get the email from your mum, she mentioned the plan you discussed on dad's birthday and she wants to confirm the date for the flight and accommandation. Now you want to find the details about this memory.

Please go to **Main Page** -> **My Memories** to find a memory related to <u>Easter Holiday plan</u>. There are tools: **By Time** and **By Event** to sort memories by the different oider. Please using them find the memory of <u>Easter Holiday plan</u>.

- How do	you think of "B	y Time" and "By E	vent" when you lo	ooking for the memory
Very Useful	Useful	Normal	Slightly Useful	Not at all
- Which	one do you thin	k you need it mostl	y?	
By Time				
By Event				
- How di	fficult do you fir	d the memory of <u>E</u>	aster holiday plar	<u>1</u> ?
0	O	O	<del></del> O	
Very Easy	Easy	Normal	Difficult	Very Difficult
Very Easy	Easy	Normal	Difficult	Very Difficult
- Can you	a explain the inf	ormation in the scr	een?	
any suggestion	s about <b>My Me</b>	mories?		
		8		

March 2014

		e email which inclu e email address on		ories once a week.
Please go to <b>Ma</b>	nin Page -> Sett	<b>ing</b> to change the e	mail address.	
- How diff	ficult do you fin	d it?	Difficult	Very Difficult
Automatica Manually u	ally sent the emulation ally sent the emulation allowers.	s, which way you lik nail. ories to your deskto		
Any suggestions	s about <b>Setting</b> ?	?		

Carole Chang

MyMemory Prototype Evaluation

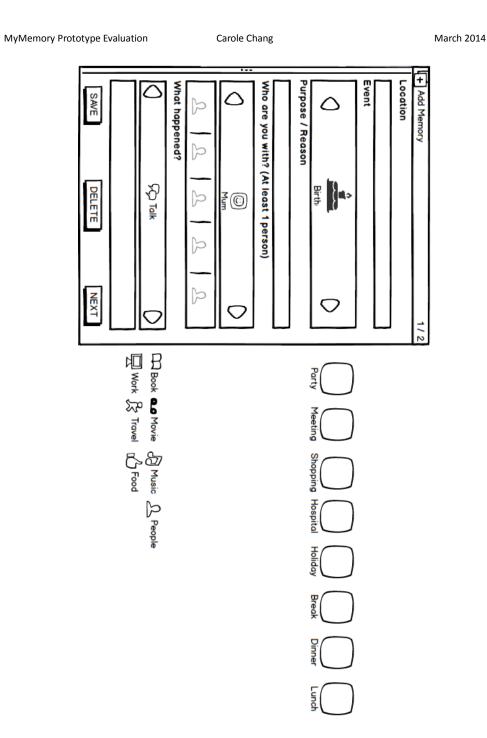
# $Appendix \ B \ Material \ for \ Interface \ User \ Study$

MyMemory Prote	otype Evaluation	Carole Chang	5	March 2014
FEEDBACKS				
1. How conve	enient is MyMemory	to use?		
0-				
Very Convenier	Convenient	Normal	Slightly Convenient	Not at all
2. How usefu	ıl is MyMemory to he	·lp ?		
0-	O			
Very Useful	Useful	Normal	Slightly Useful	Not at all
Flash C Flash C Post-its Screens Screens Voice R My Me	Memory ard Training ard Training Record Training Saver Training – Banr Saver Training – Scrol Secording Training Mories – By Time Mories – By Event	lling text on the	top	

MyMemory Prototype Evaluation	Carole Chang	March 2014
4. Which functions do you think are les	ss useful / dislike, why?	
Adding Memory Flash Card Training Flash Card Training Record Post-its Training Screensaver Training – Banner Screensaver Training – Scrolling to Screensaver Training – Scrolling to Voice Recording Training My Memories – By Time My Memories – By Event Setting	-	
Reason:		
		<u> </u>
5. Any suggestions about this prototype	e?	_
		<u> </u>
		<u> </u>

# $Appendix \ B \ Material \ for \ Interface \ User \ Study$

MyMemory Prototype Evaluation	Carole Chang	March 2014
6. Following up study Would you be willing for us to retain up studies ? If yes, Please leave you	n your contact details for related following r contact information, thanks.	
Name:		
Phone Numeber:		
Address:		
Email:		
Thank you for youre co-operation in completing this study.		



# Appendix C

# Material for Evaluating User Study of MyMemory

This appendix contains material given to the participants in the study that the interview user study, described in Chapter 8:

- C1 the approval letter from Psychology Research and Ethics Committee, School of Psychology, University of Waikato in 2015;
- *C2* the Poster for the public to recruit the participants;
- *C3* the Participant Information Sheet, which outlines the study goals and procedure as well as the participant's rights;
- C4 5 the Participant Consent Form TBI and Caregiver participant, which each participant signed at the beginning of their session;
- *C6* 7 the Demographic Questionnaire TBI and Caregiver participant, which questionnaire investigates the participant's general information;
- C8 the Strategies of PDA/Smartphone Use Form, which form investigates the participant's experience with the PDA/Smartphone;
- C9 the Assigned Task Sheet, which lists 15 tasks for the study;

## Appendix C Material for Evaluating User Study of MyMemory

- C10 the WHO Well-Being Index (WHO-5), which form investigates the participant's well-being;
- C11 the Caregiver Burden Inventory (CBI), which form investigates the caregiver-participant's burden of their TBI relatives;
- C12 the Memory Functioning Scale TBI and Caregiver participant, which form investigates the participant's memory function ability;
- *C13* the Autobiographical Memory Questionnaire, which contains the questionnaire to investigate the participant's autobiographical memory;
- C14 the MyMemory Evaluation Form, which form investigates the participant's experience on MyMemory;
- C15 the Memory Log Booklet Example, which provides information for the Caregiver-participant then they record their observation of TBI-participates performing tasks.

## C.1 Approval Letter

School of Psychology The University of Waikato Private Bag 3105 Hamilton 3240, New Zealand

Phone 64-7-856 2889 Facsimile 64-7-858 5132 www.waikato.ac.nz/psychology



4 June 2015

Carole Chang G2.06 University of Waikato PO Box 3105 Hamilton

Dear Carole

Ethics Approval Application – # 15:39

Title: My Memory: New Memory Mobile Application for Brain Injury

Thank you for your ethics application submitted for approval which has been fully considered and approved by the Psychology Research and Ethics Committee.

Please note that approval is for three years.

If any modifications are required to your application, e.g., nature, content, location, procedures or personnel these will need to be submitted to the Convenor of the Committee.

I wish you success with your research.

Yours sincerely

Dr James McEwan

Convenor

Psychology Research and Ethics Committee

School of Psychology

University of Waikato

## C.2 Poster





## MyMemory:

## New Memory MobileApplication for Brain Injury

MyMemory is a mobile application and is compatible with Android mobile devices only. It allows the people to record and train their memories.

#### We would like to talk to you, if you:

- over 16 years old, and
- had a brain injury and memory problems, and
- have someone who helps you in your day-to-day life, and
- own an Android mobile devices (the smartphone or tablet)

What is involved? You would be required to take part in an experiment that lasts 8 weeks. We will meet you every fortnight for a short interview. Every meeting will take about 60 minutes.

**Participation** is voluntary, all personal information will be kept confidential, and results will not be linked to individuals. This study has approval from the School of Psychology Ethics Committee, University of Waikato.

How do I find out more? Contact the researcher Carole Chang (PhD student), Computer Science Department, University of Waikato. email: sc200@students.waikato.ac.nz

This study is part of Carole Chang's PhD, supervised by Dr Annika Hinze, Dr Judy Bowen and Dr Steve Jones, Computer Science Department and Dr Nicola Starkey, School of Psychology, University of Waikato.

MyMemory Carole Chang sc200@students.waikato.ac.nz	Carole Chang sc200@students.waikato.ac.nz	MyMemory School Students Walkato.ac.nz	MyMemory Carole Chang	Carole Chang sc200@students.waikato.ac.nz	sc200@students.waikato.ac.nz  MyMemory	MyMemory Carole Chang sc200@students.waikato.ac.nz			
298									

## C.3 Participant Information Sheet



# MyMemory – New Memory Mobile Application for Brain Injury



#### **Information Sheet**

#### **Introductions**

I am Carole Chang, a PhD student at the University of Waikato. My research focuses on developing a computerized memory aid for people with traumatic brain injury (TBI). This study intends to examine the effectiveness of a new memory aid *MyMemory* in improving autobiographical memory function for TBI survivors. *MyMemory* is a mobile application and is compatible with Android mobile devices only. It allows the people to record and train their memories.

#### An invitation

You are being invited to take in this research study, if you:

- over 16 years old
- had a brain injury and memory problems
- have someone who helps you in your day-to-day life
- own an Android mobile devices (the smartphone or tablet)

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. To help you make you decision please read this information sheet. You may take as much time as you like to consider whether or not to take part.

#### What are the aims of this study?

The aim of this study will assess a new memory aid *MyMemory* in supporting the memory impairment of people with TBI in their daily life.

#### Who can take part in the study?

You can participate in this study if:

- a) You had a brain injury (head injury) with memory problems, and you are over 16 years of age.
- b) You own an Android mobile device.
- c) You have a caregiver or a close family member who supports or helps you, and they are also keen to participate in this study.





#### How many people will be in the study?

We estimate about 10 people (5 people with TBI and 5 of theirs caregivers/supporters) will be involved in this study.

#### What happens if I do decide to take part?

You would be required to take part in an experiment that lasts 8 weeks. We will meet you every fortnight for a short interview. Every meeting will take about 60 minutes.

#### How will the study affect me?

Taking part in this study will take some of your time and require you to complete some tasks. There are no known risks caused by this study.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, you will be given an opportunity to examine a novel mobile memory application *MyMemory* and discuss your memory problems. The results obtained from your participation may help others and improve *MyMemory* development in the future.

#### Confidentiality

The study files and all other information that you provide will remain strictly confidential, unless there is an immediate risk of serious harm to yourselves or others. No material that could personally identify you will be used in any reports on this study. Upon completion of the study your records will be stored for at least 5 years in a secure place at the University of Waikato. All electronic records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

#### Your rights

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact the convenor of the Research and Ethics Committee (via Dr James McEwan, phone 07 838 4466 ext. 8295, email:jmcewan@waiakto.ac.nz).

#### **Finally**

This study has received Ethical Approval from the Ethics Committee, Psychology School, and University of Waikato.





If you would like some more information about the study please feel free to contact the principle investigator:

Carole Chang, PhD student, Department of Computer Science, University of Waikato, Hamilton, on 07 838 4021 ext. 6011 email: <a href="mailto:sc200@students.waikato.ac.nz">sc200@students.waikato.ac.nz</a>

#### Supervisors:

Dr. Annika Hinze, Senior Lecture, Department of Computer Science, University of Waikato, Hamilton, on 07 838 4052 or email: <a href="mailto:hinze@cs.waikato.ac.nz">hinze@cs.waikato.ac.nz</a>

Dr. Nicola Starkey, Associate Professor, School of Psychology, University of Waikato, Hamilton, on 07 8562889 ext. 6472 or email: <a href="mailto:nstarkey@waikato.ac.nz">nstarkey@waikato.ac.nz</a>

Dr. Judy Bowen, Senior Lecture, Department of Computer Science, University of Waikato,

Hamilton, on 07 838 4547 or email: jbowen@cs.waikato.ac.nz

Dr. Steve Jones, Associate Professor, Department of Computer Science, University of Waikato,

Hamilton, on 07 838 4490 or email: stevej@cs.waikato.ac.nz

Please keep this brochure for your information.

Thank you for reading about this study.

## C.4 Participant Consent Form – TBI



## Research Project: Augmented Memory System on Mobile Devices for Brain Injury

Please complete the following checklist. Tick (✓) the appropriate box for each point.				
I have read the Participant Information Sheet (or it has been read to me) and I understand it.				
2. I have been given sufficient time to consider whether or not to participate in this stu	dy			
3. I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet				
4. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without penalty				
5. I have the right to decline to participate in any part of the research activity				
6. I know who to contact if I have any questions about the study in general.				
7. I agree to my responses to be audio recorded and photographs of my memory aids/strategies being used.				
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	ı			
I wish to receive a copy of the findings				
I wish to view the summary report of my interview				

#### **Declaration by participant:**

Participant's name (Please print):

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Psychology Research and Ethics Committee (Dr James McEwan, Tel: 07 838 4466 ext 8295, email: <a href="mailto:imcewan@waikato.ac.nz">imcewan@waikato.ac.nz</a>)

Signature:	Date:
	earch team:  of the research project to the participant, and have answered the believe that the participant understands the study and has given
Researcher's name (Please prin	s):
Signature:	Date:

## C.5 Participant Consent Form – Caregiver



## Research Project: Augmented Memory System on Mobile Devices for Brain Injury Survivors

Ple	ase complete the following checklist. Tick (✓) the appropriate box for each int.	YES	NO
1.	I have read the Participant Information Sheet (or it has been read to me) and I understand it.		
2.	I have been given sufficient time to consider whether or not to participate in this study		
3.	I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet		
4.	I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without penalty		
5.	I have the right to decline to participate in any part of the research activity		
6.	I know who to contact if I have any questions about the study in general.		
7.	I agree to my responses to be audio recorded and photographs of my memory aids/strategies being used.		
	nderstand that my participation in this study is confidential and that no material, which ald identify me personally, will be used in any reports on this study.		
Ιw	ish to receive a copy of the findings		
Ιw	ish to view the summary report of my interview		

#### Declaration by participant:

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Psychology Research and Ethics Committee (Dr James McEwan, Tel: 07 838 4466 ext 8295, email: <a href="mailto:imcewan@waikato.ac.nz">imcewan@waikato.ac.nz</a>)

Participant's name (Please print):	
Signature:	Date:
	n team: he research project to the participant, and have answered the eve that the participant understands the study and has given
Researcher's name (Please print):	
Signature:	Date:

## C.6 Demographic Questionnaire – TBI

WAIKATO MyMemory - New Memory Mobile Application for Brain Injury **Demographic Questionnaire - TBI** ID: Date of Birth: DD / MM / YYYY Gender Female Male Ethnicity: Status Full-time Current vocation: Part-time: hours/ week Education: What is the highest degree or level of school you have completed? ■No Schooling completed  $\hfill \Box$  High school graduate, diploma or the equivalent ☐Trade/technical/vocational training Bachelor degree Master degree Other: Specify **Marital Status:** Single Married Divorced Separated Windowed How many children do you have? How old are they? 1. Please indicate the time (year or the age) and cause of TBI you had Time: MM / YYYY Cause: Did you look medical treatment? ☐Yes ☐No Time: MM / YYYY Cause: Did you look medical treatment? ☐Yes ☐No 2. Do you have a chronic or serious health condition after post-TBI? Headaches Fatigue and Sleep Problems

☐ Impairments of Attention





☐ High blood pressures
Balance Problems and Dizziness
Chronic Pain:
Uisual problems:
Hearing problems:
Other: Specify
3. How do you try to remember?
Supporter reminder Relationship:
Paper diary and carry around
Monthly plan wall paper / Calendar
Post-it note
Writing on the hand
☐ Mobile devices (smartphone or tablet) with calendar / alarm
Google calendar or similar software on Desktop / Laptop
Social networking site: (please select the way you use)
☐Facebook ☐Twitter ☐Instagram ☐Google+ ☐LinkedIn ☐TumbIr
Other: Specify
4. Could you indicate the last time your social activity, when, what and with who?
When: MM / YYYY What: Who:

## C.7 Demographic Questionnaire – Caregiver

WAIKATO MyMemory - New Memory Mobile Application for Brain Injury **Demographic Questionnaire - Caregiver** ID: Date of Birth: DD / MM / YYYY Gender Female Male Ethnicity: Status Full-time Current vocation: Part-time: hours/ week Education: What is the highest degree or level of school you have completed? ■No Schooling completed High school graduate, diploma or the equivalent ☐Trade/technical/vocational training Bachelor degree Master degree Other: Specify **Marital Status:** Single Married Divorced Separated Windowed How many children do you have? How old are they? 1. How long have you been a caregiver? Relationship: years 2. What area do you provide help with? All of them ☐Things about Health/Medical Social life Work business Household chores Other: Specify 3. What types of strategies do you use to help them remember things? Advance remind through (please select the way you used) ☐ Face to face ☐ Text message ☐ Phone calling ☐ Voice mail ☐ Email

## $C.7\ Demographic\ Questionnaire-Caregiver$

MyMemory – New Memory Mobile Application for Brain Injury	THE UNIVERSITY OF WAIKATO 75 Where Winterge o Windpare
Writing on Post-it to them	
Post the memo on the frig door	
Other: Specify	

# C.8 Strategies of PDA/Smartphone Use Form

MX	<i>MyMemory</i> – New Memory Mobile Applica
MX = Y	for Brain Injury
	for Brain injury

MyMemory – New Memory Mobile Application for Brain Injury									
	Strategies of PDA/Smartphone Use								
ID:			Date:						
•	■ Have you ever used a PDA or smartphone before? Yes No								
•	Which ope	erating system y	ou have used? And	lroid 🗌	iOS	Windo	w_		
If th	e above re	sponse is YES p	lease complete the f	ollowing	g quest	ions re	gardin	g you	
smartphone use.									
•	When did you first begin using the smartphone? MM / YYYY								
•	How many	months/years	of experience in tota	l do you	have u	sing a			
	PDA/smar	tphone? (please	e answer even if you	have no	t used i	t recer	ntly)		
	m	onths and	years						
•	How often	did you use it l	before?						
Al۱	Always Often Sometimes Seldom Never								
•	How would	d you rate How	would you rate your	confide	nce in ι	ısing tl	ne		
	PDA/smar	tphone?							
	Very Confidence Somewhat Not that Not confidence								
COI	nfidence		confidence	confid	ence				
Plea	se answer	the following q	uestions regarding y	our PDA	/smart	phone	use.		
Seve	eral strateg	ies are listed be	elow. Please decide h	ow ofte	n you	used e	ach on	e in	
the	last two we	eeks.							
				Scale					
				4 = Al	ways				
				3 = O	ten				
				2 = Sc	metim	es			
				1 = Se	ldom				
				0 =Ne	ver				
Sma	rtphone us	e for remembe	ering information	4	3	2	1	0	
forn	n the past:								
•	Remembe	ring names of p	eople						
•	Recognizin	ng people (their	face)						
•	Remembering who someone is (recording and								





	accessing information about a person)					
•	Remembering that a particular event					
	happened in the past week					
•	Figuring out when/where something					
	happened in the past (more than a week ago)					
•	Remembering important information that you					
	were told (e.g., at a Doctor's appoint,					
	meeting)					
		Scale				
		4 = Al	ways			
		3 = Of	ten			
		2 = Sc	metim	ies		
		1 = Se	ldom			
		0 =Ne	ver			
Sma	ortphone use for remembering to do things in	4	3	2	1	0
the	future:					
•	Remembering to so a planned activity					
	(appointments, social events)					
•	Using the smartphone for directions to get					
	from point A to point B					
•	Adapting to a new routine (changing in					
	schedule or appointment time)					
•	Remembering to take important things with					
	you that are needed for an appointment or					
	you that are needed for an appointment or meeting					
•						
•	meeting					
•	meeting Remembering to pass on a message or relay					
•	meeting Remembering to pass on a message or relay important information (e.g., to a family					





going next								
The questions below should be answered only by the family member (if available)								
or by the client if s/he lives alone.								
	Scale							
	4 = A	lways						
3 = Often								
	2 = Sc	ometim	ies					
	1 = Se	eldom						
	0 =Ne	ever						
How often does your family member [do you]	4	3	2	1	0			
Spontaneously use his/her smartphone when								
planning a future activity together (without								
needing reminding to use the smartphone)?								
Schedule events in his/her smartphone								
without technical assistance (e.g., entering								
the event, setting the alarm, attaching a note								
if relevant)?								
Respond to the alarm sound by checking								
his/her smartphone (without assistance)?								
Carry out the scheduled task after responding								
to the alarm sound of the smartphone								
(without requiring further reminding)?								
Successfully complete task you or someone								
else has asked him/her to do when you/other								
person are out or not in the same room (e.g.,								
household maintenance, meeting								
you/someone some place, making a phone								
call)?								
Please describe any problems with everyday functi	_	-		-				
[you] continues to have with smartphone use that	you wi	sh coul	d be a	dresse	d by			
the memory intervention program.								

## ${\it C.8 \ Strategies \ of PDA/Smartphone \ Use \ Form}$

m <b>.M</b> S=v	<i>MyMemory</i> – New Memory Mobile Application for Brain Injury	THE UNIVERSITY OF WAIKATO

# C.9 Assigned Task Sheet

,	MyMemory – New Memory Mobile Appli for Brain Injury	cation	THE UNIVERSITY OF WAIKATO	
	Assigned Task Sheet			-
	ID:	toruala		
	Please choose TWO tasks complete them during two week in Task	ETC	AFT	A/B
	Adding <u>coffee</u> to your grocery list gets it on next grocery	Lic	AFI	А/В
	shopping.			
	Planning to visit <u>Hamilton Garden</u>			
	Visiting American Modernist Garden in Hamilton Garden			
	Taking a stroll.			
	Having a coffee with someone			
	Having a lunch with someone			
	Having a dinner with someone			
	Making a phone call to <u>someone</u>			
	Planning to visit _Hamilton Lake			
	Visiting Hamilton Lake			
	Planning to visit The Base			
	Shopping in The Base			
	Watching a TV news.			
	videning a 14 news.			
	Planning to watch a movie.			
		1		
	Watching a movie.			

# C.10 WHO Well-Being Index (WHO-5)

Frequency 5 = All of the time 4 = Most of the time 3 = More than half of the time 2 = Less than half of the time 1 = Some of the time 0 = At no time 5 4 3 2 1 I have felt cheerful and in good spirits I have felt calm and relaxed I have felt active and vigorous	WHO Well-Be	ng Index (WHO-5)	
5 = All of the time 4 = Most of the time 3 = More than half of the time 2 = Less than half of the time 1 = Some of the time Over the last two weeks 0 = At no time	ID:		
4 = Most of the time 3 = More than half of the time 2 = Less than half of the time 1 = Some of the time 0 = At no time 5		Frequency	
3 = More than half of the time 2 = Less than half of the time 1 = Some of the time 0 = At no time 5 4 3 2 1 I have felt cheerful and in good spirits I have felt calm and relaxed I have felt active and vigorous		5 = All of the time	
2 = Less than half of the time 1 = Some of the time 0 = At no time  5 4 3 2 1  I have felt cheerful and in good spirits I have felt calm and relaxed I have felt active and vigorous		4 = Most of the time	
Over the last two weeks  0 = At no time  5 4 3 2 1  I have felt cheerful and in good spirits  I have felt calm and relaxed  I have felt active and vigorous		3 = More than half of the ti	ne
Over the last two weeks  0 = At no time  5 4 3 2 1  I have felt cheerful and in good spirits  I have felt calm and relaxed  I have felt active and vigorous		2 = Less than half of the tim	e
I have felt active and vigorous  5 4 3 2 1  1 have felt cheerful and in good spirits		1 = Some of the time	
I have felt cheerful and in good spirits  I have felt calm and relaxed  I have felt active and vigorous	Over the last two weeks	0 = At no time	
I have felt calm and relaxed		5 4 3 2 1	
I have felt active and vigorous	I have felt cheerful and in good spirits		
	I have felt calm and relaxed		
I wake up feeling fresh and rested	I have felt active and vigorous		
	I wake up feeling fresh and rested		
	interested me		

## C.11 Caregiver Burden Inventory (CBI)

MX-x

# MyMemory – New Memory Mobile Application for Brain Injury

Q	WAIKATO
<b>3</b>	Te Whate Wananga o Waifuto

Caregiver Burden Inventory (CBI) ID: Phase: Frequency 4 = nearly always 3 = quite frequently 2 = sometimes 1= rarely 0 = neverFactor 1: Time-Dependence Burden 3 2 1 0 My care receiver needs my help to perform many daily tasks. My care receiver is dependent on me I have to watch my care receiver constantly. I have to help my care receiver with many basic functions. I don't have a minute's break my caregiving chores. Factor 2: Developmental Burden 4 3 2 0 I feel that I missing out on life. I wish I could escape from this situation. My social life has suffered. I feel emotionally drained due to caring for my care I expected that things would be different at this point in my life. 4 3 2 1 0 Factor 3: Physical Burden I am not getting enough sleep. My health has suffered. Caregiving has made me physically sick. I'm physically tired. Factor 4: Social Burden 4 0 I don't get along with other family member as well My caregiving efforts aren't appreciated by others in

		ę
М	J	
мЫ	VIY.	RY

	THE UNIVERSITY OF
V	WAIKATO Te Where Hitmangu o Histipato
Home	Te Whate Waterange o Washato

my family.					
I've had problems with my marriage.					
I don't do as good as job at work as I used to.					
I feel resentful of other relatives who could but do					
not help.					
Factor 5: Emotional Burden	4	3	2	1	0
I feel embarrassed over my care receiver's behavior.					
I feel embarrassed over my care receiver's behavior.  I feel ashamed of my care receiver.					
,					
I feel ashamed of my care receiver.					
I feel ashamed of my care receiver. I resent my care receiver.					

# C.12 Memory Functioning Scale – TBI

	V
М	MY IMORY

Depresent		
	THE UNIVERSITY	OF
	WAIKAT	O
3.00	Te Whate Hitnames o His	desco

	Memory Functioning Scale - TBI					
ID	Date: Pr	nase:				
Ιa	I am going to give you some examples of everyday situations where you might need				eed	
	use your memory. I want you to think about your own me		•			
	I me how you think you would manage in that situation. I		•		oose	the
an	swer which best describes how you would do. These are	the si	tuati	ons.		
Sit	uation	Free	quen	cv		
			alwa	-		
		3 =	often	1		
		2 =	some	time	s	
		1 =	rarely	/		
		0 =	neve	r		
		4	3	2	1	0
1.	You meet someone and are told their name. Later on					
	you meet then again, and you need to remember their					
	name.					
2.	You have made an appointment and need to					
	remember to go along.					
3.	You have promised to do something later in the day					
	and need to remember to do it at the right time.					
4.	You have go a set of items to sort out, some of which					
	you have seen before and some of which are new to					
	you. You need to pick out the ones you have seen					
	before.					
5.	You hear a news item on the radio.					
	a. One of your family comes in at the end and ask					
	you what was said.					
	b. Later on – say half an hour later – someone else					
	asks you what you heard.					
6.	You meet up with a group of people. Some of then					
	you've met before, others you haven't. You need to					
	recognize which ones you've met before.					



UNIVERSITY OF
AIKATO

7.	You	go to a new building and you are learning to find				
	the way around. Someone show you a short route					
	whic	h you will need to remember.				
	a.	You need to retrace the route immediately.				
	b.	You need to retrace the route again later on –				
		say half an hour.				
8.	You	have been given a message to deliver to someone.				
	You	need to remember to give that person the				
	mes	sage when you see them.				
	a.	You see them right away.				
	b.	You see them later on.				
9.	You	are being asked to give some information about				
	your	self, such as age, address, date of birth, and to				
	ansv	ver a few basic general knowledge questions.				
10	. Sor	neone asks you for today's date.				

## C.13 Memory Functioning Scale – Caregiver

MX.

	THE UNIVERSITY OF
Q	WAIKATO
100	Te Whate Witnesgu o Waifuto

	Memory Fu	ınctioning Scale - Caregiv	er					
ID:	Date:	Pł	hase:					
Ве	low are some examples of every	yday situations where a p	erson	migh	nt nee	ed to	use	
his	/her memory. I want you to thir	nk about your [partner's/	relativ	/e's] ι	nemo	ory, a	s it	
is ı	now, and tell me how you think	he/she would manage in	that s	ituat	ion.			
Sit	uation		Free	quen	су			
				alwa	•			
ì				often				
ì					etime	S		
ì				rarely neve	-			
			4	3	2	1	0	
1.	S/he meets someone and is to	ld their name. Later on						
	S/he meets then again, and S/I	he needs to remember						
	their name.							
2.	S/he has made an appointmen	nt and need to						
	remember to go along.							
3.	S/he has promised to do son	nething later in the day						
<u></u>	and need to remember to do it	t at the right time.						
4.	S/he has got a set of items to s	sort out, some of which	_	_	_	_	_	
	s/he has seen before and some	e of which are new to						
	s/he. S/he needs to pick out th	ne ones s/he has seen						
<u></u>	before.							
5.	S/he hears a news item on the	radio.						
	a. One of the family comes i	in at the end and asks						
	what was said.							
	b. Later on – say half an hou	ır later – someone else						
<u></u>	asks what was said.							
6.	S/he meets up with a group of	people. Some of them						
	s/he has met before, others are	e new. S/he needs to						
<u></u>	recognize which ones s/he has	met before.						
7.	S/he goes to a new building an	nd is learning to find the						



O.	WAIKATO To Where Wennego o Weifuto
a colline a	

	way	around. Someone shows him/her a short route			
	whic	ch s/he needs to remember.			
	a.	S/he needs to retrace the route immediately.			
	b.	S/he needs to retrace the route again later on –			
		say half an hour.			
8.	S/he	has been given a message to deliver to someone.			
	S/he	needs to remember to give that person the			
	mes	sage when s/he sees them.			
	a.	S/he sees them right away.			
	b.	S/he sees them later on.			
9.	S/he	is being asked to give some information about			
	him,	herself, such as age, address, date of birth, and to			
	ansv	ver a few basic general knowledge questions.			
10	. Sor	meone asks him/her for today's date.			

## C.14 Autobiographical Memory Questionnaire



-	THE UNIVERSITY OF
Q	WAIKATO
	Te Whate Hitnange o Hisibato

	А	utobiographic	al Memor	y Questionnair	·e	
ID:		Date:		Pha	se:	
Please think	about the	memory of		w	hile answ	vering these
questions. R	ead each i	tem carefully a	and circle t	he number tha	at most cl	osely reflects
your option.						
1. As I rem	ember the	event, I feel a	s though I	am <u>reliving</u> the	e original	event.
1	2	3	4	5	6	7
not at all		vaguely		distinctly		as clearly as if it were happening right now
2. As I rem	ember the	event, I can <u>h</u>	ear it in m	y mind.		
1	2	3	4	5	6	7
not at all	-	vaguely	7	distinctly	Ü	as clearly as if it were happening right now
3. As I rem	ember the	event, I can se	ee it in my	mind.		
1	2	3	4	5	6	7
not at all	_	vaguely		distinctly		as clearly as if it were happening right now
4. As I rem	ember the	event, I know	its <b>spatial</b>	layout.		
1	2	3	4	5	6	7
not at all	۷	vaguely	7	distinctly	U	as clearly as if it were happening right now
5. As I rem	ember the	event, I can fe	el now the	e <b>emotions</b> tha	t I felt th	en.
1	2	3	4	5	6	7
not at all		vaguely		distinctly		as clearly as if
						happening





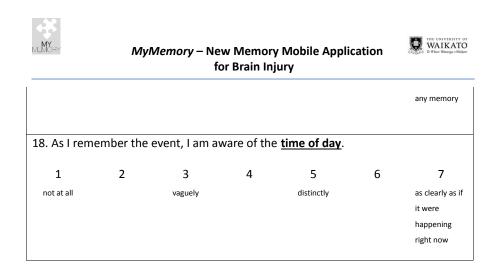
6. Since it h	annonod	I have <b>though</b>	t about th	is avant		right now
o. Since it i	iappeneu,	i nave <u>tilougii</u>	t about th	is event.		
1	2	3	4	5	6	7
not at all		vaguely		distinctly		as clearly as if
						it were
						happening
						right now
7. As I rem	ember tha	t event, I can r	ecall the <u>s</u>	etting where it	occurred	i.
1	2	3	4	5	6	7
not at all		vaguely		distinctly		as clearly as if
						it were
						happening
						right now
actually	remember		bout the	ned to them wi		_
1	2	3	4	5	6	7
not at all		vaguely		distinctly		as much as
not at all		vaguely		distinctly		as much as any memory
	ember the	vaguely event, it come	es to me in			
	ember the		es to me in 4		6	
9. As I remo		event, it come		words.	6	any memory
9. As I remo		event, it come		words.	6	any memory
9. As I remonstrated and a second a second and a second a	2 ember the	event, it come  3  vaguely  event, I feel the maparticipan	4 nat I travel	words.	ne when	7 as much as any memory
9. As I remo	2 ember the ed, that I a	event, it come  3  vaguely  event, I feel the maparticipan	4 nat I travel	words. 5 distinctly	ne when	7 as much as any memory
9. As I remo	2 ember the ed, that I al the presen	event, it come  3 vaguely  event, I feel the maparticipant.	4 nat I travel t in it agaiı	words.  5 distinctly  back to the time, rather than a	ne when	any memory  7 as much as any memory  it e observer
9. As I remo	2 ember the ed, that I al the presen	event, it come  3 vaguely  event, I feel the maparticipant.	4 nat I travel t in it agaiı	words.  5 distinctly  back to the tire, rather than a	ne when	any memory  7 as much as any memory  it e observer
9. As I remo	ember the ed, that I at the presen	event, it come  3 vaguely  event, I feel the a participant.  3 vaguely	4 nat I travel t in it agair 4	words.  5 distinctly  back to the tire, rather than a	ne when an outside 6	any memory  7 as much as any memory  it e observer  7 as much as any memory
9. As I remonder 1 not at all 10. As I remonder 1 not at all 11. Would you	ember the ed, that I at the presen	event, it come  3 vaguely  event, I feel the a participant.  3 vaguely	4 nat I travel t in it agair 4	words.  5 distinctly  back to the tire, rather than a distinctly	ne when an outside 6	any memory  7 as much as any memory  it e observer  7 as much as any memory





						any memory
12. As I reme	ember the	event, it come	s to me in	words or in	pictures <u>as a</u>	coherent
		nd not as an isc		-		
1	2	3	4	5	6	7
not at all		vaguely		distinctly		as much as
						any memory
13. This mor	ning is <b>sig</b>	nificant for my	life becau	ise it imparts	an importan	t message
		its an anchor, c		-	-	
1	2	3	4	5	6	7
not at all		vaguely		distinctly		as much as
						any memory
		in my memory agined or fabric				nber it and
1	2	3	4	5	6	7
100%						100% real
imaginary						
15. As I recal event?	I them no	w, I would you	rate the <u>e</u>	motions   ex	perienced du	ring the
-3	-2	-1	0	+1	+2	+3
As negative as		Mildly		Neutral	Mildly Positive	As positive as
any event I		Negative				any event I
have						have
experienced						experienced
16. Since it h	appened,	I have <u>talked</u> a	ıbout this	event.		
1	2	3	4	5	6	7
not at all		sometimes		many times		as often as any
						event in my life
		consequences f gs in noticeable		because it in	fluenced my	behavior,
1	2	3	4	5	6	7
not at all		moderate		quite a bit		as much as

## C.14 Autobiographical Memory Questionnaire



## C.15 MyMemory Evaluation Form

WAIKATO MyMemory - New Memory Mobile Application for Brain Injury **MyMemory Evaluation Form** Date: Phase: Mobile brand: **Android version:** How would you rate following functions on MyMemory? 4 = Very helpful 3 = Somewhat helpful 2 = Neither 1 = Not so helpful 0 = Not at all helpful Add Memory: 4 1 0 Starting with Camera Starting with New Memory Suggestions: 4 3 2 0 1 Memory: Memory details Do you think anything should be included? Taking photo Browsing gallery Sending text message Sending email Changing color label **Memory Training Tool:** 0 • FlashCard: Question details Suggestions?

1



Q.	WAIKATO
7. 40000 7	Te Whare Hitnenga o Hisijato

		<u>,                                      </u>				
Widget:		4	3	2	1	0
Cues display						
• Suggestions:						
Assistant Function:		4	3	2	1	0
Sort by Person		<b>4</b>	<b>→</b>		_	
• Sort by Location						
Default setting						
About MyMemory						
• Suggestions:		_				
Overall Evaluation						
	Scale					
	4 = Strongly Agree					
	3 = Agree	r Dicagroo				
	2 = Neither Agree nor 1 = Disagree	Disagree				
	0 = Strongly Disagree					
	0 01.01.8.7 2.008.00	4	3	2	1	0
1 MyMemory improves	my memory ability.					
	more detail how to improv	ve your m	emory a	ability?		
	·	-	•	•		

ME	MyMemory — New Memory M for Brain Injury	-	plicatio	on	THE UNIVER WAIK.	
2	<i>MyMemory</i> changes my memory behavior.  Could you explain in more detail your memory be	<b>4</b> Dehavior	<b>3</b> Changi	<b>2</b> □ ng?	1	0
3	<i>MyMemory</i> helps me to organize my life. Could you explain in more detail how to organiz	<b>4</b> — re your s	<b>3</b> Chedule	<b>2</b> — er?	1	0
4	MyMemory helps me with training my memory	4	3	2	1	0
	ability.  Is there anything else you would like us to know	/ about i	t?			
5	MyMemory could replace my memory strategies or aids one day.	4	3	2	1	0
5				2	1	

меМСяч	<i>MyMemory</i> – New Memory N for Brain Injur		plicatio	n .	THE UNIVER WAIK.	
		4	3	2	1	0
6 Iw	ould recommond other people using					
Му	Memory for their memory impairment.					
	here anything else you would like us to kno					
6 Any	y suggestions about MyMemory?					
-						

## C.16 Memory Log Booklet Example

MX.

5.

**Observations:** 

# MyMemory – New Memory Mobile Application for Brain Injury



Memory Log Booklet Example

# Memory Log Please record your family member's ability to independently remember to complete tasks (about 4 events per week). Please include these 6 elements on the record. 1. Event Title: 2. Completed Date: 3. Location: 4. People Involved:

Response to task completion (0-1)
0 = did not independently complete the

## **Publications and Contributions**

Selected results of this thesis have resulted in the following publications so far.

- 1. Hinze, A., Chang, C., Starkey, N. (2011). A psychology-based approach to augmented memory system for people with brain injury. In 3rd International Workshop on Smart Healthcare Application (part of OzCHI'11), pp.29–31.
- 2. Chang, C., Hinze, A., Bowen, J., Starkey, N. (2014). Designing a mobile memory system for people with traumatic brain injuries. *In on 5th IEEE Conference, Cognitive Infocommunications (CogInfoCom)* pp.13–18.

My contributions to publications is 75%, which includes the data collection, data analysis and writing of the first draft.

- Alallah, J. (2010). Capturing Situational Context in an Augmented Memory System. Master's thesis, University of Waikato, Hamilton, New Zealand.
- Asbcraft, M. H. (1998). Fundamentals of cognition. New York, USA: Addison Wesley Educational Publishers Inc.
- Baddeley, A., Eysenck, M. W., Anderson, M. C. (2009). *Memory*. UK: Psychology Press.
- Barker-Collo, S., Wilde, N., Feigin, V. (2008). Trends in head injury incidence in new zealand: A hospital-based study from 1997/1998 to 2003/2004. *Neuroepidemiology*, 32(1), 32–39.
- Berntsen, D., Rubin, D. C., Ebrary, I. (2012). *Understanding autobiographical memory: theories and approaches*. Cambridge; New York: Cambridge University Press.
- Blandford, A. (2014). Semi-structured qualitative studies. In Soegaard, M., Dam, R. F. (Eds.), *The Encyclopedia of Human-Computer Interaction*. Aarhus, Denmark: The Interaction Design Foundation, 2nd edn.
- Borod, J. C., Cicero, B. A., Obler, L. K., Welkowitz, J., Erhan, H. M., Santschi, C., Grunwald, I. S., Agosti, R. M., Whalen, J. R. (1998). Right hemisphere emotional perception: Evidence across multiple channels. *Neuropsychology*, 12(3), 446–458.
- BrainLine (2015). Life-changing mobile apps for people with brain injury. http://www.brainline.org/content/2013/12/life-changing-iphone-and-ipad-apps-for-people-with-brain.html. [Date accessed: 2015].

- Brewer, W. F. (1988). What is autobiographical memory? In Rubin, D. C. (Ed.), *Autobiographical Memory*, pp. 25–49. Cambridge: Press Syndicate of the University of Cambridge.
- Bright Focus Foundation (2011). Alzheimer's disease research. http://www.brightfocus.org/alzheimers/. Last accessed January 2012. [Date accessed: 2011].
- Browndyke, J. N. (2002). Neuropsychosocial factors in emotion recognition: Facial expressions. http://www.neuropsychologycentral.com/interface/content/resources/page\_material/resources\_general\_materials\_pages/resources\_document\_pages/neuropsychosocial\_factors\_in\_emotion\_recognition.pdf. [Date accessed: 2016].
- Browne, G., Berry, E., Kapur, N., Hodges, S., Smyth, G., Watson, P., Wood, K. (2011). Sensecam improves memory for recent events and quality of life in a patient with memory retrieval difficulties. *Memory*, 19(7), 713–722.
- Camp, C. J., Schaller, J. R. (1989). Epilogue: spaced retrieval memory training in an adult day-care centere. *Educational Gerontology*, 15(6), 641–648.
- Carlsson, E., Paterson, B. L., Scott-Findlay, S., Ehnfors, M., Ehrenberg, A. (2007). Methodological issues in interviews involving people with communication impairments after acquired brain damage. *Qualitative Health Research*, 17(10), 1361–1371.
- Cavallo, M. M., Key, T. (2005). The family system. In Jonathan M, S., McAllister, T. W., Yudofsky, S. C. (Eds.), *Textbook of traumatic brain injury*, pp. 533–558. Washington, DC: American Psychiatric Association Publishing.
- Chang, C., Hinze, A., Bowen, J., Starkey, N. (2014). Designing a mobile augmented memory system for people with traumatic brain injuries. In *Cognitive Infocommunications (CogInfoCom), 2014 5th IEEE Conference*, pp. 13–18.

- Cherry, K. E., Simmons-D'Gerolamo, S. S. (2005). Long term effectiveness of spaced retrieval memory training for older adults with probable alzheimer's disease. *Experimental Aging Research*, *31*(3), 261–289.
- Chittaro, L., De Marco, L. (2005). Evaluating the effectiveness of "effective view navigation" for very long ordered lists on mobile devices. In Costabile, M., Paternò, F. (Eds.), *Human-Computer Interaction IN-TERACT 2005*, vol. 3585 of *Lecture Notes in Computer Science*, pp. 482–495. Springer Berlin Heidelberg.
- Cohen, D., Crabtree, B. (2008). Qualitaive research guideliness project. http://www.qualres.org/HomeSemi-3629.html. [Date accessed: 2011].
- Conway, M. A. (2001). Sensory-perceptual episodic memory and its context: Autobiographical memory. *Philosophical Transactions of the Royal Society of London, Series B*(356(1413)), 1375–1384.
- Conway, M. A. (2005). Memory and the self. *Journal of Memory and Language*, 53(4), 594–628.
- Conway, M. A., Pleydell-Pearce, C. W. (2000). The construction of autobiographical memories in the self-memory system. *Psychological Review*, 107(2), 261–288.
- Cook, L. J. (2013). Understanding play as a powerful tool to enable learning: A review of einstein never used flashcards. *Delta Kappa Gamma Bulletin*, 80(1), 34.
- Cooper, A. (2014). About face: the essentials of interaction design. Indianapolis, Indiana: Wiley, John Wiley & Sons Inc, Wiley-Blackwell, John Wiley & Sons, Inc.
- Cunningham, S. J., Bainbridge, D., Masoodian, M. (2004). How people describe their image information needs: A grounded theory analysis of visual arts queries. In *Proceedings of the 4th ACM/IEEE-CS Joint Conference on Digital Libraries*, JCDL '04, pp. 47–48. ISBN 1-58113-832-6.

- Dalemans, R., Wade, D. T., van den Heuvel, W. J., de Witte, L. P. (2009). Facilitating the participation of people with aphasia in research: a description of strategies. *Clinical Rehabilitation*, 23(10), 948–959.
- DePompei, R., Gillette, Y., Goetz, E., Xenopoulos-Oddsson, A., Bryen, D., Dowds, M. M. (2008). Practical applications for use of pdas and smartphones with children and adolescents who have traumatic brain injury. *NeuroRehabilitation*, 23(6), 487.
- DePomper, R., Gillette, Y., Goetz, E., Xenopoulos-Oddsson, A., Bryen, D., Dowds, M. (2008). Practical applications for use of pdas and smartphones with childen and adolescents who have traumatic brain injury. *NeuroRehabilition*, 23(6), 487–499.
- Doherty, A. R., Moulin, C. J. A., Smeaton, A. F. (2011). Automatically assisting human memoriy: A sensecam browser. *Memory*, 19(7), 785–795.
- Doherty, A. R., Pauly-Takacs, K., Caprani, N., Gurrin, C., Moulin, C. J. A., O'Connor, N. E., Smeaton, A. F. (2012). Experiences of aiding autobiographical memory using the sensecam. *Human–Computer Interaction*, 27(1–2), 151–174.
- Dritschel, B., Kogan, L., Burton, A., Burton, E., Goddard, L. (1998). Everyday planning difficulties following traumatic brain injury: a role for autobiographical memory. *Brain injury BI*, 12(10), 875–886.
- Eysenck, M. W., Keane, M. T. (2010). *Cognitive Psychology: a student's handbook*. New York, USA: Psychology Press, 6th edn.
- Feigin, V., Barker-Collo, S., Krishnamurthi, R., Theadom, A., Starkey, N. (2010). Epidemiology of ischaemic stroke and traumatic brain injury. Best Practice and Research Clinical Anaesthesiology, 24(4), 485–494.
- Feigin, V. L., Theadom, A., Barker-Collo, S., Starkey, N. J., McPherson, K., Kahan, M., Dowell, A., Brown, P., Parag, V., Kydd, R., Jones, K., Jones, A., Ameratunga, S. (2012). Incidence of traumatic brain injury in new

- zealand: a population-based study. *The Lancet Neurology*, 12(1), 53–64.
- Ferguson, S., Friedland, D., Woodberry, E. (2015). Smartphone technology: Gentle reminders of everyday tasks for those with prospective memory difficulties post-brain injury. *Brain Injury*, 29(5), 1–9.
- Fitzgerald, J. M., Broadbridge, C. L. (2013). Latent constructs of the autobiographical memory questionnaire: a recollection-belief model of autobiographical experience. *Memory (Hove, England)*, 21(2), 230.
- Fitzgibbon, A., Reiter, E. (2003). Memories for life. Tech. rep., Grand Challenges for Computing Research Draft Proposals.
- Gentleman, D. (2001). Rehabilitation after traumatic brain injury. *Trauma*, 3, 193–204.
- Giraldo, C., Helal, S., Mann, W. (2002). mPCA–A mobile patient caregiving assistant for Alzheimer patients. In *First International Workshop on Ubiquitous Computing for Cognitive Aids (UbiCog'02)*.
- Glisky, E., Wilson, B., Kapur, N. (2004). Technological memory aids for people with memory deficits. *Neuropsychological rehabilitation*, 14(1), 41–60.
- Gordon, W. A., Hibbard, M. R. (2005). Cognitive rehabiltion. In Jonathan M, S., McAllister, T. W., Yudofsky, S. C. (Eds.), *Textbook of traumatic brain injury*, pp. 655–660. Washington, DC: American Psychiatric Association Publishing.
- Groome, D., Dewart, H., Esgate, A., Gurney, K., Kemp, R., Towell, N. (1999). *An introduction to cognitive psychology: processes and disorders*. East Sussex, UK: Psychology Press.
- Gwern.net (2015). Spaced repetition. http://www.gwern.net/Spaced% 20repetition. [Date accessed: 2015].
- Hardy, R. M., Oyebode, J. R., Clare, L. (2006). Measuring awareness in people with mild to moderate alzheimer's disease: Development of the

- memory awareness rating scale-adjusted. *Neuropsychological Rehabilitation*, 16(2), 178–193.
- Hart, T., Buchhofer, R., Vaccaro, M. (2004). Portable electronic devices as memory and organizational aids after traumatic brain injury: A consumer survey study. *The Journal of Head Trauma Rehabilitation*, 19(5), 351–365.
- Head Injury Society Waikato Inc (2013). THINK! The Head Injury Network for Kiwis. http://www.thinknz.org.nz/. [Date accessed: 2015].
- Heffner, C. L. (2015). Chapter 4.2 ABAB: A-B-A-B Design. http://allpsych.com/researchmethods/ababdesign/#.VW5CVEaTV5p. Last accessed July 2015. [Date accessed: 2015].
- Heimonen, T. (2009). Information needs and practices of active mobile internet users. In *Proceedings of the 6th International Conference on Mobile Technology, Application & Systems*, Mobility '09, pp. 50:1–50:8. ISBN 978-1-60558-536-9.
- Heun, R., Bonsignore, M., Barkow, K., Jessen, F. (2001). Validity of the five-item who well-being index (who-5) in an elderly population. *European Archives of Psychiatry and Clinical Neuroscience*, 251(2), 27–31.
- Hewitt, J., Evans, J. J., Dritschel, B. (2006). Theory driven rehabilitation of executive functioning: Improving planning skills in people with traumatic brain injury through the use of an autobiographical episodic memory cueing procedure. *Neuropsychologia*, 44(8), 1468–1474.
- Hinze, A., Chang, C., Starkey, N. (2011). A psychology-based approach to augmented memory system for people with brain injury. In *3rd International Workshop on Smart Healthcare Applications (part of OzCHI'11)*, pp. 29–31.
- Hinze, A. M., Chang, C., Nichols, D. (2010). Contextual queries express mobile information needs. In *Proceedings of the 12th International Conference on Human Computer Interaction with Mobile Devices and Services*, pp. 327–336. New York, USA: ACM.

- Hodges, S., Berry, E., Wood, K. (2011). Sensecam: A wearable camera that stimulates and rehavilitates autobiographical memory. *Memory*, 19(7), 685–696.
- Holtzblatt, K., Wendell, J. B., Wood, S. (2004). *Interactive Technologies:* Rapid Contextual Design: A How-to Guide to Key Techniques for User-Centered Design. Morgan Kaufmann.
- van den Hoven, E., Eggen, B. (2008). Informing augmented memory system design through autobiographical memory theory. *Personal and Ubiquitous Computing*, 12(6), 433–443.
- van den Hoven, E., Sas, C., Whittaker, S. (2012). Introduction to this special issue on designing for personal memories: Past, present, and future. *Human–Computer Interaction*, 27(1–2), 1–12.
- James, W. (1890). *Principles of Psychology*. New York: Henry Holt and Company.
- James Cook University, School of Business/IT (2016). Lecture notes: Human computer interaction: Lecture 2: Data gathering, analysis, interpretation and presentation. http://www.kopo.com/wp-content/uploads/2013/03/HCI-Week2\_LectureNotes.pdf. [Date accessed: 2016].
- Jonathan M. Silver, D. B. A., Yudofsky, S. C. (2005). Psychotherapy. In Jonathan M, S., McAllister, T. W., Yudofsky, S. C. (Eds.), *Textbook of traumatic brain injury*, pp. 609–640. Washington, DC: American Psychiatric Association Publishing.
- Kavakli, M. (2015). Gender differences in it adoption and gestural communication: science behind stereotypes & implications on human computer interaction. *International journal on advances in life sciences*, 7(3–4), 65–74.
- KCSOFT (2012). Expirydate, iphone app available online. http://www.kcsoft.com.au/ExpiryDate/index2\_eng.html. [Date accessed: 2016].

- Knight, R. G., O'Hagan, K. (2009). Autobiographical memory in long-term survivors of severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, 31(5), 575–583.
- Kraus, J. F., Chu, L. D. (2005). Epidemology. In Jonathan M, S., McAllister, T. W., Yudofsky, S. C. (Eds.), *Textbook of traumatic brain injury*, pp. 3–26. Washington, DC: American Psychiatric Association Publishing.
- Kuan, C.-Y. (2004). Impact of cognition function in post-head injury patients or post-cingulationy patients. Master's thesis, Kaohsiung Medical University, Kaohsiung, Taiwan.
- Lee, M., Dey, A. (2007). Providing good memory cues for people with episodic memory impairment. In *ACM SIGACCESS conference on Computers and accessibility*, pp. 131–138. ACM.
- Lee, M., Dey, A. (2008). Lifelogging memory appliance for people with episodic memory impairment. In *Conf. on Ubiquitous computing Ubi-Comp '08*, pp. 44–53. ACM.
- Levine, B., Svoboda, E., Hay, J. F., Winocur, G., Moscovitch, M. (2002). Ageing and autobiographical memory: Dissociating episodic from semantic retrieval. *Psychology and Aging*, 17(4), 677–689.
- Ley, R. G., Bryden, M. (1982). A dissociation of right and left hemispheric effects for recognizing emotional tone and verbal content. *Brain and Cognition*, 1(1), 3–9.
- Mcallister, T. W., Flashman, L. A., Sparling, M. B., Saykin, A. J. (2004). Working memory deficits after traumatic brain injury: catecholaminer-gic mechanisms and prospects for treatment a review. *Brain Injury*, 18(4), 331–350.
- McDowell, S., Whyte, J., D'Esposito, M. (1997). Working memory impairments in traumatic brain injury: evidence from a dual-task paradigm. *Neuropsychologia*, 35(10), 1341–1353.
- Mulder, S., Yaar, Z. (2007). The user is always right: a practical guide to creating and using personas for the Web. New Riders.

- Nielsen, J. (2012). Thinking aloud: The first usability tool. http://www.nngroup.com/articles/thinking-aloud-the-1-usability-tool/. [Date accessed: 2015].
- Nist, L., Joseph, L. M. (2008). Effectiveness and efficiency of flashcard drill instructional methods on urban first-graders' word recognition, acquisition, maintenance, and generalization. *School Psychology Review*, 37(3), 294–308.
- Novak, M., Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *Gerontologist*, 29(6), 798–803.
- Ogden, J. (2012). Trouble in mind: stories from a neuropsychologist's casebook. New Year: Oxford University press.
- Oriani, M., Moniz-Cook, E., Binetti, G., Zanieri, G., Frisoni, G. B., Geroldi, C., De Vreese, L. P., Zanetti, O. (2003). An electronic memory aid to support prospective memory in patients in the early stages of alzheimer's disease: A pilot study. *Aging and Mental Health*, 7(1), 22–27.
- Parkin, A. J. (1997). *Memory and amnesia: an introduction*. Oxford: Blackwekk Publishers Inc, second edn.
- Paterson, B., Scott-Findlay, S. (2002). Critical issues in interviewing people with traumatic brain injury. *Qualitative Health Research*, 12(3), 399–409.
- PatientsLikeMe.com (2012). Patientslikeme. http://www.patientslikeme. com. Last accessed January 2012. [Date accessed: 2012].
- Petrelli, D., Whittaker, S. (2010). Family memories in the home: contrasting physical and digital mementos. *Personal and Ubiquitous Computing*, 14(2), 153–169.
- Pollack, I. W. (2005). Psychotherapy. In Jonathan M, S., McAllister, T. W., Yudofsky, S. C. (Eds.), *Textbook of traumatic brain injury*, pp. 641–654. Washington, DC: American Psychiatric Association Publishing.

- Priestley, R. (2012). Molecular master chef. In *New Zealand Listener*, pp. 30–31. New Zealand Listener, December 1-7, 2012.
- Putnam, C., Kolko, B., Wood, S. (2012). Communicating about users in ictd: Leveraging hci personas. In *Proceedings of the Fifth International Conference on Information and Communication Technologies and Development*, ICTD '12, pp. 338–349. New York, NY, USA: ACM.
- Rainlendar (2012). Gallery-simple view. http://www.rainlendar.net/cms/index.php?option=com\_rny\_gallery&Itemid=41. Last accessed January 2012. [Date accessed: 2013].
- Ranganath, C., Flegal, K. E., Kelly, L. L. (2011). Can cognitive training improve episodic memory? *Neuron*, 72(5), 688–691.
- Richmond, J. (2012). Digital parrot on android. Comp590 report, The University of Waikato, Hamilton, New Zealand.
- Robinson-Riegler, G., Robinson-Riegler, B. (2008). *Cognitive Psychology:* applying the sceinec of the mind. USA: Pearson Education, Inc, second edn.
- Schweer, A. (2011). Augmenting Autobiographical Memory: An Approach Based on Cognitive Psychology. Ph.D. thesis, University of Waikato, Hamilton, New Zealand.
- Schweer, A., Jones, S., Hinze, A. (2009). Trails of experiences: navigating personal memories. In *Proc. of the CHINZ*, pp. 105–106. ACM.
- Sellen, A. J., Whittaker, S. (2010). Beyond total capture: a constructive critique of lifelogging. *Commun. ACM*, 53, 70–77.
- Skarr, A., Zielinski, K., Ruwe, K., Sharp, H., Williams, R. L., McLaughlin, T. F. (2014). The effects of direct instruction flashcard and math racetrack procedures on mastery of basic multiplication facts by three elementary school students. *Education and Treatment of Children*, 37(1), 77–93.

- Souchay, C., Moulin, C. J. A. (2007). *Memory in the Real World*, chap. Memory dysfunction. Hove, US: Psychology Press, 3 edn.
- Stapleton, S., Adams, M., Atterton, L. (2007). A mobile phone as a memory aid for individuals with traumatic brain injury: A preliminary investigation. *Brain Injury*, 21(4), 401–411.
- Svoboda, E., Richards, B. (2009). Compensating for anterograde amnesia: A new training method that capitalizes on emerging smartphone technologies. *Journal of the International Neuropsychological Society*, 15(4), 629–638.
- Svoboda, E., Richards, B., Polsinelli, A., Guger, S. (2010). A theory-driven training programme in the use of emerging commercial technology: Application to an adolescent with severe memory impairment. *Neuropsychological rehabilitation*, 20(4), 562–586.
- Taylor & Francis (2012). Special issue on designing for personal memories: Past, present, and future. *Human–Computer Interaction*, 27(1–2), 1–198.
- Tcherkassof, A., Bollon, T., Dubois, M., Pansu, P., Adam, J.-M. (2007). Facial expressions of emotions: a methodological contribution to the study of spontaneous and dynamic emotional faces. *European Journal of Social Psychology*, 37(6), 1325–1345.
- Tracy K. Wade, J. C. T. (2001). Mobile phones as a new memory aid: a preliminary investigation using case studies. *Brain Injury*, 15(4), 305–320.
- Vani Rao, P. R., Spiro, J. (2005). Fatigue and sleep problems. In Jonathan M, S., McAllister, T. W., Yudofsky, S. C. (Eds.), *Textbook of traumatic brain injury*, pp. 369–384. Washington, DC: American Psychiatric Association Publishing.
- Volpe, R. J., Mulé, C. M., Briesch, A. M., Joseph, L. M., Burns, M. K. (2011). A comparison of two flashcard drill methods targeting word recognition. *Journal of Behavioral Education*, 20(2), 117–137.

- Wang, J. W., Lin, W. C., Lin, H. Y., Chang, Y. W., Cheng, H. C. (2008). *Psychology*. Taiwan: Pro-Ed Publishing Company, second edn.
- Ward, H., Shum, D., Dick, B., McKinlay, L., Baker-Tweney, S. (2004). Interview study of the effects of paediatric traumatic brain injury on memory. *Brain Injury*, 18(5), 471–495.
- Ward, T. N., Levin, M. (2005). Headaches. In Jonathan M, S., McAllister, T. W., Yudofsky, S. C. (Eds.), *Textbook of traumatic brain injury*, pp. 369–384. Washington, DC: American Psychiatric Association Publishing.
- Willingham, D. B. (2004). *Cognition: the thinking animal*. New Jersey, USA: Prentice Hall.
- Wilson, B. A., Evans, J. J., Emslie, H., Malinek, V. (1997). Evaluation of neuropage: a new memory aid. *Journal of neurology, neurosurgery, and psychiatry*, 63(1), 113–115.
- Woodberry, E., Browne, G., Hodges, S., Watson, P., Kapur, N., Woodberry, K. (2015). The use of a wearable camera improves autobiographical memory in patients with alzheimer's disease. *Memory*, 23(3), 340–349.
- Zagami, J. M., Parl, S. A., Bussgang, J. J., Melillo, K. D. (1998). Providing universal location services using a wireless E911 location network. *IEEE Communications Magazine*, 36(4), 66–71.