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Exploring Community-Based Health Care Using Mobile Applications

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This thesis is submitted in partial fulfillment of the requirements for the
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*Thanks to all who walked with me and kept me going by your support and encouragement,
especially mom and dad, Alex Robinson, Nick Lim, Lee Warwick, Li Lian & Andrew Lim.*

In memory of Estrong, Franky, Ginny, Kupo and Twitch.

Abstract

Chronic illness are conditions that last for a long period of time, and these illnesses require a substantial amount of medical treatment and attention from the hospitals and carers. Unfortunately the limited health resources in hospitals often result in patients receiving substandard treatment, and were often sent off with self-manage their condition. Studies have shown that patients who received little to no support are more likely to struggle with managing their condition, which often results in avoidable complications. This thesis aims to implement a mobile application, targeted towards people with traumatic brain injury and depression, by exploring different memory and social systems and data visualization techniques.

Table of Contents

Table of Contents	i
Table of Figures	iv
Table of Tables	vi
Chapter 1: Introduction	1
1.1 Motivation.....	1
1.2 Aim and methodology.....	3
1.3 Structure of this thesis.....	4
Chapter 2: Background considerations	5
2.1 Traumatic brain injury	5
2.2 Depression.....	5
2.3 Long-term impact of depression and TBI.....	6
2.4 Impact of culture and socio-economic factors	7
2.5 Summary	9
Chapter 3: Related Work	10
3.1 Social support systems	10
3.1.1 Telephone-based support	10
3.1.2 Internet-based support.....	11
3.2 Memory aid systems	12
3.2.1 The Digital Parrot.....	13
3.2.2 MyMemory	15
3.2.3 Autominder	16
3.2.4 LifeView	17
3.3 Summary.....	19

Chapter 4: Design considerations	22
4.1 Identifying personas.....	22
4.2 Constructing scenarios	23
4.3 Examples of interactive timeline visualisations.....	24
4.3.1 Riots in England (The Guardian)	25
4.3.2 The Decade in Books (The Guardian)	26
4.3.3 The Wayback Machine	27
4.3.4 British History Timeline	29
4.3.5 100 Years Legacies - The lasting impact of World War 1 (Wall Street Journal)	30
4.3.6 Summary of interactive timeline:.....	31
4.4 Paper prototype designs for timeline interface.....	32
4.4.1 Matrix-grid pattern.....	32
4.4.2 Z-pattern accompanied with grouping	34
4.5 User feedback on prototype designs	36
4.5.1 Methodology	36
4.5.2 Results.....	37
4.6 Final paper prototype design.....	41
4.7 Summary	46
Chapter 5: Design implementations.....	47
5.1 Technical declaration	47
5.2 Database architecture	47
5.3 Navigational flowchart.....	49
5.4 Paper prototype vs digital prototype	50
5.5 Interface layout	54
5.6 Scenario walkthrough	60
5.6.1 Case 1: Entering a new entry (adding a new memory)	60
5.6.2 Case 2: Updating an existing entry	62

5.6.3	Case 3: Creating comments / Writing suggestions on memories.....	63
5.6.4	Case 4: Browsing and searching for a memory	65
Chapter 6: User evaluation and results		67
6.1	Structure of the evaluation	67
6.2	Participant feedback.....	68
6.2.1	Findings in evaluation.....	68
6.2.2	General suggestions	70
6.2.3	Comparison between focus group discussion and usability study	72
6.2.4	Summary	73
Chapter 7: Conclusion.....		74
7.1	Summary of the research.....	74
7.2	Future work.....	75
References.....		78
Appendix.....		84
7.3	Appendix I	85
7.4	Appendix II	89
7.5	Appendix III.....	94
7.6	Appendix IV.....	103

Table of Figures

Figure 1: Māori’s mental health model.....	8
Figure 2: Graphical view of cue information (Schweer, Jones & Hinze, 2009).....	14
Figure 3: Sample of a prototype of the MyMemory annotating page.....	15
Figure 4 : the three main component within the Autominder system (Pollack et al., 2003).....	17
Figure 5: Example of Recording Capture (Left). Annotation of A Phone Call Event (Right) (Mathur et al., 2012).....	18
Figure 6: Life log visualization module (Mathur et al., 2012).....	19
Figure 7 : An example of the path of time	24
Figure 8: Interactive Timeline (The Guardian, 2011).....	26
Figure 9: Using icons to display information in a Z-layout Pattern (The Guardian, 2010).....	27
Figure 10: The Wayback machine interface (The Internet Archive, 2015).....	28
Figure 11: British History Timeline (The BBC History Website Team, 2014).....	29
Figure 12: 100 years legacies (Source: Wall Street Journal).....	30
Figure 13: Matrix styled timeline (Model A).....	33
Figure 14: Minimalized Matrix style Timeline (Model B).....	33
Figure 15: Organizing information by Phases (Model C).....	34
Figure 16: Under each phase each memory are then organized by years	35
Figure 17: Expanded mock up prototype of Model D.	35
Figure 18: Example of timeline visualisation design on a paper prototype presented to the user.....	36
Figure 19: Main page interface.....	42
Figure 20: Timeline (year) Interface.....	42
Figure 21: Adding a new Memory interface.....	43
Figure 22: Friend List Interface.....	43
Figure 23: Notification interface.....	43
Figure 24: User profile Interface	44
Figure 25: Flowchart of the Digital Memory Chest.....	45
Figure 26: Entity Relationship diagram of the system	48
Figure 27: Flowchart displaying navigational structure of the Digital Memory Chest.....	50
Figure 28: Memory Page (Paper prototype).....	51
Figure 29: Memory Page(Digital prototype)	51
Figure 30: Comment Page (Digital prototype)	51
Figure 31 : Timeline (year) the paper prototype.....	52
Figure 32:Timeline(year) implemented in the digital prototype.....	52
Figure 33: Original design from the paper prototype	53
Figure 34: Added information shown in the Digital Implementations	53

Figure 35: Create a new memory User Interface 55

Figure 36: Pop up dialog that allows user to add a phase instead of adding a year 55

Figure 37: Update a Memory phase..... 57

Figure 38: Timeline(phase) interface 58

Figure 39: Timeline (year) interface 58

Figure 40: memories that doesn't have a year are kept in the "uncategorized" section 58

Figure 41: Memory Page user interface..... 59

Figure 42: Scenario walkthrough for "add a new Memory" 61

Figure 43: An expanded drop down window appears when user clicks on the "I can't remember" button..... 62

Figure 44: Clicking on the edit icon to edit a memory 63

Figure 45: "View Comments" in memory page leads the user to the Comment Page 64

Figure 46: Clicking on 'child' icon allows sam to browse memories related to 'child' 65

Figure 47: Navigation to the Timeline(year) after picking a phase 66

Figure 48: Example of a memory entry submitted by the participant (name blurred out for anonymity) 69

Table of Tables

<i>Table 1: List of Currently Available Media Social Support</i>	<i>19</i>
<i>Table 2: Summary of devices/media analysed.....</i>	<i>20</i>
<i>Table 3: Summary of each Interactive Timeline</i>	<i>31</i>
<i>Table 4: Comparing changes made in Figure 28(old) model vs Figure 29& Figure 30.</i>	<i>51</i>
<i>Table 5: Comparing changes between Figure 31 (old) vs Figure 32(new) in Timeline (year)</i>	<i>52</i>
<i>Table 6: Comparing changes between Figure 33(old) vs Figure 34(new) for timeline (phase).....</i>	<i>53</i>
<i>Table 7: Summary of user permissions.....</i>	<i>60</i>

Chapter 1: Introduction

The first chapter explains the motivation of this research, its aim and methodology, and clarifies the structure of this thesis.

1.1 Motivation

Chronic illnesses (or long-term illnesses) are conditions that last for a long period of time, and in many cases it can never be cured completely (WebMD, 2014; Department of Health, 2004). Examples of chronic illness include diabetes, heart disease, arthritis, traumatic brain injury, physical impairment (hearing / sight) and many others (Center for Managing Chronic Disease, 2011). Causes of chronic illness vary between individuals.

To improve the quality of life for chronic illness patients, hospitals and community health centres provide treatment and rehabilitation services. These treatments may include long-term control medications, dietary and lifestyle advice. Even with the number of treatments offered by health centres, this does not guarantee patients a full recovery from their medical conditions (Department of Health, 2004). Many patients are required to adjust to a different lifestyle as advised by health care professionals'. Hence this may affect the patient's emotional and mental stability in their time of adjustment, and it is crucial that adequate support and supervision is given to patients suffering from chronic illness.

A substantial amount of medical treatment and support is needed for patients with chronic illnesses. Often patients with chronic illnesses are advised by their healthcare provider on how to self-manage their condition. This however requires a lot of support from families and carers to help master and sustain their self-care behaviours (Roter et al., 1998). Unfortunately the cost for one-on-one basic health care is too costly in time and money, and uses a giant proportion of health resources (National Health Committee, 2007). Statistically, those patients who received little to no support are more likely to struggle managing their conditions, often resulting in avoidable complications, up to and including extensive hospitalization. (Seeman, 2000 ; Stroebe, 2000).

Collectively the healthcare system has not been giving enough attention to chronic illness patients, especially people with a lower socioeconomic status (meaning people whose incomes cannot support long term health care expenses). It has been observed that many Caucasians patients have been tolerant towards this mediocre treatment and seldom voiced out their dissatisfaction. In contrast, patients with a stronger cultural values felt the lack of appropriate ethics and respect towards their belief and culture, resulting in them being less inclined to visit a medical centre for treatment (Ellison-Loschmann & Pearce, 2006).

There are a number of reports regarding racial and ethnic disparities in hospitals. In the United States, inferior health statuses have been documented for African-Americans, people of Hispanic origin, American Indians, and other minor groups of indigenous races (Collins, Hall & Neuhaus., 1999). Other reports from the United Kingdom and Europe show similar documentations (Geiger, 2001). In New Zealand, it is reported that Māori's and indigenous groups have a sub-optimal health treatment in comparison with Caucasian's living in New Zealand (Davis et al., 2006). Qualitative studies shows different cultural practices (religions, beliefs, lifestyles), practitioner insensitivity towards cultural practice of different groups, socioeconomic status, communication issues (language barriers) and patients personal experiences were contributing factors to poor treatment outcomes.

Social and ethnic disparity experience while receiving treatment in hospitals may build a barrier between practitioners and patients. Patients may be less inclined to seek medical treatment due to the fear of being judged or shamed for their lifestyle. For those who do seek medical treatment, they may face difficulties; language barriers make conversation and conceptualisation in English during treatment difficult, especially in times of stress. (Fiscella et al., 2002).

Based on the issues related to after-care treatment, and the ethnic disparities during treatment, the main goal of this research is to formulate a solution that combines the use of ideas in technology to support of their condition.

1.2 Aim and methodology

The aim of this project is to design and implement a software system that promotes community and social support for families and people that suffers from long-term illness. This project focus predominately on families with a person suffering from Traumatic Brain Injury. We aim to take guidance from indigenous cultures, such as understanding the culture of diverse races and their family upbringing values. In this thesis we will be taking guidance from the Maori's culture, by doing so, we may be provided a better understanding of the patients' background, of which allows more sensitive approaches to treatment, as well as explaining the context of the issue better to them.

Our goals is to design, implement and evaluate a mobile software system of which allows family members and friends to provide support and aid to TBI patients; and support people mentally with remembering memorable events and helping them with integrating with the community.

The research method focus on designing user-centred software, focusing on providing social support and memory aid for people with TBI and depression. Our secondary design focus will look into approaches that provide a simple usability system that is community centred, where carers, family and friends may communicate with the user through this software.

The desired outcome of this project is to fully achieve the aims and goals of the project, however with a combination of related work in fields such as psychology, social studies, computer science and user interface designs, we understand that this thesis may not cover all this aspects to their fullest extent. However, we do hope that this thesis constitutes an initial step towards culturally-aware software for families and communities with a person suffering from long-term illness.

1.3 Structure of this thesis

This thesis is divided into chapters, each of which addresses the following topic:

Chapter 1 provides the motivation for this thesis and defines the overall focus and aims for the research.

Chapter 2 provides the literature review on the topics of two different kinds of chronic illness (TBI and depression), issues of disparities found in health care systems, and the effects of social and community support towards these people.

Chapter 3 will analyse existing digital systems and research produced by others. Systems that were analysed include social support system and Memory aid systems. This chapter sets the scene and criteria that we should be looking for in our application.

Chapter 4 provides the personas and scenario created in the research, previous work done on timeline visualisation, and our paper prototype model of the timeline interface in the prototype. The prototype was then presented to a small focus group, in which feedback and suggestions was reported and outlined.

Chapter 5 outlined the technical implementation of the digital prototype. This includes summarising the database architecture of the system, functions of the digital prototype, as well as a scenario walkthrough of the functions available.

Chapter 6 reports on the findings and results based on the user evaluation conducted. The chapter describes first the structure of the evaluation, then participant's feedback from the study.

Chapter 7 provides a conclusion to the thesis, as well as a proposal for future work.

Chapter 2: Background considerations

In this chapter, two types of chronic illness (Traumatic Brain Injury and depression) will be examined to discuss their cause (in Section 2.1 and 2.2) and the effect of that both illnesses have with regards to the long-term care and the lives of people that are affected (Section 2.3). In Section 2.4, claims of disparities found in New Zealand's healthcare will be reviewed to gain a better understanding of the current issues and their impact on people with chronic or life-long illnesses. The chapter finishes with a summary of the issues identified and their significance for this thesis.

2.1 Traumatic brain injury

Traumatic Brain Injury (TBI), or intracranial injury, is a leading cause of death and disability in children and young adults worldwide and New Zealand (Langlois et al., 2006). People with TBI suffer from memory impairments, such as forgetfulness (Johnson, 2010) and difficulty forming new memories (Kennedy, 2006). The severity of these impairments varies according to the nature of the injury, which may be due to falls, accidents, and/or assaults (Feigin et al., 2013). Many TBI cases have been “under-reported, not well diagnosed, and are poorly managed.” (Chang, 2014).

The majority of TBI incidents recorded include children, young adults and older people (Schneier et al., 2006). According to Feigin et al., male adolescents between 15 and 25 years old are the highest risk group. In New Zealand, a higher TBI rate was noted for Māori compared to non-Māori (Barker-Collo et al., 2009), with data showing Māori are three times more prone to suffered from it (Barker-Collo et al., 2012). Further reports show that a higher incidence of moderate to severe TBI occur in rural populations (73 /100 000 person per year) than urban populations (31/100 000 person per year), with a 2.5:1 ratio difference.

2.2 Depression

Depression is described as a mental disorder with the following characteristics: a state of low mood and aversion to activity where thoughts, behaviour feeling and well-being is affected (Salmans, 1997). Depression may be trigger by a variety of reasons. A number of factors that trigger depression

include medical illness, life changes (death, natural disaster), environmental changes, or genetics. Common symptoms include sadness, negative thoughts, apathy, lack of energy, and the inability to enjoy normal events in life (Guillamondegui et al., 2011 ; Frances et al., 2002). Symptoms of depression vary for each individual, hence making diagnosis complicated. Failure to address depression increases the chance of risky behaviours such as abusing drug use or alcohol addiction, and in severe cases, suicide.

Analyses of hospital inpatient data shows the rates of admission to psychiatric hospitals were lower for Māori than for non-Māori in the 70's (Pomere & Boer, 1988). However the patterns of admission during the 80's and 90's show an increase rate of Māori seeking psychiatric hospitalization (Ministry of Māori development; 1993; 1996, Pomare, 1995). Christchurch Health and Development conducted a study where the results show the proportion of youth at 18 years old with mental disorder is high. Among that, 55% of Māori included in the study had at least one mental disorder within the previous 3 years, compared with 41% of non-Māori youth who participate (Horwood & Ferguson, 1998).

2.3 Long-term impact of depression and TBI

Depression may be triggered by biological, psychological and social factors (Fan et al., 2009). Depression is the most frequent secondary condition for patients, and has consistently proven to affect a number of areas several years after the injury (Corrigan et al., 2001). According to Starkley et al., (2009), depression in TBI patients may be triggered by physical (inability to function normally) or emotional distress (cognitive changes). The study conducted by Gordon et al., (2006) reveals that TBI is associated with high rates of depression and other mental health conditions.

Depression reduces quality of life, impairs the ability to function normally in social and work roles, and causes self-doubt and difficulties in taking action, all of which can delay recovery from TBI (Agency for Healthcare Research and Quality, 2011). This issue was brought to attention recently, and interest towards different roles of psychosocial functioning after TBI towards the recovery of patients have been looked into (Goranson et al., 2003; High et al., 2006). Among the various well-being factor which influence patients, greater attention were paid towards areas of community integration (High et al., 2006; Fleming et al., 1999), and social support. A study using a “Community

Integration Questionnaire” (CIQ), conducted and analysed by Goranson et al., (2003), had shown an improvement of patient's’ wellbeing (better health outcome). Other researchers have found that incidence of depression increase where social support is lacking in their stage of rehabilitation (Kozloff, 1987; Elsass & Kinsella, 1987; Prigatano, 1986).

2.4 Impact of culture and socio-economic factors

While many cases of poorer health outcomes of Māori were attributed to lower socioeconomic status (such as poverty, the inability to pay for medical treatment), there is a significant contribution made by racial and ethnic disparities in the quality of medical care. International literature (Arango-Lasprilla & Kreutzer, 2010; Jamieson et al., 2008; Arango-Lasprilla et al., 2007) has identified disparities towards accessibility of health services, as well as treatment outcomes of indigenous and other minority cultures.

In New Zealand, evidence of racial disparities was found in Māori access to support for treatment (Jansen et al., 2008). Despite ACC statistics showing evidence that Māori are 1.5-2.5 times more prone to injury; they are less likely to access appropriate rehabilitation. According to (Elders, 2013) current health care environment is catered predominantly towards the dominant group, and that it is not culturally safe for minorities like the Māori (Wilson & Barton, 2012). Lack of knowledge of the severity of their injury, fear of getting ridicule or “put on the spot” of which they were unable to articulate their problem clearly (Clemenger BBDO, 2004) resulted in Māori being reluctant to ask questions, or complain even when observing a substandard of care (Wilson & Barton, 2012)

One of the reported causes of racial disparities, is the use of insensitive language towards the upbringing and culture of Māori during treatment (Barker-Collo et al., 2009), rude and disrespectful as well as having poor communication (Jansen et al., 2009), which creates negative experience that create a perception of bias (Bryant & Campbell 1996; Health Waikato 2001).

Treating Māori patients without taking into consideration of their culture may negatively impact the effectiveness of interaction between Māori’s and their doctor, thus resulting lower health outcome. In some cases, Māori patients prefer to seek traditional treatment over modern medicine as they do not consider Pakeha as appropriate services provider (Jansen et al., 2008). Māori holds a more holistic view towards health (Pere, 2008) from Caucasian’s. Hence, Māori prefer to seek treatment

within their *whanau* (extended family) instead of seeking medical help in the hospital (Elder, 2013). The term *whakama* (translated as shyness or embarrassment) was seen as a barrier to healthcare, as Maori's patients were too shy to describe their illness (Bryant & Campbell, 1996; Cram & Smith, 2003).

Elder (2013) proposed an approach to long-term community-supported care that is culturally sensitive and rooted within Māori culture. The approach, *Te Whare Tapa Whā* (the four-walled house) is a Māori health model of which describes the four cornerstone of Māori health. The model describes four elements of well-being; *Taha Tānana* (physical body), *Taha Wairua* (spiritual health) and *Taha whānau* (family Health) and *Taha Hinengaro* (mental health).



Figure 1: Māori's mental health model

Figure 1 shows the symbol of a wharenuī (big house), which illustrates the four dimension of Māori's wellbeing. This model is used by Māori to describe their sense of well-being (Durie, 2001), and should one of the four dimension be missing or damage, the person may become 'unbalanced' and subsequently unwell (Ministry of Health, 2015). In a traditional Maori approach, the inclusion of the *whānau* (family) and the balance of the *hinengaro* (mind) are considered to be equally as important as the physical manifestation of illness (Ministry of Health, 2015). Elder (2013) further deduct this concept with the importance of family in optimising rehabilitation outcomes for TBI

patients. This model of health have also been discuss and resonate widely by international researchers, demonstrating the importance of family in optimising rehabilitation outcomes of people with TBI (Anderson, 2005; Yeates et al., 2002). This thesis is inspired by Elder's work with TBI and depression patients and whanau, which aims to develop a digital system as a medium for minorities to receive social support in a culturally sensitive environment.

2.5 Summary

This thesis is concerned with alleviating the long-term impact of conditions such as TBI and depression. TBI may occur to people who had a fall, accident or assault. While cases of TBI may happen to anyone, the majority of the TBI incidents happen to male adolescents between 15 and 25 years old. The cognitive changes in a TBI patient's day-to-day- activities may also trigger a secondary condition (depression).

The well-being of TBI and /or patient with depression are affected by various psychosocial factors. In this chapter, studies have shown that the social support and community integration contributes towards the effectiveness of patient's personal well-being and rehabilitation (when it is used correctly). Māori (and other indigenous groups) may practice a different culture of which certain condition cannot be explained accurately in modern medicine, which contributes to a major factor of racial disparities for them.

Based on the concept of Māori's mental health-model, it is understood that the role of *whanau* plays an important role in the rehabilitation process of these patients. This research aims to create an application which includes the concept of a culturally sensitive environment that enables family to support people with TBI or depression in post-treatment care, combining techniques used in aiding TBI patients with memory problem.

Chapter 3: Related Work

As outlined in Chapter 2, poor health outcomes occur when there is a lack of professional help during treatment, as well as the lack of social support for patients that has been discharged from the hospitals. Intervention to help support these patients has been done in various ways in the past. For example, an older generation of ICT (i.e., Telephones) were used by professional carers to communicate with elderly people, their families, and other carers (Carretero, 2012), especially in rural areas (Hogenbirk et al., 2005). The use of the Internet to provide social support has gradually been more recognizable recently as well (Carretero, 2012).

To learn about the types of technology used currently for supporting people with TBI and Depression, this chapter will analyse available devices used currently for social support (Section 3.1) as well as related research work on memory systems (Section 3.2).

Evaluation will be based upon how well the system is capable of improving communication and social support, the relation towards depression and memory impairment, as well as its relevance to the goal of this thesis.

3.1 Social support systems

According to Lin et.al (1979), social support is described as a “support accessible to an individual through social ties to other individuals, groups, and the larger community.” Adequate social support was found to have a protective factor in resilience to stress, decrease the functional consequences of trauma-induced disorder (eg. posttraumatic stress disorder) (Southwick et al., 2005), and improve the overall wellbeing of a person’s physical health outcomes (Uchino, 2004). In this section, we’ll be looking into two existing types of social support used.

3.1.1 Telephone-based support

Telephony is an old technological device used to communicate with two or more individuals at a distance. The telephone can be used to provide self-management training, mental support, as well as providing a platform for patients to discuss and seek advice with their carer remotely (Hogenbirk

et al.,2005), leading to better self-management, improved well-being, and better health outcomes (National Kidney Foundation, 2009). Several studies have shown that telephone support could improve, to some extent, the subject's psychological status and perceived social support (Wells et al., 1993).

In the healthcare sector, telephone-based support is used in the care of patients after post-operative care. It has been a key tool in the care of the elderly, as it enables carers to communicate with the elderly people, their families and carers (Carretero, 2012). Patients may receive regular phone calls from professional careers, as well as family and friends, instead of scheduling face-to-face visits, to keep tabs on their physical well beings.

Telephones also allow relative anonymity. In one study of telephone-based mutual support for depression, participants noted in favour of telephone based support as it is easier to be 'honest' and 'open' about their problem, without the fear of being judge (Travis et al., 2010). It is also harder to monitor, as patients may lack the initiative to call back on a regular basis. According to Thompson (2007), long intervals between phone calls were found to be ineffective for stress management.

Telephones are not designed to keep a large record of information. The ability to revisit previous phone calls data are only limited to a very small amount of calls for the user, which may not be useful for people with TBI.

3.1.2 Internet-based support

The internet has been use widely to mobilize peer support, by providing health information to the public (Siow et al., 2003), promoting healthy behaviour among the older generation (Slootmaker et al., 2005), and helping older people to communicate with others to reduce their social isolation and loneliness (Westlake et al., 2007). Studies shows the use of ICT can open up possibilities of self-training to manage long term diseases (Weinert, Cudney & Winters, 2005; Klemm & Wheeler, 2005; Pierce et al., 2004), improvement of physical and mental wellbeing (Lam & Lam, 2012) and building connections (Hill & Weinert, 2004).

Users may seek support and advice in various platform, such as Chat Rooms, ListServes, Blogs or Internet Support Groups (Tate, Wing & Winett, 2001; Gold et al., 2007; Bennett et al., 2010). Chat rooms are online discussions that are conducted over the internet in a synchronous manner. Chat

rooms include groups of people who messages each other over the internet, where topics of interest can be discussed. ListServes are email sent to people who are part of a mailing list, which may be used as a primary discussion tool, threaded discussion, or a notification of new posts to discussion board. Blogs are personal journal or diary hosted online, which are read by interested individuals (Baker & Moore, 2008). Blogs can be used as an asynchronous form of communication, where readers may seek pieces of information at a different time from the time it is posted. Internet Support Groups (ISG) as the term suggests are support groups and promotes self-help rather than being therapeutic in nature (Kernsmith & Kernsmith, 2008). ISG may be managed by one or more individuals, where people could share their experience and advice. Individuals may also seek help from these ISG. These kind of groups are asynchronous (Kernsmith & Kernsmith, 2008), as discussion and post can be done when each user is using their computers. Participants are offered emotional support, as well as medical information or treatment options (Sullivan, 2003), which can be invaluable to people who rely on them to help sustain a healthy lifestyle.

Currently existing internet programs have been developed for diabetes education and self-management support, weight management, and peer-support advice (Heshka et al., 2003). While the internet programs were predominantly tailored towards weight management, studies shows peer support in these program boost the effectiveness of social support (Tate et al., 2003).

The system that supports a rich variety of ways of supporting people mentally with their illness however does not support memory storage well. As most internet based support and advice were supplied for multiple users, it is difficult for a user to review chat logs, emails or forum for information. Browsing through old records can be tedious and time consuming, even for an average user.

3.2 Memory aid systems

Memory is a process where information is encoded, stored and retrieved (Miller, G. A. 1956). It allows us to draw on past experiences in order to use this information in the present (Sternberg, 1999). This information (memory) may be taken in many different forms, such as images, sounds and semantic. Memory storage is categorized into Short Term Memory (STM) or Long Term

Memory (LTM). STM is responsible for storing information temporarily and determining if it will be dismissed or transferred on to LTM, usually involving rehearsal and meaningful association.

According to Chang (2014), there are “five factors of memory” used by humans that support the recollection of information. These five factors of memory;- Location (landmarks, name or address of a place), activity (actions, activity or conversation), people (names and faces, person size, etc), emotions and time (day, date, or the representation of a period of an event) are closely related to an autobiographical memory of an individual, which affect the memory of TBI individuals.

It is noted that several memory aid system introduced by previous researchers use the concept of autobiographical memory as the core of the system (Schweer, Jones & Hinze, 2009; Chang, 2014; Mathur, 2012; Pollack, 2003). This section covers several examples of these devices that aid a person with memory problem.

3.2.1 The Digital Parrot

The Digital Parrot (Schweer, Jones & Hinze, 2009) is an augmented memory system used to store autobiographical memory. General autobiographical examples include, “What is the name of the country John had his 21’st birthday party?” The system was developed based on computer technology and cognitive psychology. The computer technology aspect looks into data models, storage mechanisms, and visualization and access paradigms. The cognitive approach imitates the model of human memory system.

The system is available as a desktop or mobile version for Android. According to Schweer, Jones & Hinze (2009) contextual cue information such as time, location, people or weather improve users ability to recall memory. The system utilizes cue information of special events and relevant information to create a network of memories in a graph, which includes semantic information and associations, as shown in Figure 2. The desktop version was designed to retrieve stored information through four navigational approaches: type navigation, timeline navigation, map navigation, and keyword search. Reports of discomfort however (such as headache) were noted when TBI patients used the system, as the system does not provide the mobility of usability in a daily context (Schweer, Jones & Hinze, 2009).

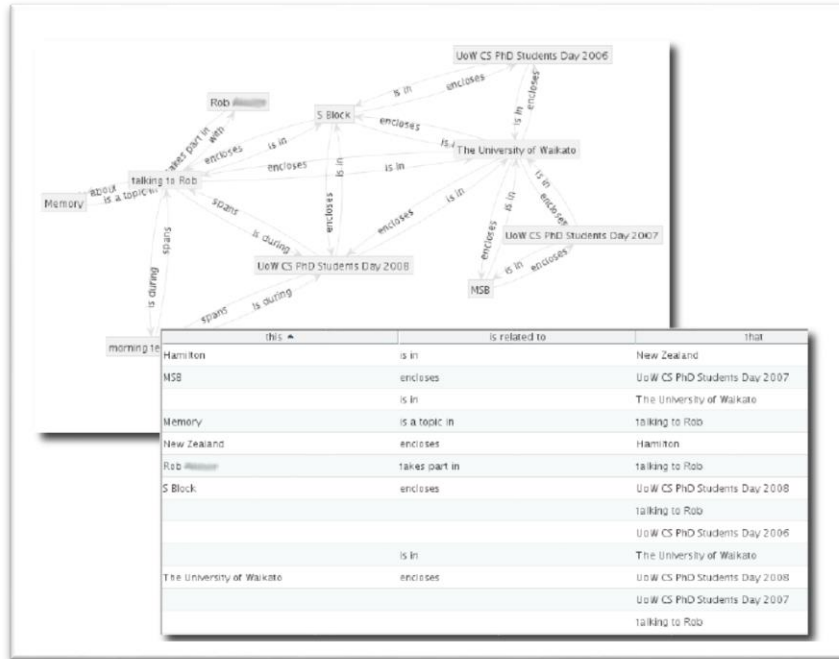


Figure 2: Graphical view of cue information (Schweer, Jones & Hinze, 2009)

A mobile prototype build using the concept of the Digital Parrot was built for Android devices. This system displays a list of data, grouped according to columns (in the form of this, is related to, or that). Options such as reorganizing data, filtering, and the ability to use the device while mobile improved the usability of the Digital Parrot. However the system deals with a huge amount of data and options, which is still too complicated for people with TBI.

The research on the Digital Parrot was designed to be used by a single user. It was not designed to share and allow community support. Hence the user is unable to share their problems to others easily, likewise carers and family are unable to help them electronically through this device. Schweer's (2011) designed for a desktop version had been shown to be successful in supporting memory retrieval, however TBI patients report difficulties using it as the use of it often leads to headache (Schweer, 2009). Richmond (2012) uses the concepts of the Digital Parrot and developed a mobile prototype for Android devices, however despite the change it is still not an ideal solution for people with TBI as it is too complicated.

3.2.2 MyMemory

MyMemory (Chang, 2014) is a memory aid system developed to assist TBI patients, focusing on the rehearsal of memories instead of reminders to train the memory of people with TBI. The system was inspired by the Digital Parrot, and was designed to support visual and auditory cues, with the target group catered towards people with TBI.

The system offers three options of memory recording, which are, digital, photograph and audio recordings. From a study conducted by Chang (2014), five factors of memory were noted to help TBI patients remember better. The five factors of memory (location, activity, people, time, emotion) were used as a basis to the memory cue design. This information can be annotated and stored, as shown in Figure 3. MyMemory uses both visual attraction (using different colours for different categories) and repetition (flashcards, post-it, screensavers) to help TBI patients remember better. MyMemory also utilized voice-recorded notes as a way to trigger people's memory. This is done using both a mobile phone and a Karotz(Wi-Fi enabled ambient electronic device in a shape of a rabbit).

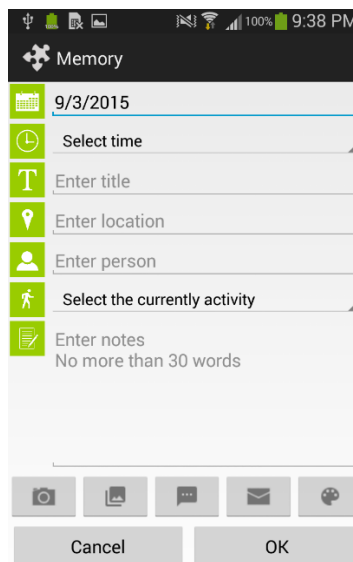


Figure 3: Sample of a prototype of the MyMemory annotating page

The device was built to assist TBI patient memory through rehearsing. In order to do so, a certain degree of recalling and reminding is used repetitively to help patients remember a certain set of

memories. Users are able to access memories kept long ago stored within the system. The device is also designed for single user, hence information and memory stored within the system is only accessible by the user. No form of social is provided, as the system was not designed to support the patient's psychologically.

3.2.3 Autominder

Studies have suggested the quality of life for older people who remain at home is better than those who were allocated to institutes (Rivlin 1988). Autominder is a cognitive orthotic system which aims to help older adults with mild to moderate memory impairment to remain at home longer. The goal of this system is to provide reminders to the user about their daily activities, by modelling the user's daily plan, observing and tracking the execution of a user's plan, and deciding an appropriate time to execute the reminder.

The system consists of three main components: the Plan Manager (PM), the Client Modeller (CM), and the Personal Cognitive Orthotic (PCO), see Figure 4. The Plan Manager manages a user's daily plan, such as adding a new activity or updating a new activity. Plans may be updated manually by a user or having the device decides if plans needs to be updated. The Client Modeller monitors execution of the plans by using an on-board sensor, which feeds back information (such as location, time and action taken by a user) to the PM on the current activity a user is performing. The system made as of date is constrained to only detect the current location of the client, and feeds back information to the PM. The last component in this system, the PCO, is responsible for deciding what reminders to issue and when.

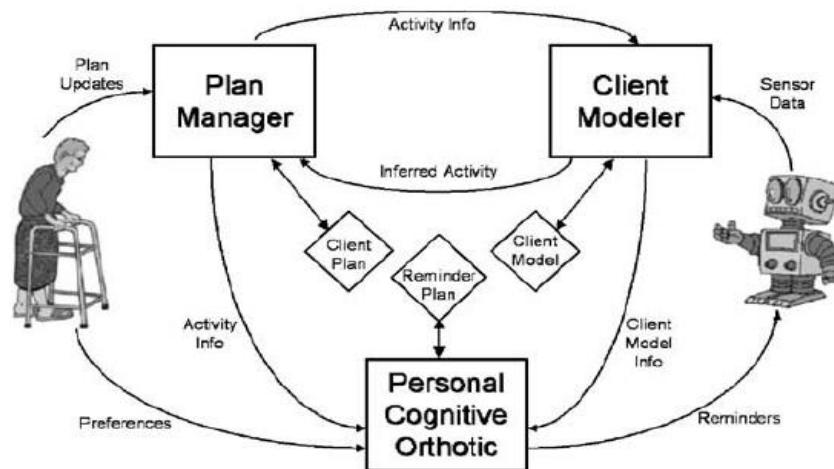


Figure 4 : the three main component within the Autominder system (Pollack et al., 2003)

Autominder was designed as a reminder to help older people by aiding them with their daily schedule. The system does not provide an extensive social support for users. It doesn't support communication, where a major part of social support is involved there. The system helps scheduling day to day activity, but it doesn't allow memories to be recorded.

3.2.4 LifeView

According to Brewer (1988), the use of location, people and Meta information about an event produces strong cues for recalling. LifeView is a life logging visualization tool that focuses on two use cases: The ability to recall sentimental memories, and the ability to share these memories with people. The main use case "Sentimental Recall" aims to provide users' the ability to look back at past experience for sentimental reasons, while the "Sharing" use case was designed to share these memories to friends and relatives. The visualization uses these contextual cues to enhance user's ability to recall and remember past experiences.

An Android application was built to record three kinds of data: Text, call logs and video/pictures taken from the phone's camera. Users were given administrative power to manage their data, such as sharing or removing existing information. For segmenting the data, the user will need to manually annotate data to form a visual representation of the data (see Figure 5). Textual events were visualized using cartoons, as according to (Sellen et al.,2007) images captured by the users serve as important cues for remembering past memories (see Figure 6). Visual representations of memories

are stored in a timeline, where the user can see important cues of a memory. To share a particular life log (or event) with a friend, users may share this memory by sending it through the email address of a person.

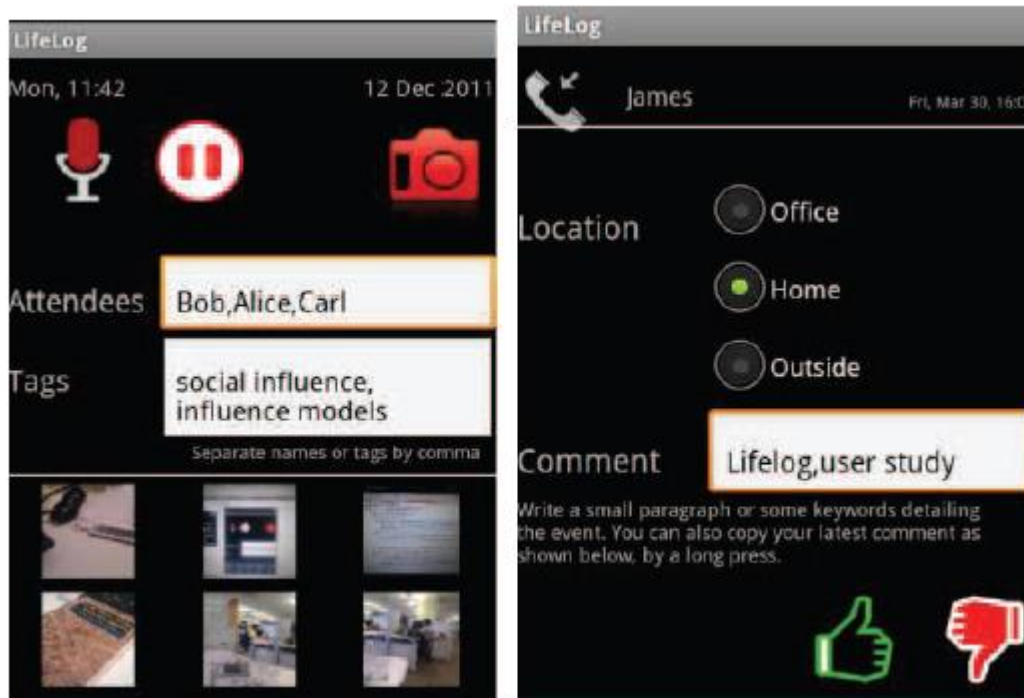


Figure 5: Example of Recording Capture (Left). Annotation of A Phone Call Event (Right) (Mathur et al., 2012)

LifeView allows users to store memories and share a particular set of memories to friends and family. The device was designed for an individual's personal use, hence social support was not extensively supported in the system. LifeView allows users to share memories one way but it is lacking the ability to share memories in both ways (friends cannot contribute memories to the user's timeline by adding past memories). Friends and family are unable to provide support or aid to the user. Memories stored in LifeView are cartoonized to improve recalling a memory. The system does not support reminding; hence users cannot use this system to remind themselves of upcoming activities.

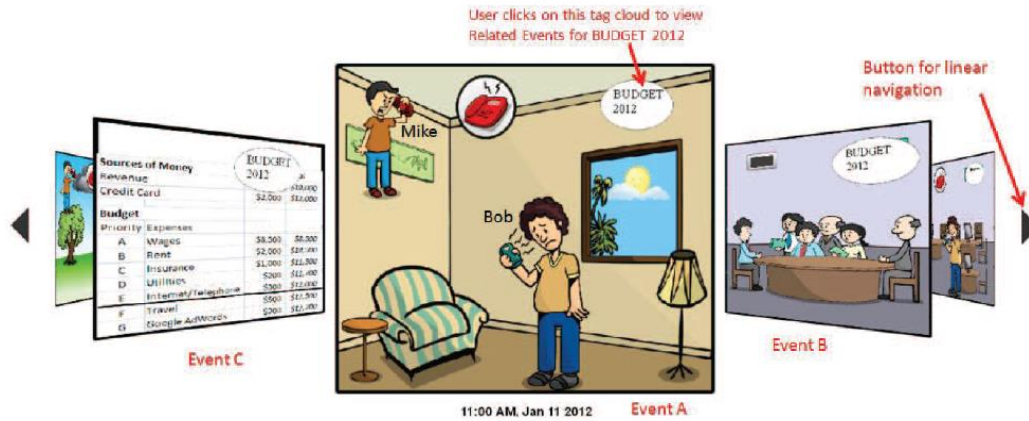


Figure 6: Life log visualization module (Mathur et al., 2012)

3.3 Summary

This chapter reviewed technology that help people with memory problems, as well as technology that promotes community social support. While not all the systems were directed towards people with TBI or depression, the systems support these patients socially with the use of technology. We looked into the advantages and disadvantages of current system used to support after-care patients socially, which is summarized in Table 1.

Table 1: List of Currently Available Media Social Support

	Advantages	Disadvantages
Telephone-Based Peer support	<ol style="list-style-type: none"> 1) Patients may discuss their problems with “relative anonymity” and privacy 2) Allows Interaction between 2 or more 3) Helps with patients who are shy to describe their problem face to face 	<ol style="list-style-type: none"> 1) Patients may be reluctant to share their telephone numbers and pay the cost of long distance calls. 2) Harder to monitor /Follow up on a patient
Web and Email-based programs	<ol style="list-style-type: none"> 1) allows anonymity /privacy 2) Allows asynchronous and synchronous conversation 	<ol style="list-style-type: none"> 1) Some patients may not be computer literate / no internet access

A summary of the devices and media used to support people' was analysed and summarized down in Table 2 to highlight the strength of each feature for TBI (Memory impairment) and Social support. The availability of feature types (Communication/social support or Memory Support) are indicated by absence (-), partial presence (+-), and the full presence (+) in the table.

Communication / Social Support compatibility	Memory Support Type
a. Peer support, mutual assistance, information exchange	I. Recalling
b. Online consultation	II. Reminding
c. Training on care giving	III. Rehearsing
d. Communication with care recipient; access to her status, assistance planning etc.	
e. Sharing	

Table 2: Summary of devices/media analysed

	Communication / Social Support Compatibility					Memory Support			Target User	Memory Storage	Privacy
	a	b	c	d	e	I	II	III			
Digital Parrot	-	-	-	-	-	+	-	-	Personal use	+	+
MyMemory	-	-	-	-	-	+	-	+	Personal use	+	+
Autominder	+-	-	-	-	-	-	+	-	People with memory problem	-	+
LifeView	+	-	-	-	+-	+	-	-	Personal use	+	+
Telephone-Based Peer Support	+	-	+	+	+	+-	+-	-	After Care Patients	-	+-
Web and Email-Based programs	+	+	+	+	+	-	-	-	Multiple users	-	+-

From

Table 2 we can see many systems are used to support either people with memory problems, or aiding people with social support, but not both. While there is evidence some systems (such as LifeView and internet based support) may have tried to support both memory problems and social support, these system have not been developed extensively to support both criteria fully. This creates a scene for this project to design and implement a system that aids people with TBI and depression, both by supporting them socially and with their memory.

Using the information collected, we decided to design and implement a system, dubbed the “Digital Memory Chest”, a system that support both a person with memory problems, as well as providing social support to these people.

The desired outcome of this design is a prototype of an Android application that stores, retrieves and organizes memories that a user collected over a lifetime, as well as allowing friends and family of the user to support them socially by sharing memories and commenting on existing memories.

Based on our analysis, we prepared the following features for our Memory Chest. The ability to

- a. Store, organize and search existing memories in the system,
- b. Add memories into the system, especially memories related to special moments/events in a lifetime.
- c. Open social communication - such as providing suggestions to a memory, to contribute to a memory.

This list of high level features are used as the starting point for design consideration in Chapter 4.

Chapter 4: Design considerations

Using the list of high level features outlined in Chapter 3, this chapter describes the implementation of a mock-up paper prototype of the Digital Memory Chest, based on the personas (Section 4.1) and scenarios created (Section 4.2), as well as examples of application of the use of timeline interfaces (Section 4.3). Section 4.5 describes methods used in the focus group study conducted and the result outcome of the study. The final paper prototype design was finalised in Section 4.6.

4.1 Identifying personas

The Digital Memory Chest was designed for two different types of users:

- a. Main user: The main user will be a person suffering from TBI or any other long-term illness. They will manage their memories found using the software.
- b. Secondary user: They use the software to share memories, or comment on memories on the main user's profile, or provide additional information to the main user on a memory that has missing entries. They may have their own personal profile.

To explore the design options, two different personas were created based on these user types.

Persona 1: Sam (Main user)

Sam is a 20 year old university student who was recently involved in a car accident, and consequently suffered from mild traumatic brain injuries. This affects his ability to recall memories after the crash well. The inability to recall a memory over his lifetime have left Sam feeling depressed and alone, and his friends and family are seeking ways of helping him to cope and recall memories that he failed to do so alone.

Persona 2: Joan (Support person)

Joan is Sam's cousin. The recent car accident event that has damaged Sam's ability to remember the good times has saddened Joan, and she is looking for ways to support Sam by preserving his memories virtually.

4.2 Constructing scenarios

Scenarios were created to visualise how the system would achieve the main purpose of the Digital Memory Chest. These scenarios were created with the aid of several participants in the focus group, and several requirements listed in Chapter 3 (Section 3.3).

Scenario 1: Adding memories to the System (by Sam)

Sam found photos of his trip to India with his best friend, Lee, when he was a young adult. Sam remembers the towns and historic monuments he visited, but could not remember the duration of the time he spend there. Using the information that he remembers, Sam would like to add these information into his Memory Chest.

Scenario 3: Adding memories to the System (for a friend)

Joan holds some pictures and videos of her sister's birthday party where both Sam and Joan's family were present. Joan would like to share this memory with Sam, who could not remember it very well. Joan entered her login details before gaining access to her own account, where she search for Sam under her friends list. Joan created a new event for Sam in his timeline, where she entered details related to that event, along with the pictures and videos she has on her computer.

Scenario 4: Searching / browsing for memories

Sam and Joan were talking about a trip to the zoo they went to as kids with their families. Sam and Joan could not remember the year they went to the zoo, but knew that Sam was around 10 years old, and it was a trip with their family in Australia. Using this information, they have decided to look up on pictures and videos related to this event through the Sam's timeline in the Digital memory chest app.

Scenario 5: Updating / editing a memory

Sam and his friends were at a school reunion when they were having a conversation about the time they won the national basketball championship. Sam remembers entering that memory into his Timeline, but did not fill up all the details related to that event. Together with his friends, Sam updates his memory entries with the freshly discussed information.

Scenario 6: Adding a comment (Contributing / Sharing Memories)

Joan was browsing Sam’s timeline when she found a memory of Sam and her when he was camping out in Taruanga. Joan noticed there were several information about the memory was not registered, for example, Sam left out any descriptions of what happened during his time out in that camping trip. Joan would like to tell Sam about fun facts of what happened during that trip with him.

4.3 Examples of interactive timeline visualisations

The Digital Memory Chest aim to stores life events of a user. This may involve:

- c. Storing /adding pieces of information of a memory,
- d. Retrieving memories within the system
- e. Organizing these information in such that it is easily accessible and easy to search for

In Section 3.2, we discussed the psychological aspect of how humans recollect their memory, but not how to design a system that allows people to interact with these memories, should it be stored in a device. This section analyses several examples of information presented using timeline concepts.

‘Time’ is a measurement of the duration of events and the intervals between the said events. It is also used as a measuring system to chronologies a sequence of events (also referred as Timeline) (Oxford Dictionary, 2011). The metaphor “time is space” (Lakoff & Johnson, 1980), explains how human imagine time as a path along which they talk. Traugott (1975) explained this by describing how we relate our current place along the path as “now”, to a place along the path which happened, which is “then”. The position of “now” along the path would be our primary reference point.



Figure 7 : An example of the path of time

According to Mitchell (2004), the primary variable in designing time-related information is the reference point (“when did an event happen”), a measurable time scale (time, day, month, year), and its visual arrangement. Visual arrangement depends on the data itself (Aigner et al., 2007) and the limitations of the design media (Mitchell, 2004).

To visualise the use of timeline in a modern context, a few interactive timelines made by other designers were explored and documented. These systems were evaluated according to the following criteria:

- a. Is the system easy to navigate,
- b. Is the system simple to use,
- c. Does the system organize existing information well,
- d. Is the timeline organization suitable for use by people with TBI.

This section will explore several interactive timeline interfaces and their practicality for people with TBI.

4.3.1 Riots in England (The Guardian)

The Guardian published an interactive chronological timeline (Figure 8) which outline the most important incident that occurred during the riot in England and how they spread over the different neighbourhoods. A scrollable 3 dimensional timeline designed to look like a ‘road’ was intended to allowed user to watch how the riots unfold itself. Individual events are marked with an icon that represent the event. If an icon is selected by the user, they may receive greater details about that particular incident.

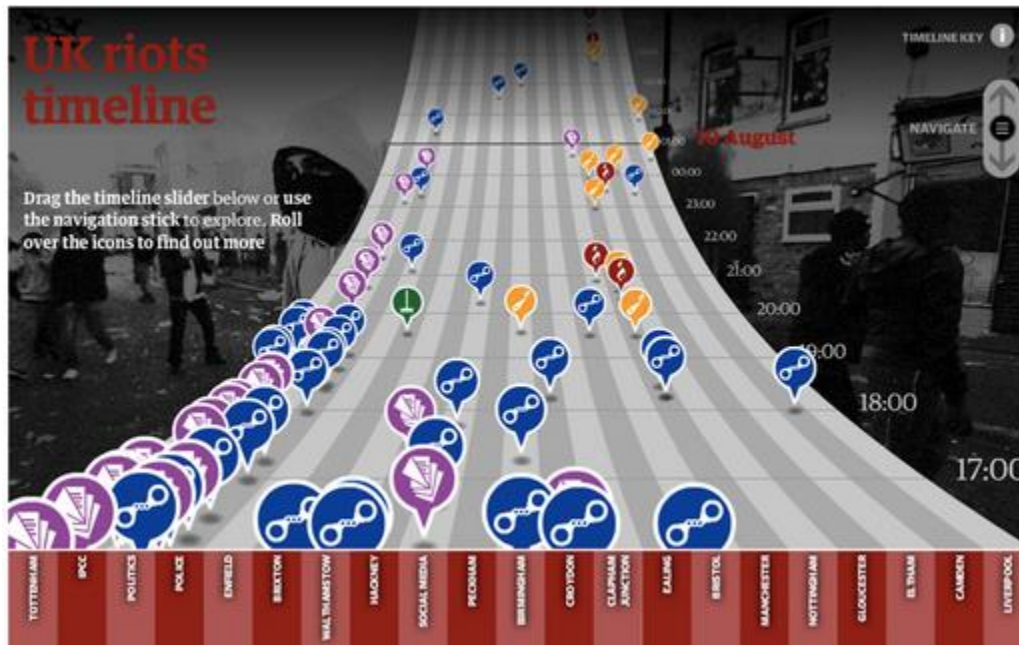


Figure 8: Interactive Timeline (The Guardian, 2011)

The system provides a simple navigational structure for users to navigate linearly between the chronological timeline of the events. It also provides users with a quick summary of incidence that occur during the riot. The disadvantage of this system however, it is difficult to know what “incidence” occurs during each event, without clicking on the icons. This system also may not be suitable to store a person’s lifetime memories, as may be too difficult for a person like Sam to remember precisely what they do or when did the memory happen on a specific day without constantly writing a memory log (Chang, 2009).

4.3.2 The Decade in Books (The Guardian)

The Decade in Books (Figure 9) displays information about selected literacy stories in the last 10 years (of which the interactive visualisation was created). Each book is represented by a little icon displaying an image of the author, on the front cover of the book. When these icons are selected, a brief description of the book is display, with the link to the full story. Colours were used to represent the years in which these books were published. Icons were arranged in a Z-layout pattern, of which the oldest book is located at the top left hand corner of the interface, and the latest book may be found at the bottom right corner, making the interface easy to navigate, and easy to use.

4.3.4 British History Timeline

The British History (Figure 11) is an interactive timeline represents individual events in a dotted graph. Each dot represents an event with a brief summary of what was happening at that time. The timeline uses a scroll bar to navigate back and forth the timeline. Colour coding on the scrollbar allows representation of how long ago a particular event occurred relative to the current time the user is at. The user may zoom in and out of the timeline as well to reduce or increase the amount of information they would like to see (a close up view would provide a more in-depth information of a particular event, where a further view would only provide a summary/title of an incident).



Figure 11: British History Timeline (The BBC History Website Team, 2014)

While this system organized information well and it is easy to navigate backward and forward, it is still too complex for searching for information. There is too much information provided, and may

be overwhelming for people with TBI. The lack of visual cues and graphics makes recognition difficult for people with TBI to remember a piece of memory.

4.3.5 100 Years Legacies - The lasting impact of World War 1 (Wall Street Journal)

An interactive timeline on the impact of World War 1 was published in the Wall Street Journal (Figure 12). Here events are categorized by various categories, such as culture, politics and so forth. Clicking on the icons (represented by a picture and a title) would enable the user to retrieve further information about an event. This approach is similar to the decade in books (Figure 9).



Figure 12: 100 years legacies (Source: Wall Street Journal)

The picture and text that depict each individual thumbnail enables user to quickly identify and recognize particular information. Having the ability to filter each individual elements into categories limits the amount of information that may be displayed on the current screen. This system however does not organize their data chronological. The user would not be sure of the sequencing of time in relation to the information that is provided.

4.3.6 Summary of interactive timeline:

From Section 4.3, we examine unique approaches made by other designers on the different timeline visualisation methods. A summary of these information may be referred to in Table 3.

Table 3: Summary of each Interactive Timeline

	Advantages	Disadvantages
Riots in England Design Pattern: Chronological 3D ‘road’ timeline.	<ul style="list-style-type: none"> • Easy to follow timeline. 	<ul style="list-style-type: none"> • ‘timestamp’ for events too specific.
The Decades in Books Design Pattern: Z-layout	<ul style="list-style-type: none"> • Easy to distinguish information by year. 	<ul style="list-style-type: none"> • Limitation on information displayed • Difficult to search
Wayback Machine Design Pattern: Matrix (Calendar) with bar graphs	<ul style="list-style-type: none"> • Highlights show available information 	<ul style="list-style-type: none"> • Quick summary of information is unavailable
British History Timeline Design Pattern: Dotted graph	<ul style="list-style-type: none"> • Colour coding of events by year • Quick navigation between events 	<ul style="list-style-type: none"> • Cluttered information, requires better way of sorting • Quick summary of information is unavailable
100 Years Legacies Design pattern: Organized information based on categories	Information organized by category	<ul style="list-style-type: none"> • No distinct event timeline

In Table 3, the advantages and disadvantages of each interactive timeline are described. It is however not tested and proven how a TBI patient would handle these types of interface. Using a combination of these ideas and techniques, we will prototype several models of interactive timelines, and perform a study to identify the most appropriate design for our Digital Memory Chest.

4.4 Paper prototype designs for timeline interface

Through exploration of design space, four different interface designs for the timeline visualisation were created based on the examples of timeline interfaces described in Section 4.3. It was mentioned earlier on that certain approaches may not be suitable for our data representation, but to validate our hypothesis we modelled these approaches to gain insights and feedback from participants in a focus group study, described later in the chapter.

Two main methods of visual representation of timeline were used: A matrix grid pattern (used mostly by calendars and timetables), and a Z-layout pattern accompanied by the use of categories to group up similar memories.

This section describes the two methods and their respective designs, using Scenario 4 (browsing and searching for memories) as the foundation to the prototypes walkthrough.

4.4.1 Matrix-grid pattern

A Matrix-grid pattern is a method of arranging content in a common template, with each item's visual weight should be similar. Two variations of the timeline interface (Figure 13 and Figure 14) shows two different matrix-grid interface design based on the concept used by the Wayback Machine (Section 4.3.3).

Memory entries are organised according to days, months and years. If a specific date (eg, 12 Feb, 2001) contains a memory, these would be highlighted on the calendar (Figure 13). Clicking on this icon would direct users to the Memory page, which contains a detailed information of a particular memory. For a user to navigate between years, a back and forward arrow button is location beside the timeline header, or they may use the navigational buttons on the right hand side of the interface.

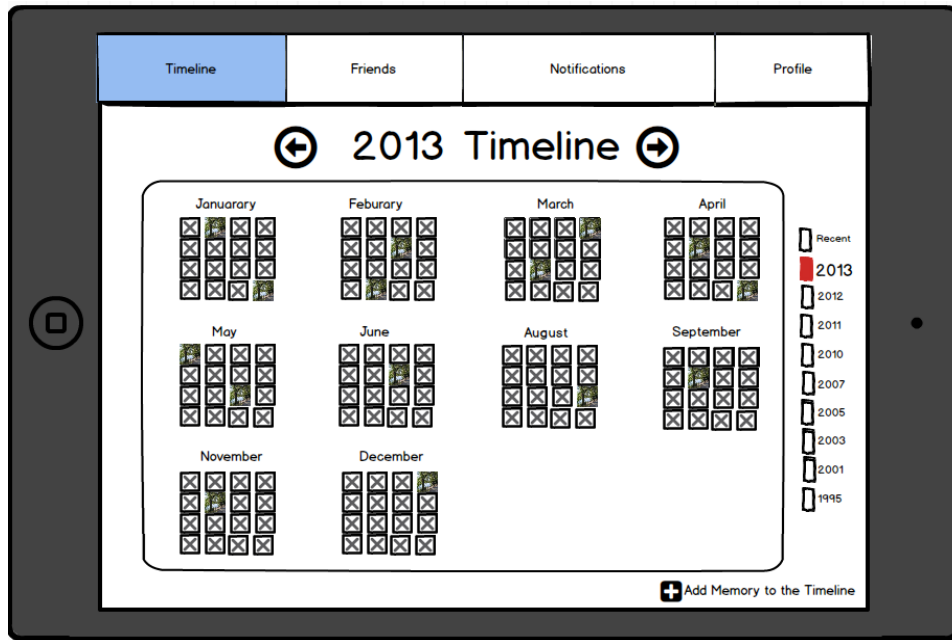


Figure 13: Matrix styled timeline (Model A)

The alternate model in Figure 14, shares similarities to Model A in how memories are organised by dates, however this time only dates that has a memory is displayed to minimize clutter and unnecessary information. Figure 14 also uses a scrollbar instead of navigational buttons to navigate between years instead.

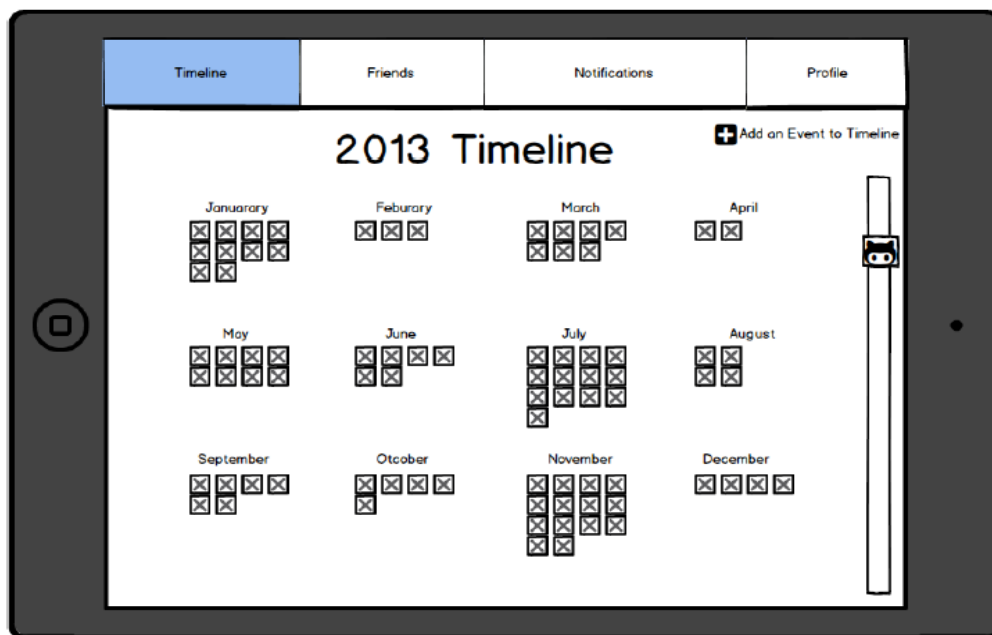


Figure 14: Minimalized Matrix style Timeline (Model B)

4.4.2 Z-pattern accompanied with grouping

The second design pattern, the Z-layout describes a general pattern the eyes move through when they looked at evenly distributed, homogenous information (ref). Examples of the use of this pattern were seen in the example discussed in Section 4.3.2.

Figure 15 and Figure 17 uses the Z-pattern layout to organised memories in a chronological method, while enabling the approach of grouping related memories according to age-groups. For example, an event that occurred during Sam’s 20th’ birthday may be found under the category of “Young Adults”.

For Figure 15, a little icon is displayed on each phase, where the user may click on it and be directed towards the timeline (year) page (Figure 16). On the page where users are redirected after clicking on a specific age group, events can be sorted according to years, and each event is associated by a title and an image of the event associated to it.

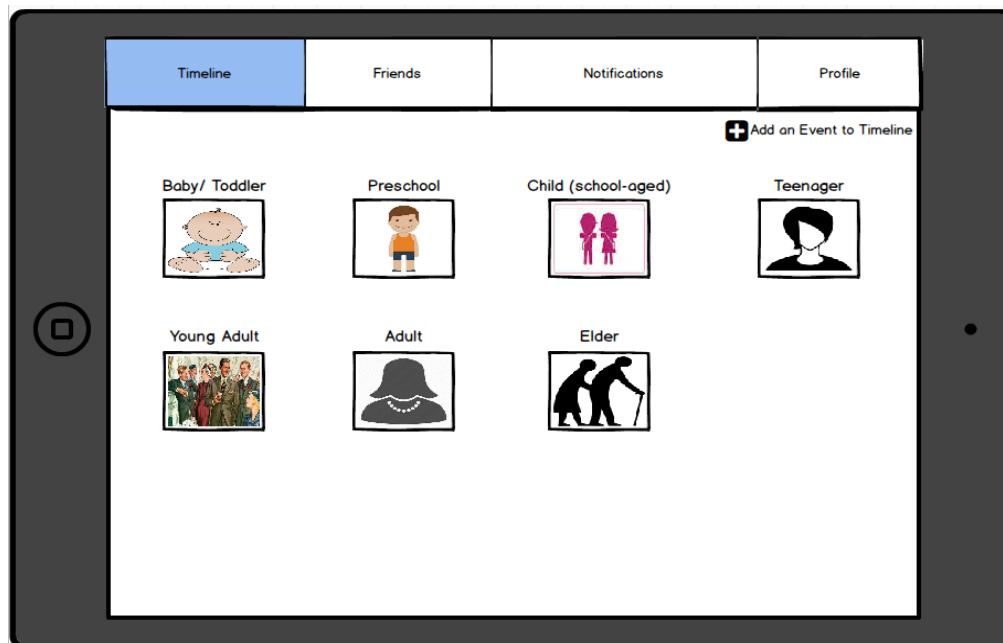


Figure 15: Organising information by Phases (Model C)

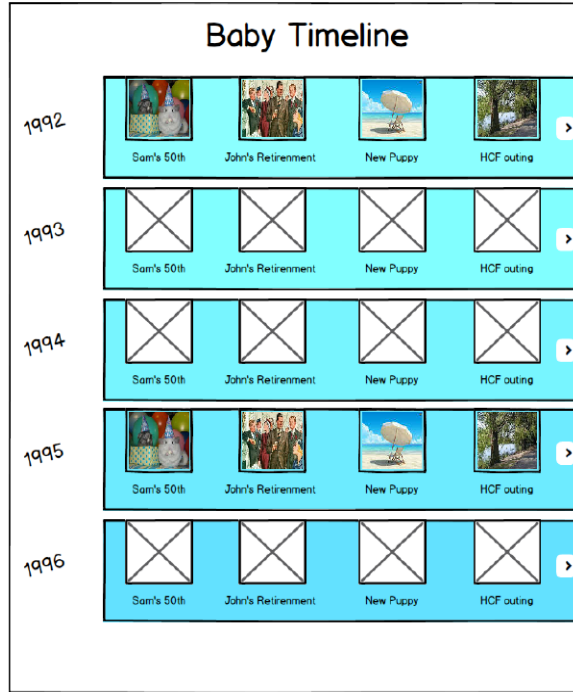


Figure 16: Under each phase each memory are then organised by years

Figure 17 displays all events in the main page according to its age group. When an event is selected, a window located on the top of the screen would displays a brief summary of the memory (such as titles, month, short summary of the selected event), together with a link to the main memory page.

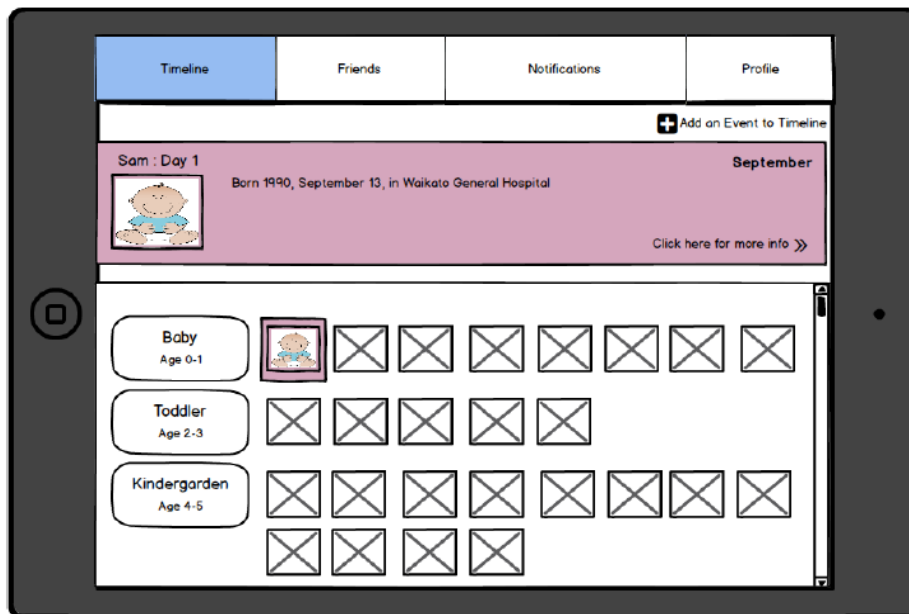


Figure 17: Expanded mock up prototype of Model D.

4.5 User feedback on prototype designs

To evaluate the concept and ideas designed in the prototypes, a small focus group study was conducted.

4.5.1 Methodology

Two participants were invited to the focus group to discuss and evaluate the usability of the different versions of the prototype presented. Participant A is a TBI patient and Participant B is a supporting family member. They were chosen to provide input on their perspective as the patient and the supporting family member.

A meeting time and location was set up after receiving approvals from the ethics committee. The meeting had three phases: 1) introduction of project and ethical consent for study, 2) familiarisation with interface prototypes, and 3) feedback and discussion.

At the beginning of the meeting, the participants were given a brief summary of the research, including the motivation and approach taken in the research project. They could ask questions about the project and the study, and were asked to sign the ethics consent paper shown in Appendix I. They were also request to provide their consent to participate in the study, as well as to be audio recorded during the discussion.

They were then introduced to the paper prototype designs of the interfaces outlined in Section 4.4 (namely Model A, B, C and D) as shown in Figure 18.

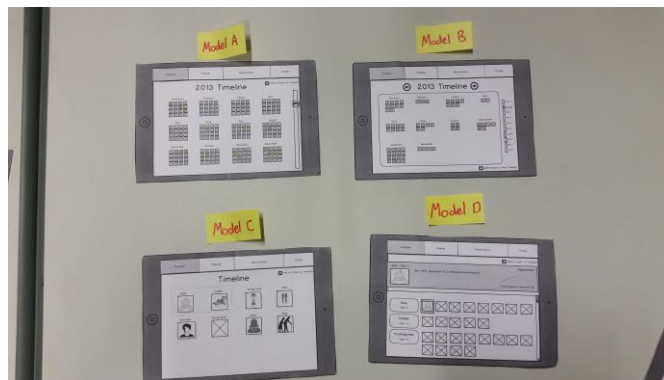


Figure 18: Example of timeline visualisation design on a paper prototype presented to the user

The two participants were given a quick overview of the different designs and interaction elements used in each version of the paper prototypes, using the scenarios introduced in Chapter 4.2. They were asked to familiarise themselves with the interaction elements and prototypes, and to ask questions about their functionality if anything remained unclear.

They were then asked to select a preferred prototype based on the following criteria:

- a) Layout of the interface – Does the system follow real-world convention, are every information contain within the layout needed / useful
- b) Presentation of data – Does information appear in a natural and logical order, how much instructions does a user needs to remember in order to perform a sequence of action
- c) Suitability to our target users – How complicated is the system designed for people with Brain Injury.

After participants preferred model was selected, a discussion was conducted to gain insights on further improvement on the chosen model. Participants were asked to share thoughts on how they imagine themselves using the system, and if there is any further suggestions on the current design itself. The participants' answers and the ensuing discussion of advantages and disadvantages of each prototype were recorded and are summarised and discussed below.

4.5.2 Results

Preference of prototype. Based on the models presented, the usage scenarios and their own scenarios, Participant X and Y had both chosen prototype Model C as their preferred model. They argued that the interface looks 'simpler' and 'easier to access, as noted by Participant A.' Participant A reasoned this by explaining how it is easier to associate a piece of memory by different phases in a lifetime. Participant A reported recalling memories by estimating how old he was when an event happened. He reported remembering them even better through association with thoughts such as "when I was a teenager", and not by the exact age, such as "when I was 15".

Participant A also explained that Model A and Model B required the ability to remember an event by a specific day and date, which he felt could be 'tedious' and 'frustrating'. This information was supported by participant B, who argued that it would be hard even for a person without TBI to

remember a specific memory by a specific date. She felt that accessing memories using the methods suggested in Model and Model B would induce “frustration” to both people with and without TBI.

Design suggestions. The participants were asked for any design suggestions on how the system may be improved. We list the suggestions by the participants below:

1. Providing flexibly on the types of memory a user may add to the system

From a quick look on the types of memories saved on examples of the paper prototype, Participant B deducted that the system aims to store only the positive memories. Participant A commented on how both positive and negative memories were equally important for the development of a person's growth, which was Participant B agreed on. Participant A stressed that negative memories would allow him to reflect on the past, and look back to see how these negative events may have changed him over the course of his illness. Participant A also pointed out that it is important to not disregard the negative memories, as this may affect a person's recovery in a long run. While both participants noted that the ability to include any types of memories a user wants in their system has its benefits, they also pointed out that people who are suffering from depression may not want to view these memories. Particularly Participant B stressed that bad memories have the potential of triggering a relapse of their illness, or make current illnesses worse.

2. Identify contributors of memories.

It was also suggested that having the ability to identify which user had contributed on a particular piece of memory would help a user to distinguish “whose memory it was”. Participant B elaborated on how different people remembers a memory differently, such as a memory of “Sam when he was a child” may be remembered differently from Sam's parents and his siblings. Hence participant B believes having an option that allows the user to know who contributed to a memory would allow the user to have a broader view of what happen in a particular event.

3. Functions supporting peer-to-peer interaction

Several suggestions were provided to support the functionality of enabling peer-to-peer interaction between a person with TBI or depression, and friends and family members that would want to support them socially. Some of the suggestions provided were:

- a. Adding a place where people may reflect on who the user was/were before (How have the accident changed you as a person over the years, how did Sam overcome his depression, who were there when Sam was coping with his condition) – Participant B
- b. Linking related memories (memories about Sam’s recuperate activities are related to his accident, Joan may have a memory in her profile that Sam was part of, and would like to share it with Sam).- Participant B
- c. Having a randomised memory pick every day, and displayed on the main screen to remind the user of memorable memories that happened. –Participant A

4. Layout suggestions

A couple of layout suggestions were given by participants A and B.

- a. Participant A suggested combining the ‘baby’ and ‘toddler’ phase together. These two phases are generally memories contributed by the user’s parents, and not a personal memory that the user may recall.
- b. Participant B suggested to allow users to customise how the timeline is organised, for example the ability to organised based on different life phases (as presented in this application) or by locations, such as “where do you live”.

5. Further Usage scenarios

At the end of the discussion, participants were asked to visualise situations where they might use the system, and provide some examples of these situations.

- a) Participant A imagined using this system both individually and collaboratively. He would like to use this system during his free time to look back at memories that he may not remember clearly, or as a point of reference where he may look at it with friends and family to recall his memories on a past event.
- b) Participant A also saw the entering of information into the system as a collaborative effort, an effort which he may be surrounded by friends and family when he enters information about a memory. This is triggered by the recollection of times in the past his family gather together, and discussed about an event that occurred in the past. In such an occasion, he may want to note down a memory for safekeeping. Hence he thinks this system would assist him

either by allowing him to quickly add a new memory entry with the aid of information shared by his family members.

- c) Participant B envisions herself using the system by contributing memories to a friend's memory chest. For example, she would like to share her POV of a particular memory they she may be part of. They pointed out that memories may be remembered differently by different people, based on their perspective and role in a particular memory. Both participant A and B agreed that having a different perspective of a memory would enrich what actually happen, and provide a wider perception of that particular piece of memory.
- d) Participant B suggested giving friends and family the ability to contribute information to an existing memory in the system. Information such as location, people part of the memory, dates and images may not necessary be available (or remembered) by the owner of the Memory Chest Application, and by giving friends and family the ability to suggest these information, this would provide them the ability to include these missing information that they may not have.
- e) Memories a person experience over their lifetime includes positive memories (happy, encouraging, feeling belong), and negative memories (accident, embarrassment, emotionally painful memories). Participant A and B think it is useful to include even the both good and bad memories as this gives a chance to accept that these bad memories did happen to give them a closure of mind to move on.

Discussion

The focus group discussion had provided useful feedback on the design aspect of the prototype, as well as insights on how someone with TBI handles memory loss, the measures taken to help them to recall memories, and the importance of social support received by the patient in his process of recovery. We also received a better perspective of how a carer, or someone in the family supports the patient to cope with their memory loss on a day to day basis.

We discussed possible design suggestions that may be included within the system. There were several ideas contributed by the participants that prove to be valuable and great ideas to be used for the system, such as adding a random memory picker for user to view a random memory each day, or linking memories between user profiles, if both user share similar memory of a specific

event. However, these ideas needed further development and background research on the concept to make it a realization.

The original intention was to create a memory chest which includes ‘memorable’ memories, which by definition, selected memories that promotes positivity and good memory in which the user may look back and reflect on. The inclusion of negative memory into the Memory Chest as suggested by the participant highlights the importance of these memories, however people with severe mental disorder may not handle the negativity of a bad memory as well as someone with mild mental disorder. There is a need for further background study on categories of people with such disorder is needed to understand the best approach in handling such memories.

We decided to use the design preferred by the participant, and used that model as a basic structure of the system. We also modified parts of the prototype to include ideas suggested by the participant, including: 1) Adding names of the contributors to a memory, 2) Adding a label to a memory to identify a positive or negative memory, 3) Adding a location to suggest/share information about a memory, 4) Combining baby and toddler phase together. We finalized our paper prototype design, as shown in Section 4.6.

4.6 Final paper prototype design

From the discussion in the focus group study, the paper prototype design for the timeline representation of data was adjusted to suit with suggestions made by the participants, as well as the expected outcomes we intended on achieving from this. Other sections of the paper prototype, including functions such as managing memories (adding, editing, removing), and navigational structure were not widely discussed, as it is then necessary to be implement and test to access its usability on an Android device by users.

This section outlines the final paper prototype design, with adjustments made in accordance to the suggestions provided by the participants, as well as other functions within the system which was modelled and designed.

Interface layer

Description

Main Page (Timeline – phase)

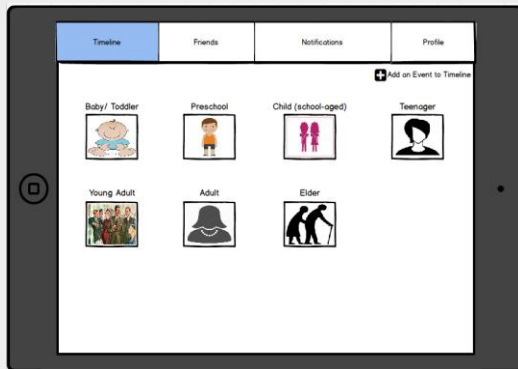


Figure 19: Main page interface

Also known as the Timeline(phase) page
Shows groups of phases that the user may select
Baby/toddler combined as suggested by participants.

Timeline - year

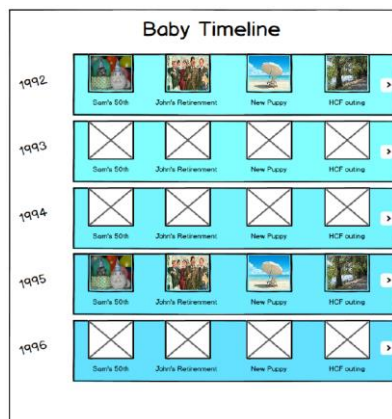


Figure 20: Timeline (year) Interface

Timeline (year) organises memories by year,
based on the phase chosen. Under each year
'rows' contain memories happened in that year.

Under each memory contains a title, and an
image related to that year.

Create a new Memory entry page

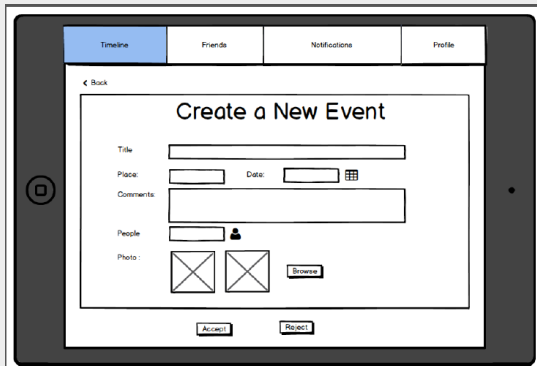


Figure 21: Adding a new Memory interface

Information that may be added into a memory entry consist of:

Title, Location, Time, Description,

People(present), photos

Suggestions added:

User may choose to add this memory as a good or bad memory

Friend List Layer

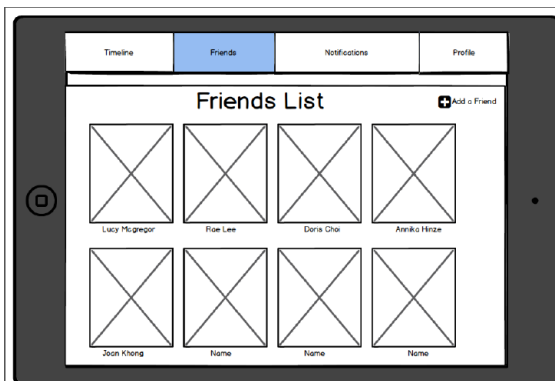


Figure 22: Friend List Interface

A layer which allows the user to invite friends and family member into the system as contributors.

Notifications

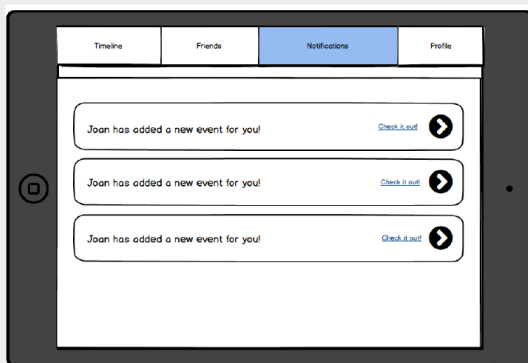


Figure 23: Notification interface

When a secondary user contributed a memory entry into the main user's profile, the main user would receive a notification that someone has contributed a memory.

User Profile

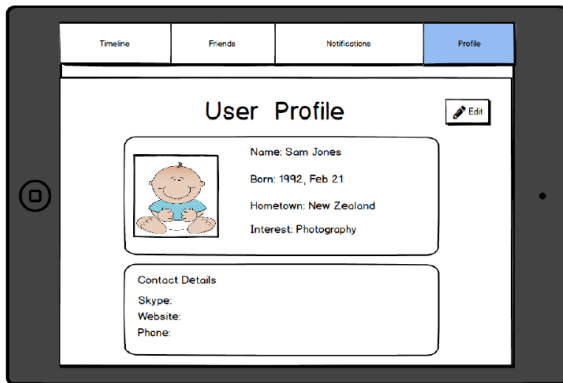


Figure 24: User profile Interface

A general biography page for the user. This may be used by peers/ people in their contact list to identify the profile they are browsing.

A prototype design flowchart is created as shown below:

1	Timeline(Phase)	5	Notification
2	Timeline(Year)	6	User Profile
3	Memory Page	7	Friends List
4	Create a Memory	8	Friend's Main Timeline Page

Flowchart diagram of the Digital Memory Chest Interface

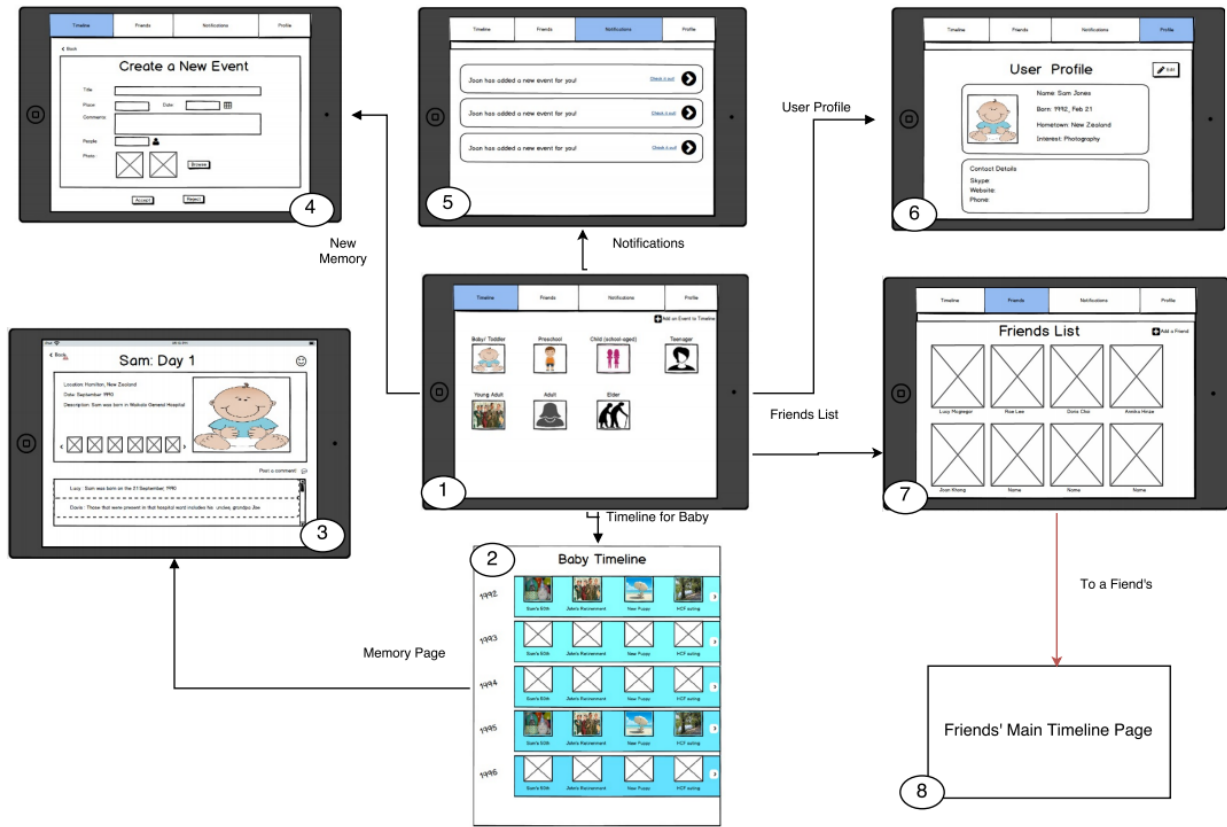


Figure 25: Flowchart of the Digital Memory Chest

From the flowchart, *Timeline(Phase)* may be visualised as the user’s ‘Main’ interface screen. Sam (the persona) may look at his *Memory Page*, *Create a New Event*, view *Notifications* or his *User Profile*, or search up contacts in his *Friend List*. If the system is used by another user (eg. Joan) who wants to look into her friends Timeline, they may do so by selecting a friends profile in *Friend List*. The system will navigate Joan into Sam’s *Timeline(phase)*, when that is selected.

4.7 Summary

In Chapter 3, related software and system designed for people with TBI and Depression were explored. The strength and shortcomings of these systems were identified and examined. Using the requirement analysis build at the end of chapter 3, we formulated a solution to address these shortcomings. The system was named the “Digital Memory Chest”.

The “Digital Memory Chest”, will be a system designed to help a person suffering from TBI to store and retrieve memories, and allowing friends and family to support them. To achieve this, a requirement analysis was determined in Chapter 3 to decide what functionality is needed to build, supported by several personas (Section 4.1) and scenarios (Section 4.2) of how a user may interact with the system.

Using the information obtain from related work systems made for people with TBI and Depression (Section 3.1 and Section 3.2 respectively), examples of visual representative of timeline (Section 4.3), and requirement needed to build the Digital Memory Chest, several models of a mock-up paper-prototype of the system were designed. These prototype were presented to a focus group of participants, where they were asked to examine and provide feedback on which model was most suitable for our main users. The feedback and suggestions were used to improve on the prototype designs, which will be used to implement a digital prototype.

Chapter 5: Design implementations

In the previous chapter, feedback was sought from participants in the focus group. Using these feedbacks we created a design, which was modified based on some of the suggestions by the participants. We implemented several functions, primary focusing on how to view, browse, and manipulate memory entries (such as creating or editing) as well as exploring peer-to-peer support features by implementing an ‘adding comments’ function.

This chapter reports on technical tools (Section 5.1) used during the implementation of the application, summarising the database architecture structure (Section 5.2), a summary of the navigational flowchart of the implemented android application (Section 5.3), comparing design differences between the paper prototype and digital prototype (Section 5.4), introducing describing interface layouts and functions (Section 5.3) and demonstrating a scenario walkthrough of the prototype (Section 5.4).

5.1 Technical declaration

The application prototype uses Android Studio as its development platform, with its SDK version set to be 4.1. The application itself was built using a combination of XML, Java, and SQLite database, of which XML is used to design and structure the front-end layout. Java was the main language of programming, and SQLite is used as the database system to build the database and back-end function. The prototype was also built on a 7-inch Android tablet for testing.

5.2 Database architecture

To achieve the following function, a database structure was created to define the architecture of the system. The architecture consists of the following main tables: Memory, Phases, and Comments. In each Phase there may be more than one Memory within phase, but not more than one memory in multiple phases. Similarly each comment are unique to individual Memory and may not be retrieved from a different memory. The following diagram illustrates the architecture flow of the system.

Phases contain a 'start year' and 'end year' to determine which phase category a new memory should be organised in.

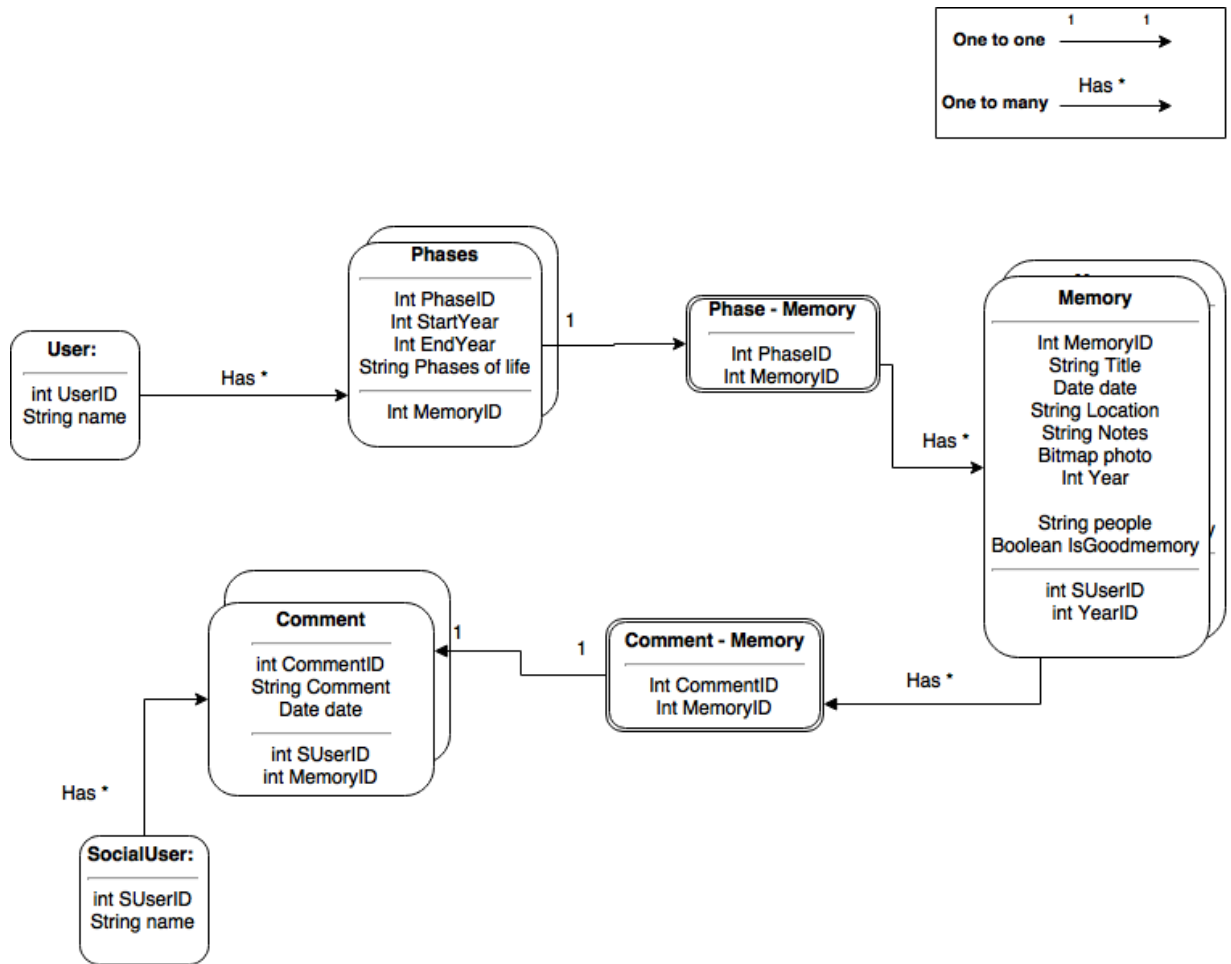


Figure 26: Entity Relationship diagram of the system

For this research, data entries are stored locally within the system. Information such as media and text added to the system are stored and retrieved locally within the android application itself. This means all interaction has to be done within the same tablet. The user may pick their role (secondary user/primary user) by choosing the 'swap' option. The system checks to see which user is currently active, and swap between interface layers.

```

let main user equals 1;
let secondary user equals 0;
if swap is true then
    set secondary user to 1;
    set main user to 0;
    get timeline to display as secondary user's view;
end if

else
    get timeline to display as primary user's view

```

Secondary users in the current system do not own a personal profile, they may add a comment to a memory, in which the comments stores the secondary user's ID. This approach was done purely to counter the absence of a server stored database system, and to enable a small scale testing to see how the primary and secondary role user may affect one another.

5.3 Navigational flowchart

The Digital Memory Chest consists of 5 main functions: Add a memory, update existing memory, add comments to a memory, and browse memory entries. These functionalities were used to investigate how the system support a person with TBI and / or Depression with their memory and mental (social) support.

A flowchart of the interface navigational map is created as shown in Figure 27. Blue arrow indicate the direction in which the main user may navigate around the system, while red arrow indicate the secondary user accessibility in the main user's profile. Rectangle represent interface layers, and circle represented secondary interface (eg pop-up windows).

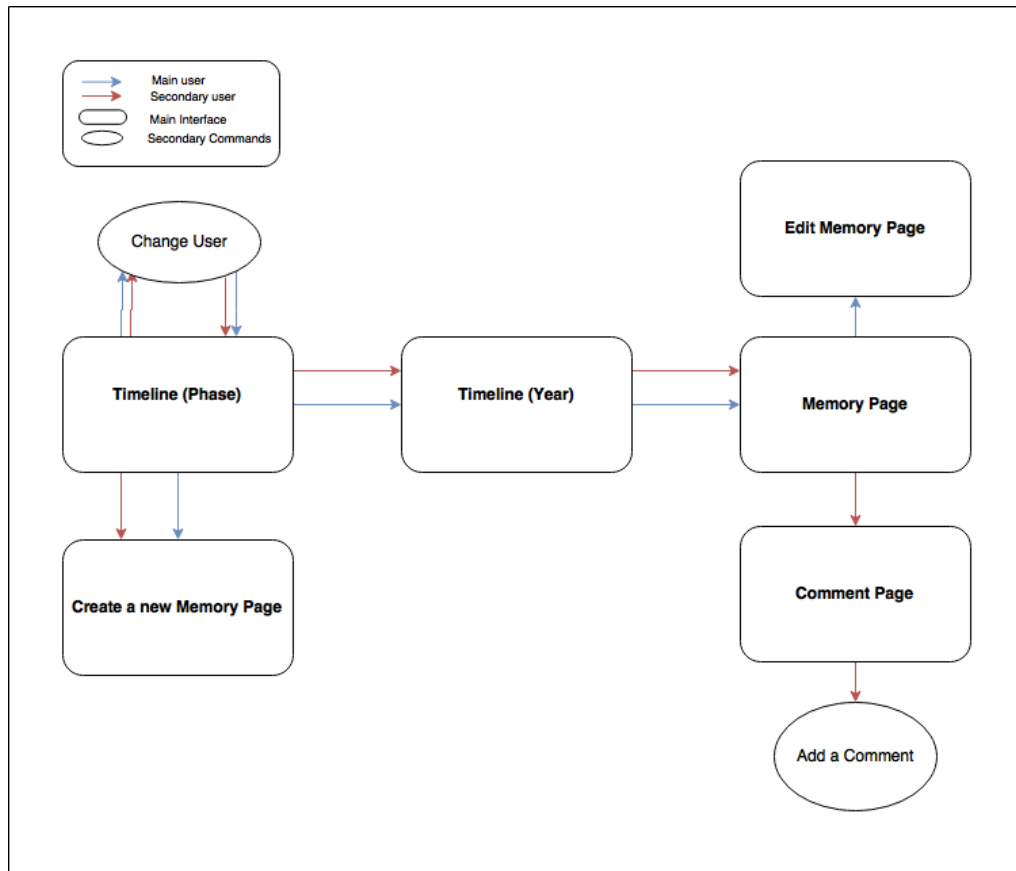


Figure 27: Flowchart displaying navigational structure of the Digital Memory Chest

5.4 Paper prototype vs digital prototype

While the majority of the prototype implemented is designed to look similar to the paper prototype, slight modifications were made during the digital prototype implementation to suit the goals of the research. We have chosen to implement only the main features of the prototype, which consist of the memory management system and the social interaction section, in order to test the effectiveness on the user study. Additionally, some interface adjustments were made to suit the design standards of Android, as well as the API that was available for us. The major changes include:

Separating Comment from Memory Page: In the final paper prototype model described on Section 4.6, memory entries and comments by the secondary users are displayed on the Memory Page.

This design was changed for digital prototype implementation to separate ‘memory entry’ to ‘comment page’ as there are too much information displayed on the same page, which makes the layout looked cluttered and unorganised.

Table 4: Comparing changes made in Figure 28(old) model vs Figure 29& Figure 30.

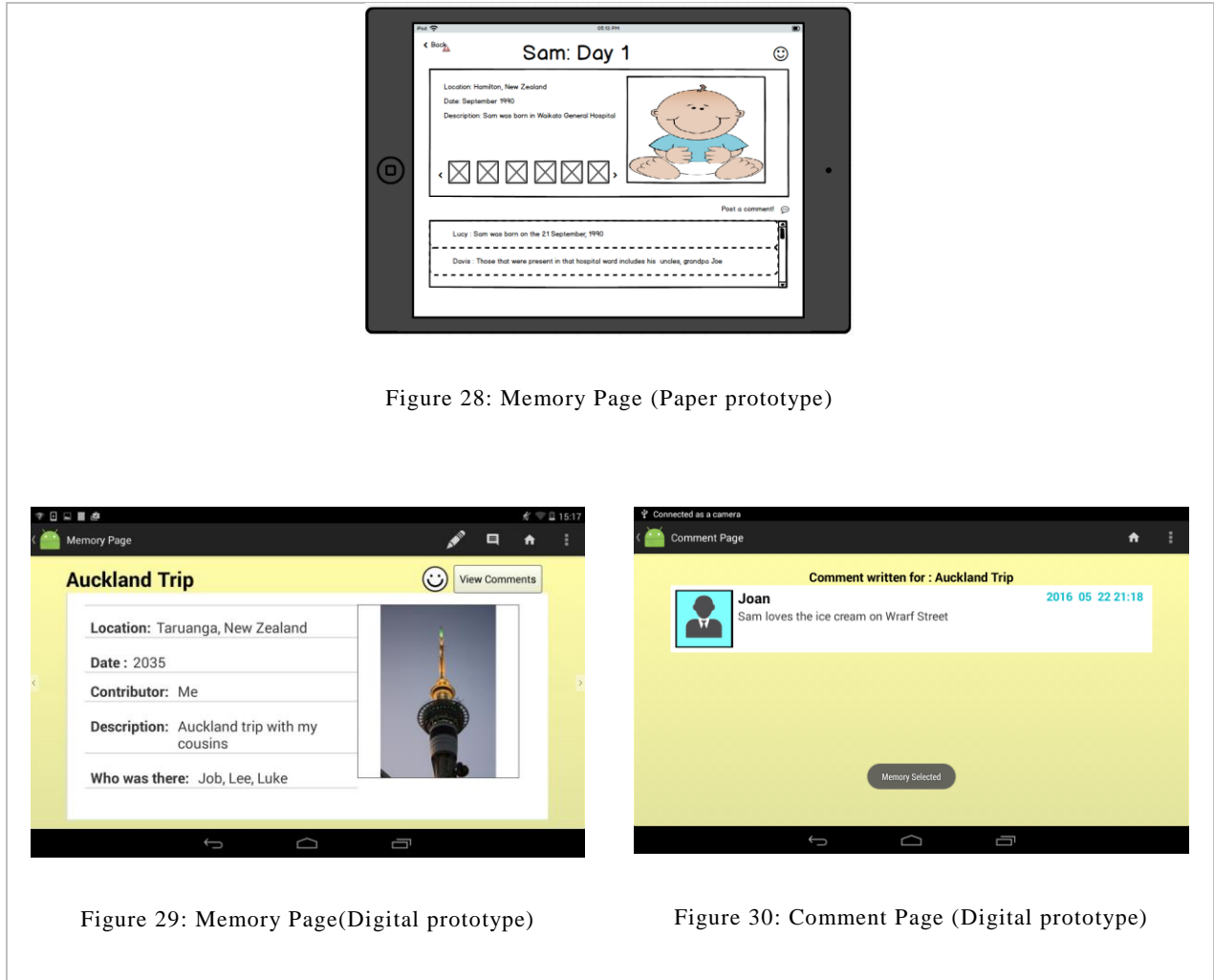


Figure 28: Memory Page (Paper prototype)

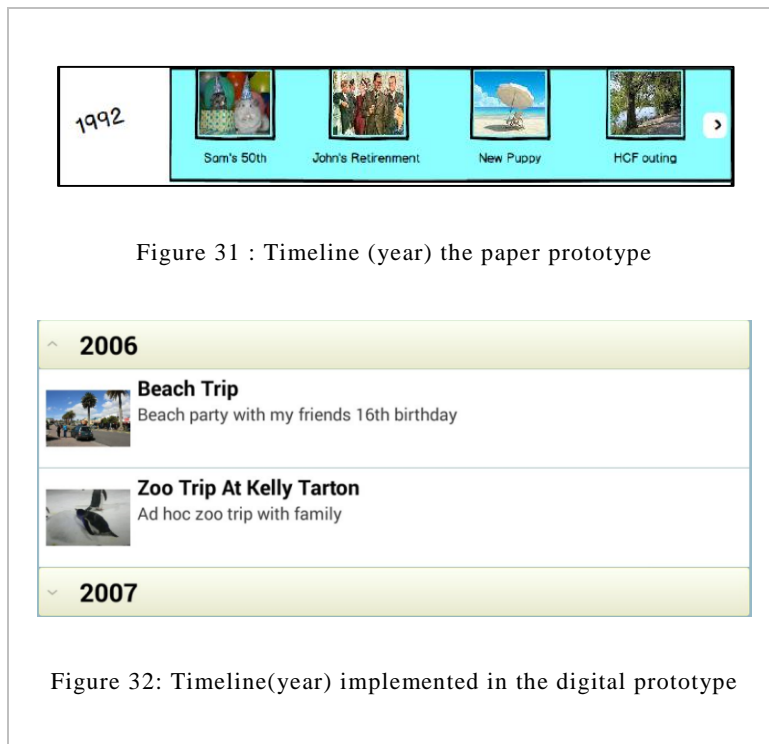
Figure 29: Memory Page(Digital prototype)

Figure 30: Comment Page (Digital prototype)

Using a Drop down menu for Timeline (phase): In the original Timeline (phase) interface, memories in each individual year are displayed in a single row. Any additional memories in that specific row may be viewable by clicking on the arrow button, located on the right hand side of the row.

During the digital prototype implementation, this approach was less practical than what it was drafted in the paper prototype. If the Digital Memory Chest contains a large volume of memory to be added in that specific year, looking through that system would be tedious and difficult. In addition to that, certain memories may contain similar activities, such as a camping trip in Te Puke in 2007, and another camping trip in the same location in 2008. It would be difficult for the user to identify what happened between the two camps with just a title.

Table 5: Comparing changes between Figure 31 (old) vs Figure 32(new) in Timeline (year)

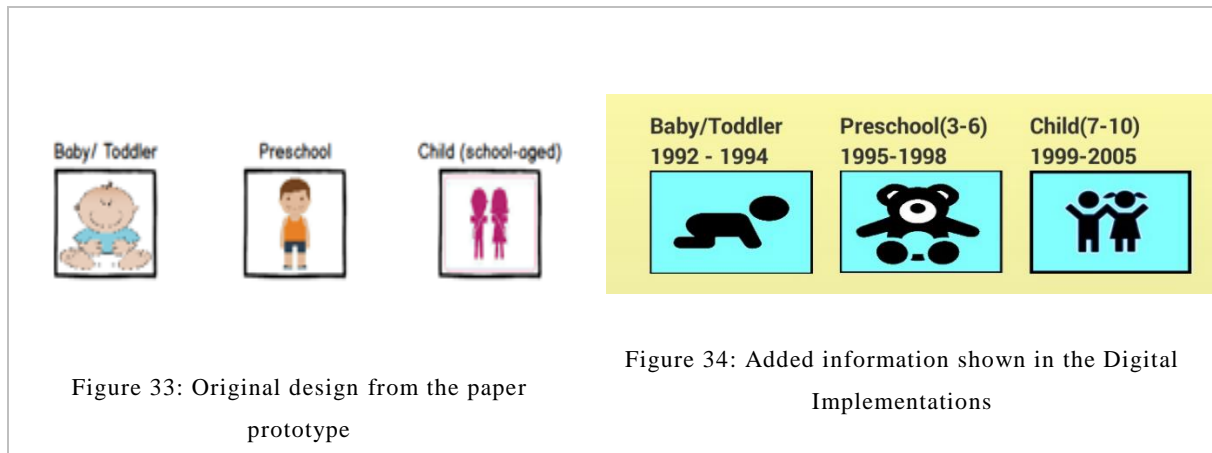


To counter this issue, a drop down menu was used instead to display memories. When a user clicks on a year, the drop down menu expands and displays memories that are stored in the year selected. Each memory contains an image, a title, and a short blurb of the memory.

Adding additional information into Timeline(year): Timeline(year) as described in Section 4.6, groups memories by ‘phase’. A user may identify different phases by its ‘title’ and an image associated to that phase. In the Digital prototype implementations, additional entity ‘year’ and ‘age’ was added on to the interface layer. This is to reduce the ambiguity of the phases timeline, and to

address questions such as ‘what year range would the lifetime phase teenage be?’ or ‘Where would I find a memory when I was 21 years old’.

Table 6: Comparing changes between Figure 33(old) vs Figure 34(new) for timeline (phase)



Restrictions to how ‘time’ in memory is used. In the focus group study, it was discovered that the recollection of ‘time’ in a particular memory for individuals are unique. Some people remembers a memory by the recollection of time based on sequential events that happen before or after (‘this happen before we took our finals’, ‘we went on a trip after brother’s graduation.’), and others may have vivid memory of how old they were when a memory happened (‘I was a young adult when...’). Hence there is a variable method of approach one could organise their memory in the timeline.

In this project, memories are sorted either by year, or by the phase that exist within their lifetime. This approach was chosen to evaluate how effective is it for the user to add memories to their Digital Memory Chest, as well as how would it affect their abilities to look for a memory on a later date. Participants in the user study found this approach relatively easy to operate around, but suggested more freedom to decide how they may enter several time formats entry into their system.

5.5 Interface layout

As outlined in Section 4.1, The Digital Memory Chest may be used by two different types of user;

- *Sam, the main user who may have memory impairment or requires social support*
- *Joan, the secondary user who aims to use this system as a means of supporting Sam.*

As the main user, Sam has full access to his profile, which allows him to *add a memory* to his timeline, *update a memory*, and *retrieved information* about his memory. On the other hand, Joan as a secondary user who aims to use this system as a means of supporting Sam may use this system to *browse a memory* in Sam's timeline, *add a memory* for Sam, providing suggestions to missing information in Sam's memory, and reflecting on Sam's life by *adding comments* to his memory.

This section outline each individual interface, its purpose to the system, and how Sam and Joan may interact with the interface.

Create a new memory

According to Chang (2009), human recollect memories primarily on five factors: Location, activities, people, emotion and time. These factors were used in the Digital Memory Chest as 'attributes' kept in a memory entry to help a person to recall a memory.

In the Create a new Memory interface, a user may enter attributes such as *title, location, date, people, description, contributors, memory type (good or bad memory)* in the Digital Memory Chest. The user may be upload their memory as a 'bad' or 'good' memory, depending on which selection is chosen at the 'upload' section.

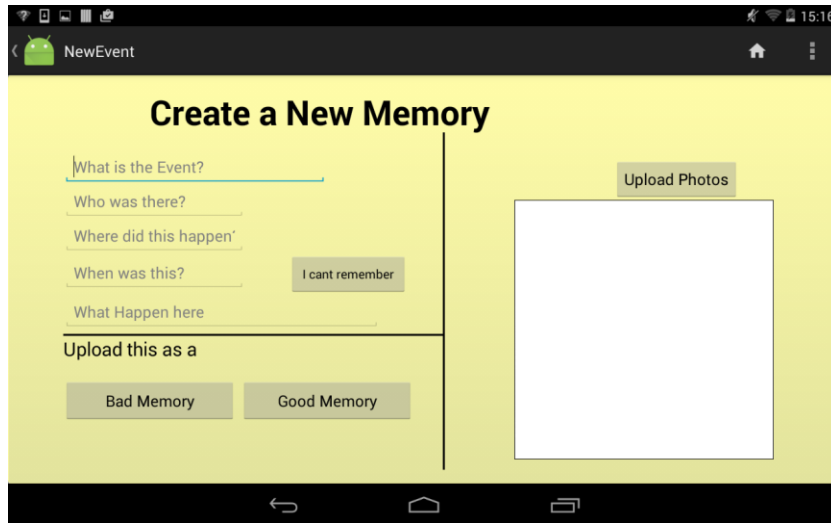


Figure 35: Create a new memory User Interface

Handling missing information on 'time': In Section 4.3.3, we acknowledged that time is relative for people with TBI, and it is difficult for them to recall memories based on date (Chang, 2014). To counter this issue, an additional 'I can't remember' button is added. If the user forgets, or could not remember the date a memory occurred, they may use that button to categorise that memory based which phase did the memory happened (Figure 36). 'year' attribute would remain empty until the user modified the uploaded memory.

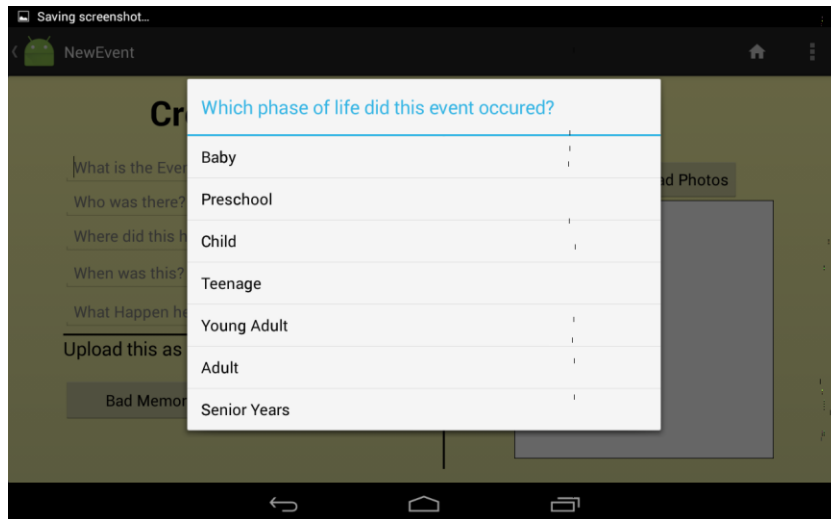


Figure 36: Pop up dialog that allows user to add a phase instead of adding a year

When the memory is submitted by the user, the system would first check to see if a date was provided. If there is no date given for a memory, the system would check which phase did the user

set this memory to be. Using the information provided, these memories are added to the table of phase respectively. Below is an example of a pseudo code written shows how the system handles this.

```
if int_year is not NULL
  for list of phase available;
    if int_year is within the correct phrase (start_year,end_year);
      add memory to phase;
      break;
    end if
  end for
end if
else
  user's phase_choice = phase;
  loop through phase list for (phase);
    add memory to phase;
  end else
```

This function may be used by both Main and Secondary users. The contributor attribute will change according to who has uploaded a memory. For instance, if Sam is the one adding the memory, the contributor attribute would state “me” as the contributor; likewise the attribute would be state Joan as the contributor if she was the one who added this memory. These differences can be seen in the Memory Page.

Edit a memory

Memory entries available with the system may be incorrect, contain missing information, or a user would like to make slight adjustment to what is displayed. Hence an option to update an existing memory is provided to resolve this issue. For the Digital Memory Chest, fields that are updatable are: *title*, *people*, *locations*, *year*, *photo*, and *people*.

Fields that are not editable are: *contributor* (the original person who upload this entry) and its *memory type* (bad / good memory). Only the primary user may make changes to their own memories

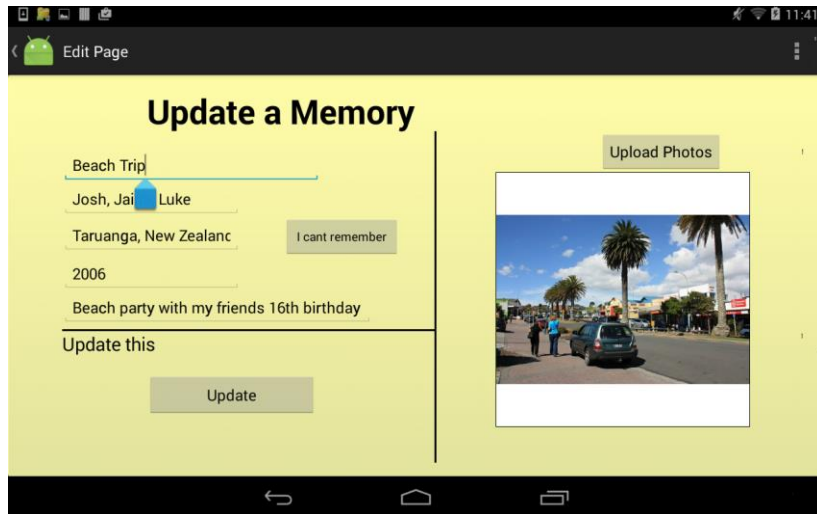


Figure 37: Update a Memory phase

Comments page

The ‘Comment page’ is the interface layer where secondary users may add a short message related to a specific memory. Messages may include; an encouragement message related to a specific memory, additional information about a memory from a different perspective, or a place for the main user to reflect on the comments contributed by their social circle.

Adding a comment may be done by clicking on the “add a comment” button, which would bring up a comment dialog for the user to input some text.

Timeline (phase) and Timeline (year)

The Digital Memory aims to provide a solution that helps TBI patients to recall a piece of memory that they may have forgotten , or as a way to promote positivity to people who may be suffering from depression, by means of reflecting, remembering, and looking back at good memories. The timeline (phase) and Timeline (year) interface is designed to support this

Timeline(phase) displays a list of ‘phases’ that a user may experience in their lifetime. Phases are identified by title, year, age, and icon images. A user may choose to view memories based on the phase they choose. For example, if Sam is looking for a memory that happened in his teen years, he may click on the teenage icon to look for a piece of memory. Memories in Timeline (phase) are identifiable by the title, its image, and a short description of the memory.



Figure 38: Timeline(phase) interface

Timeline (year) is the interface after Timeline(phase), once the user has selected a phase to view. In this layer, memories are sorted by years. For instance, a trip to Auckland in 2001 would be kept in the 2001 section of the list.

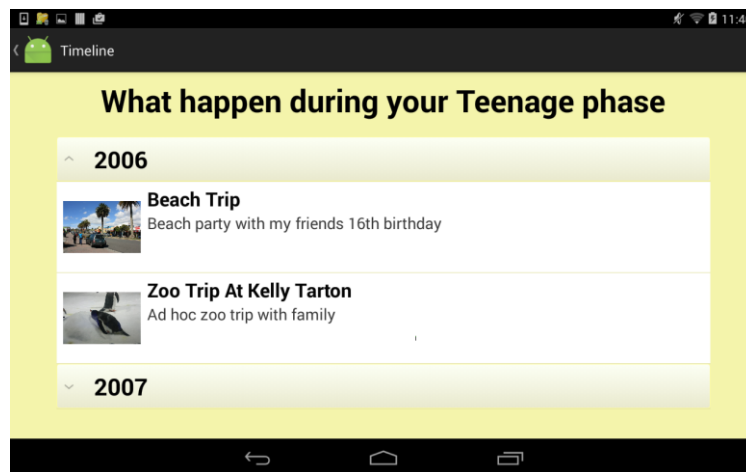


Figure 39: Timeline (year) interface

If a particular memory does not have a year provided within the memory entries, this would be labelled as “uncategorised”, as shown in.

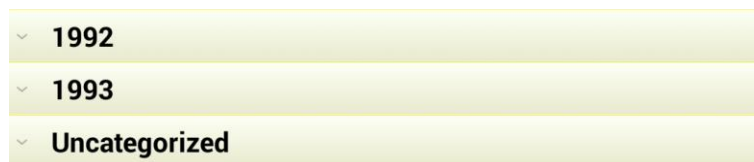


Figure 40: memories that do not have a year are kept in the "uncategorised" section

Memory Page

The Memory Page shows a full description of a piece of memory added by users. Information's that is viewable by the user includes; Title of the memory, Location this memory occurred, Who was there, Description of the memory, when (what year) this memory occurred, and who added this memory into the system. Both the main user and secondary user have access to this layer, however only the owner of this memory (Main user) has permission to modify, delete or make changes to this memory.

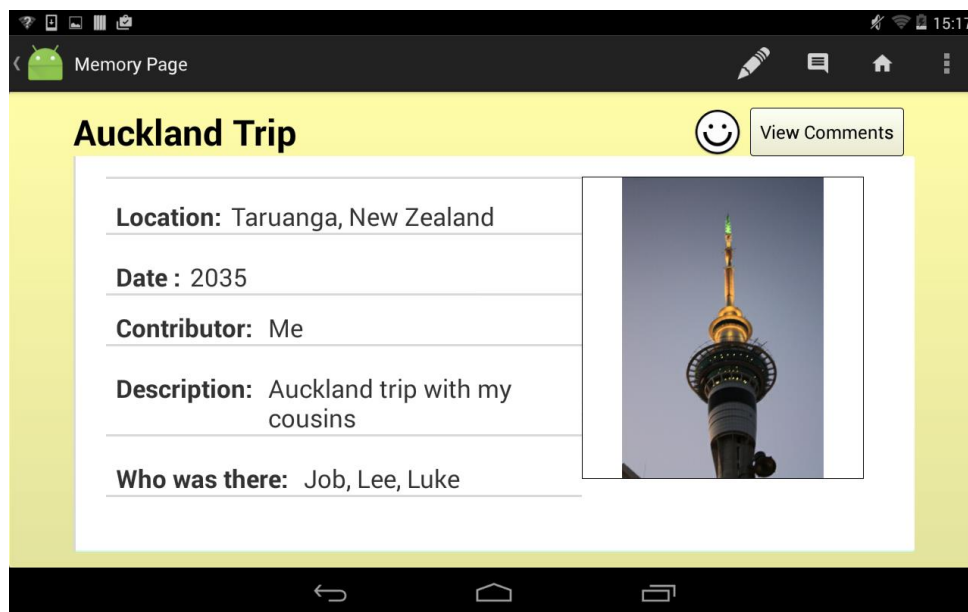


Figure 41: Memory Page user interface

Summary

The interface layers set up were designed to support the four main functionality of the Digital Memory Chest. The four main functions (create, edit a memory, add a comment and browsing memories) contain specific users permissions, depending on what role the user is currently operating the system as. The following table outlines the user permissions based on the role they are currently using the system as.

Table 7: Summary of user permissions

	Main user	Secondary user
Create a memory	yes	yes
Edit a memory	yes	no
Browse a memory	yes	yes
Add a comment to a memory	No (view only)	yes

5.6 Scenario walkthrough

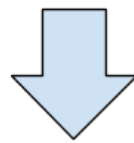
The following cases present walkthrough of the Digital Memory Chest, based on the scenarios created in Section 4.2.

5.6.1 Case 1: Entering a new entry (adding a new memory)

Using Scenario 1 from Section 4.2:

“Sam would like to add a new memory entry into his timeline”

To add a memory, Sam would first be on the ‘Main Page’. A button that states “Add an event to Timeline” is available for Sam. Clicking that button would direct him to a new screen layer titled ‘New Event’. In here, Sam may enter any relevant information regarding that memory entry.



Selecting "Add an Event to Timeline" option

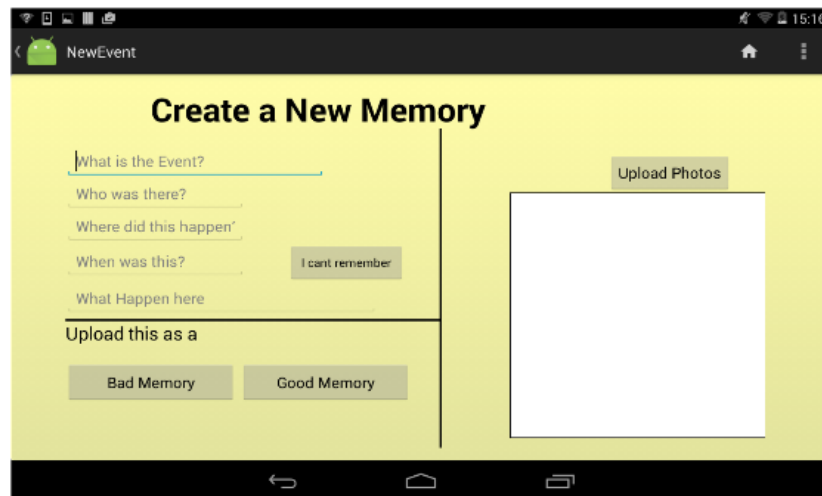


Figure 42: Scenario walkthrough for "add a new Memory"

If Sam could not remember specifically what date or year a piece of memory occurred, he may choose to categorise his memory by phase instead. For example, the event that occurred when he was a young adult (mid-twenties), he may leave the date option empty and categorised it as “young adult”.

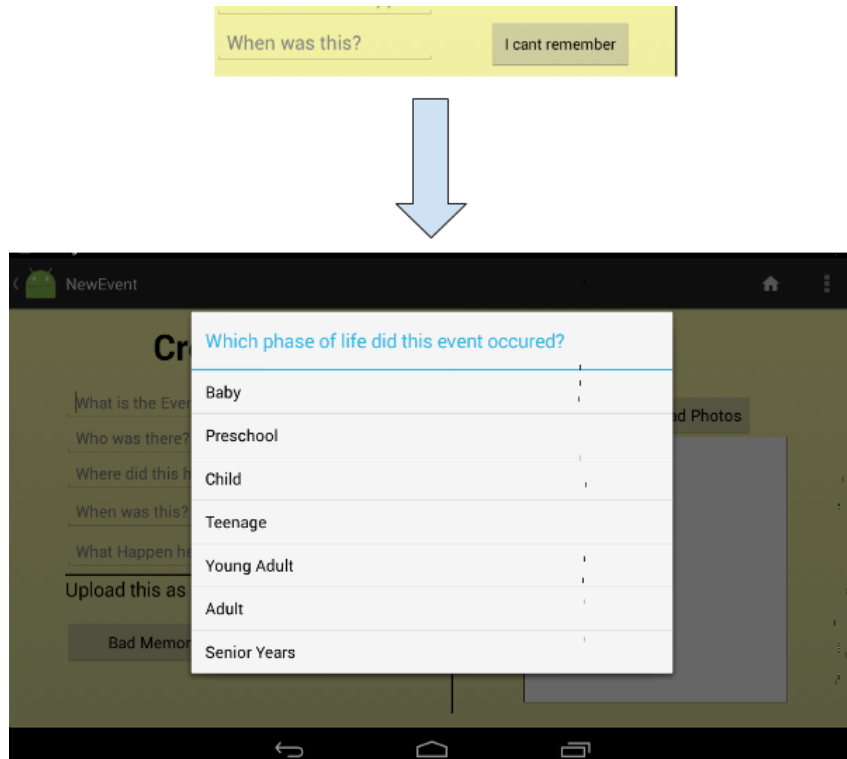


Figure 43: An expanded drop down window appears when user clicks on the "I can't remember" button

Once Sam is satisfied with the information he added, Sam may upload this memory as a “good memory” or a “bad memory”.

5.6.2 Case 2: Updating an existing entry

For example, if Sam has a memory entry about his college graduation, but this entry does not have a date provided in this entry, he may wish to add a date to this entry later on when this piece of information is available.

Given the scenario (using examples from page 23):

“Sam updates his memory entries based on new information mentioned by his friends.”

Assuming Sam found the memory he was looking for (refer to Section 4.2 for browse/search walkthrough), and is currently on the ‘Memory Page’ interface, Sam would click on a pencil icon, demonstrated in Figure 44. Sam would be sent to the ‘Edit memory Page’, where he is able to make the necessary changes needed to update his memory chest.

To do this, Sam would need to search for a particular memory, as demonstrated in Case 1. From the Memory Page, Sam would have to enable edits (this is represented by a pencil icon). This would allow Sam to “update” his memory in the “Edit a Memory” page. Clicking on the “update” button would append new changes into the current Memory.

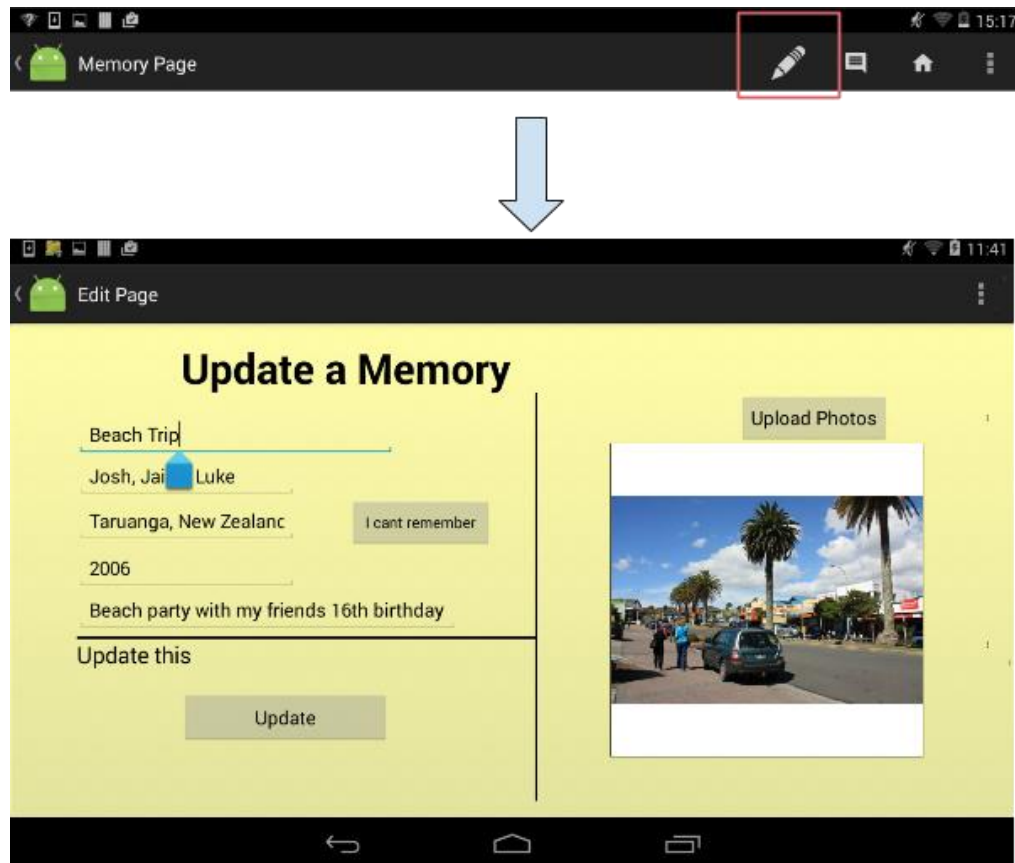


Figure 44: Clicking on the edit icon to edit a memory

5.6.3 Case 3: Creating comments / Writing suggestions on memories

The previous scenarios and interface walkthroughs have mostly described examples of situations of which the Digital Memory Chest handles memory storage and retrieval. This scenario walkthrough would describe how the system manages social support contributed by the secondary users.

For example:

“Joan would like to talk about an interesting fact about Sam’s Graduation”

In this scenario, Joan is currently looking at Sam’s memory on his Graduation ceremony in the ‘Memory Page’ layer. Joan may add a comment by first clicking on the “view comment” option in

Sam's memory page. From there she may "add a comment" into the system by clicking on the button.

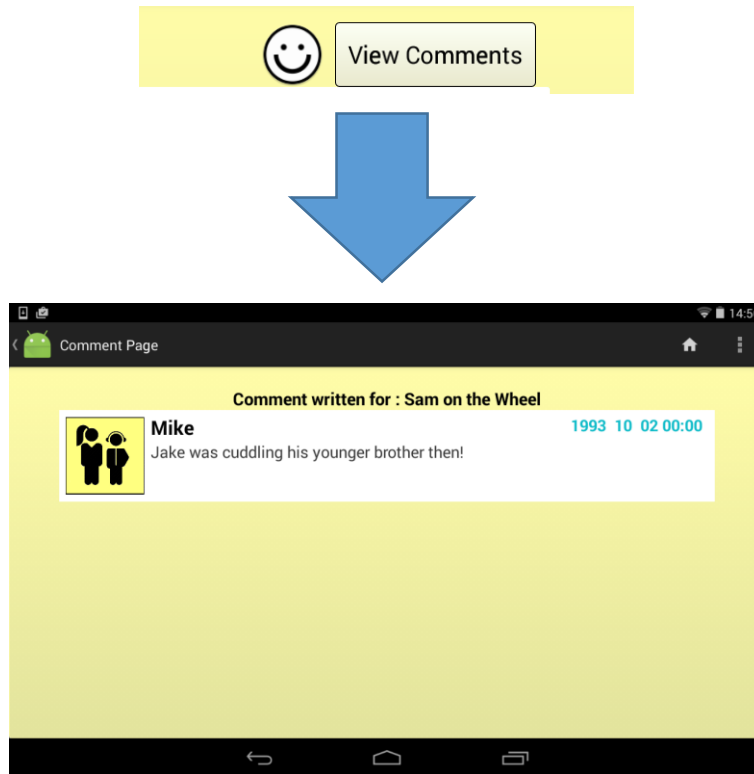


Figure 45: "View Comments" in *Memory Page* leads the user to the *Comment Page*

5.6.4 Case 4: Browsing and searching for a memory

Consider the scenario written in Section 4.2:

“Sam is browsing memories that happen when he was a teenager”



Figure 46: Clicking on 'child' icon allows sam to browse memories related to 'child'

To look for memories that happen when he was a teenager, Sam will have to click on the icon that says “teenager”. This will direct Sam into to the Timeline (year) interface layer. This layer shows all memories that happen in the ‘child’ phase, organised by its years.

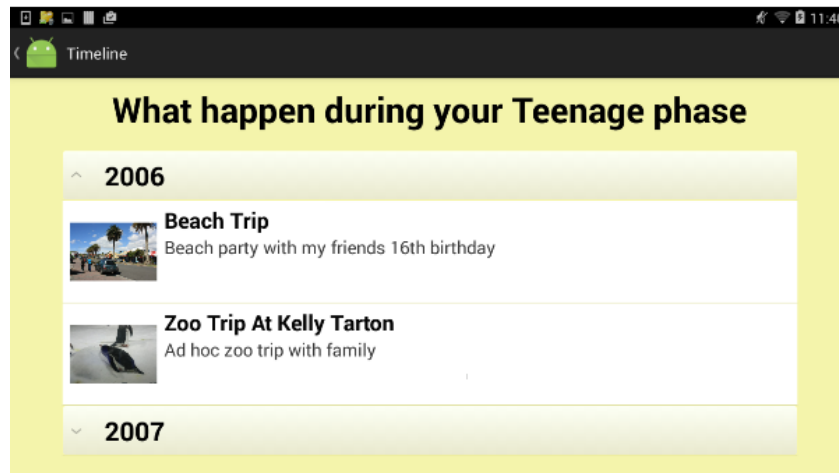
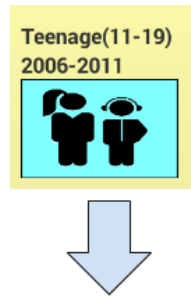


Figure 47: Navigation to the Timeline (year) after picking a phase

To view a memory, Sam may click on the memory available in the drop down list. If Sam clicks on the memory “Beach Trip”, the system would lead Sam to the Memory Page with information regarding “Beach Trip”.

Chapter 6: User evaluation and results

To evaluate the usability of the digital prototype that was described in Chapter 5, we conducted a user test with participants of the focus group.

This chapter reports on the structure of the evaluation (Section 6.1) conducted in the usability study, and the outcome of the study from the feedback received (Section 6.2). Feedback received from the study includes: details on the results from the evaluation (Section 6.2.1), general suggestions that arise during the discussion (Section 6.2.2), and the comparison of results obtained through the focus group and usability study (Section 6.2.3).

6.1 Structure of the evaluation

The two former participants (Participant A – with TBI, and Participant B – the supportive family member) from the focus group were invited to test the usability of the digital prototype. The user study was divided into three sections: 1) introduction of the study materials 2) user testing for the duration of three weeks, 3) follow up interview on evaluation outcomes.

The first meeting introduced the purpose of this study. They were also provided a participant information sheet (Appendix II) for further clarity of the user study and their role as a participant. Participants were also requested to sign a consent form, stating they agreed to participate in this user study and to have their opinion recorded on a follow up interview.

After receiving their consent to participate in the study, participants were presented with the digital prototype model, with explanation of its capabilities. They were given a brief walkthrough of the different interface screens of the digital prototype, without providing too much assistance on how to actually navigate to them. In addition, participants were given a manual (Appendix IV) designed to be used only if participants encountered difficulty in operating the system, the scenarios introduced in Chapter 4, as well as a set of questionnaire (Appendix III) created to rate the usability of functions used to completed the tasks mentioned in the scenarios.

Participants were given three weeks to test out the system, in which they were encourage to use the system whenever they found a situation prompt them into using them. During the duration of the study, participant may contact the researcher if there are any queries. They were asked to fill up some task-specific questionnaire that focuses on examining the usability of functions available.

After the completion of the three weeks user testing, participants and researcher meet up once again to share their experience and discuss any complications and issues they faced. Any research materials and task specific questionnaires participants were asked to filled up were returned to the researcher, where answers were review and to discuss their choice.

6.2 Participant feedback

An overall positive feedback was given to the usability of the system. Participants had minimal trouble completing the task given (see Appendix III for task questions). Overall feedback indicates that the application is useful in storing and preserving important memories, browsing for memories and simple to learn.

6.2.1 Findings in evaluation

From the study, participants were encourage to test the prototype during their spare time, or whenever they thought it is an appropriate time to use it. We found out by using this approach, the participants' did not actively engaged with the system. Upon enquires why the system was not actively used, the participant did not feel the need to enter a large amount of memory entries, as they would have to return the system after the study. On the occasions that the participant was using the system, they used the system in a collaborative effort; they sat together and added some memory entries into the system together. They choose to do it this way as they were unfamiliar with the system, and were working together to figure out how to use the application. Participant B commented that the minimalist design approach of the system makes it not difficult to enter a memory entry when the user is travelling, or sitting in a location while waiting for someone.

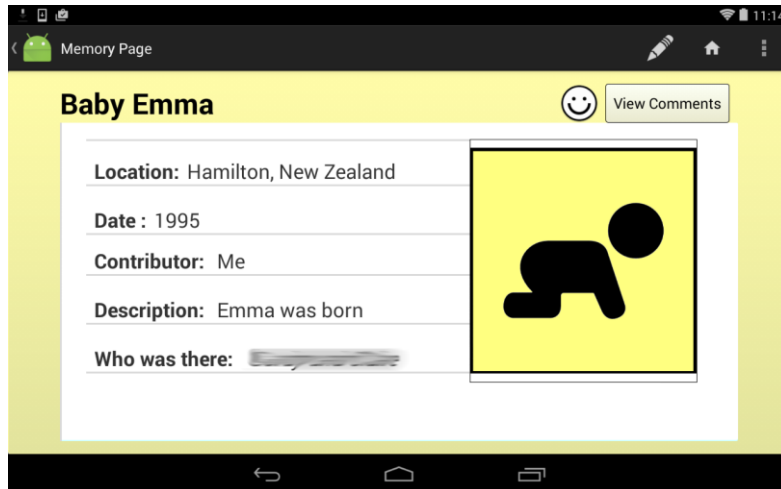


Figure 48: Example of a memory entry submitted by the participant (name blurred out for anonymity)

During the duration of the study, several tasks were specifically given to the participants to evaluate. In these tasks, participant identified several minor usability issues. These issues are described below;

1) Adding a memory

Participant A and B found entering data entries into a new memory not difficult. However, the time entry (“when did this happen”) was not explicitly clear to the user on what to do, and the participants struggled to work around this. For instance, they were unsure if time takes in the format in months (mm), months and year (mm/yy), or day, months and year (dd/mm/yy) together.

Suggestions: Suggestions were given to allow user the freedom to decide what to enter into the time entry in a memory. It was suggested that user may use a drop down ‘calendar’ picker to decide “when” a memory occur. Ideally this would mean the user may decide how detail they choose to enter the memory timeframe

2) Adding a Comment

Participant B found it difficult to add a comment into Participant A’s memory. The “add a comment’ button was not where she expected it to be in the interface. Participant B expects to find the button on the interface layer (Memory page layer) before the Comment Page layer.

Suggestion: Participant B suggested adding the option to add a comment both on the Comment Page and the Memory Page. This way she may add a comment to the main user's memory immediately, rather than visiting the comment page.

3) Icon to edit a memory

Participant A commented that to them the “edit” icon image on the Memory Page felt more an icon used to modify the system's setting, rather than an actual function within the system. The positioning of that icon gave participant an initial hesitant to click on the icon as he was unsure of its function.

Suggestion: Instead of placing the “edit” icon on the activity bar of the system, Participant A suggest having the edit icon located below the activity bar. Participant B also admit this may be a personal preference as they are both more accustomed to using iPhone applications instead of android application.

6.2.2 General suggestions

Other than the suggestions provided regarding the usability of the system, participants were asked if there were any other changes they would like to see on the system. These suggestions were discussed and documented as described below;

Customising information displayed on the Main Page. The information that is displayed on the Timeline (phase) interface layer consists of: phase name, age of the user in that phase, the year range of a particular phase, and an image related to that phase. The current system does not allow customisation of this information. Suggestions were made by Participant B to enable the user to customise and manipulate how this information's are display on the Timeline (phase) interface. She argued that the user should be able to modify text describing the phase's name, year range, as well as allowing the user to choose what images they may use to represent a phase.

Adding additional tags to memories for searching / sorting. Current memories are sorted by phases, participant A would like to be able to view his memories by tags. For instance, Sam may want to look back at memories related to “holiday”. To achieved this, the user should be allow to

provide different (and multiple) tags to an individual memory to enable searching and sorting of memories.

Flexibility with sorting memories by 'Dragging and dropping'. Participant B suggested that users should be able to organise memories by “dragging and dropping”. She argued that certain memories may be related to one another, or that the user might find out a certain memory occurred before the preceding memory. Enabling the ‘drag and drop’ capacity would improve the flexibility and efficiency for users who would want to organise these memories quickly.

Increasing the different methods of social interaction between users. It was also noted that both participants rated the level of “perceived social support” the system allows a user was average. Participant B suggested that the secondary user should be given a wider range of approaches that allows them to support the main user socially. Sending pictures, voice / audio recordings or sharing a memory from their own profile were examples of such social support mentioned by participant B.

Addressing privacy concerns and sensitive issues. It was noted as well participants do not find any cultural sensitive issues that may be a cause of concern. With the current implementation, there is minimal social interaction between users. With the suggestions of adding several different methods of social interaction, we discussed issues related to the privacy of the main user’s profile. This includes who may see memory entries found within the system, how we handle the friend /contact list, and permissions to submit / post an entry within the system. Participant B suggested that since this is used as a personal 'journal' the user should be given full administrative rights in handling their private contacts and permissions, such as: the ability to invite (or remove) a contact and control what his or her contact may contribute, this includes who may share a memory or comment on a memory. She suggested that external contact (i.e. secondary user) should only have access to any private information by ‘invitation’, and the main user have the option to remove a contact from his profile should they have any reason to do so.

6.2.3 Comparison between focus group discussion and usability study

Over the course of this research, a focus study and a usability user study were conducted. From the focus study, we managed to obtain the following information:

- a) Gaining understanding of how TBI patients cope with their memory loss, and approaches they use to overcome their situation.
- b) Participant's preferred model of the paper prototype design chosen, their perception and ideas on how to improve on the paper prototype model created.
- c) Further exploratory ideas on how this system may help people suffering from TBI or depression to cope with their illness.
- d) Identifying different types of memories which may affect a person emotionally, and ethical concerns regarding handling the various type of memories (eg, positive or negative memories).

Data collected from the user study was primarily directed towards the actual implementation of the system. This includes:

- a) Identifying usability issues regarding the use of the actual system.
- b) Evaluating the impact ('usefulness') of each function in relation to the goals we aim to achieve for this research.
- c) Further suggestions and improvements that may enhance the usability of the system
- d) Discussing further social support capabilities, as well as approaches with handling user's private information, to protect a user's cultural background and upbringing.

From the focus group study and the usability study, customisations have been strongly emphasised by the participant. They argued that having alternative approaches to performing a sequence of actions (such as date time format for a memory, different approaches to memory sorting) would allow a user to customise the system to suit to their circumstances and needs. This option was not developed on the digital prototype implementation as it requires further development of the software architecture of the system, as well as an extensive background research in design patterns used on an Android system. We used suggestions provided by the participant that are closer to the design

concepts created to produce a prototype that focused more toward providing a simple system that addresses the problem founding this research, rather than providing multiple options to solve a single problem.

The outcome of both studies provides an opportunity for future work, where further exploratory ideas may be researched and developed based on the findings we found in the focus group, at the same time building on an improved version of the current digital prototype model, based on the suggestions and issues found in the usability study.

6.2.4 Summary

The findings of this study have given us insights on the usability of the system, and we identified potential usability issues that may hinder the users' experience. We found that participants did not actively use the system, but we found the system was simple and quick to use, which may not be too intrusive to use in public areas. Overall we received a positive response from the participants, who support the idea of the implementation of the Digital Memory Chest.

Chapter 7: Conclusion

This chapter would describe a detailed summary of the research (Section 7.1) and potential future work (Section 7.2) for researchers to work on.

7.1 Summary of the research

In Chapter 1, it was noted that a one-to-one health care basis can be costly in both time and money, and hospitals do not always have the resources to care for these people. Chronic illness patients require a large amount of social support from families and carers to cope with their conditions. Motivated by the role of the whanau (family) practiced by the Maori's, the research aimed to design an approach which implemented a culturally sensitive, user-centred application focused on providing social support and memory aid for people with TBI and depression. Chapter 2 outlined the relationship of Traumatic Brain Injuries (TBI) or depression, as well as identified issues both illnesses have with regards to the long-term care and the lives of people that are affected.

Various software designs and traditional methods geared towards caring for people with brain injuries (with memory problems) or TBI were examined in Chapter 3. We found the software and methods were not designed to provide a solution that supports both issues. Hence we formulated a unique approach for this to allow a user to store their memories; at the same time friends and relatives are able to provide social support remotely through the system. We named the system the 'Digital Memory Chest'.

The development process was divided into two phases: designing a paper prototype (Chapter 4) and creating a digital prototype (Chapter 5). In the paper prototype process we utilised a combination of ideas presented by the academic papers summarised in Chapter 3, and an interactive timeline interface made by others in order to provide a solution to the problem.

Several versions of the paper prototype models were created (Chapter 4, Section 4.4) using a combination of ideas that manage memories digitally, social support methods, and timeline

visualisation techniques. These models were introduced to a small participant focus group study (Section 4.5). In the focus study, we identified the most suitable model to be used for the digital prototype, according to how suitable the interface was designed for our targeted users. Additionally, the focus study discussed further design suggestions for the chosen model, and different usage scenarios that may be included into the system.

Using the paper prototype preferred by participants in the focus group discussion and usability suggestions, modifications were made on the prototype, which was then implemented into a Digital prototype (Chapter 5). The application was built using a combination of tools, which included XML for the front-end interface, Java as the main language for programming, and SQLite used as the main database structure.

A qualitative user study was conducted (Chapter 6) to evaluate the usability of the application and how well it addressed the stated problems. From that, we found that the system is good for storing memories, as well as retrieving it. Participants found minimal issues that hindered them from performing the actions available to them. Positive feedback was given on the simplicity of the system functions, which allowed the user to perform the designed actions easily. Navigation of the system was reported to be mostly clear, as participants found it relatively easy to navigate to their desired locations. We can deduct that the system designed is suitable to be used to achieve the aim of this research.

The evaluation of the user study shows that we have successfully concluded that the system is suitable for people with TBI, with its minimalistic design approach and clear navigation structure, while maintaining acceptable standards of social support capabilities. Further research work may be done in the future, which are outlined in Section 7.1.

7.2 Future work

Based on the user study and findings reported in our results, we discovered the potential of future work and research that may be done to this project. Among some of the features that were not implemented as noted in Section 4.5.2, several ideas and concepts require further development and background research in order to validate their feasibility to the system. Some of the future work ideas are described below:

Customisation: This idea had been repeatedly emphasised by the participants during the focus study, as well as the user study. There are several ideas of customisation that the participants suggested, and we believe these ideas provide additional user control and freedom to the system. Suggestions includes:

I. Enabling variable approaches to sorting / organising memory structure.

Examples includes grouping memories by places a user stays, grouping by special tags ('birthdays', 'parties', 'reunions', 'camps'), or enhancing the user interface to allow quicker/easier way of sorting memories by 'drag and drop'.

II. Enabling filtering of memories.

Sorting memories based on users preference. This may involve hiding bad memories stored within the system, or enabling user to view only a certain category of memories.

III. Allowing user to customise naming of groups.

The user may add, remove, rename a group, as well as include various attribute / tags to the group description to enable easier sorting / organising.

Visual interaction and cue: The current system is limited to the basic interaction design to perform a task in a specific order. The system does not take a huge conscious in providing shortcuts to speed up certain interactions. For instance, editing the date of a memory may be performed by dragging and dropping it into appropriate groups, instead of manually changing the date in the "edit" button, found in individual memory. Suggestions for improvement include:

I. Adding accelerators , such as a 'drag and drop' features to group images quicker,

II. Providing clearer visual cues, such as a more noticeable notifications when an task is performed (adding/ removing /editing memories), or when the user made a mistake when he or she is performing a task (error messages).

III. Using drop down menus that allows a user to add a new tag(s) to the system.

IV. Notify a user when a contact or friend has contributed a memory or added a new comment to the system.

User's privacy control permission: This has been discussed in the user study, as stated in section 6.2.2. The user should be allowed to decide:

I. Who they want to invite into the system.

- II. What permission these invited members are allowed to do. (eg. who can edit, comment, or view only).
- III. How we handle memories that the main user does not wish to include into their memory chest (approve/disapprove a memory).
- IV. Blocking / removing a contact should the need require.

Further background research on cultural sensitivity and appropriate approaches on how to deal with a user's privacy is needed to validate these proposed ideas.

Database structure and quantitative user study. The current database structure allows the user to perform core actions needed to perform tasks that were designed to be executed on the Digital Memory Chest. These actions are however limited to perform within a single android device. To allow proper testing on its effectiveness with peer-to-peer interaction, it is required that this database structure is built on a server based system. This allows each user to have their own personal profile, and may view another individual's profile by retrieving information from the server. With that in mind, a quantitative user study should be perform to evaluate the effectiveness of the system in terms of its social interaction abilities, as well as how this will support the main user.

Social interaction and support: We discussed with participants on different approaches that allows a user to interact and support a user, and some of the ideas proposed include sharing: pictures, audio recording, video recording, and linking memories by (tagging friends), sharing, or posting messages to friend's profiles.

These are the recommendations and proposed future work that may be apply to future research and researcher who seek to pursued further studies on this topic.

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Appendix

7.3 Appendix I

Participant Information Sheet and Consent Form on Focus Group Study

Participant Information Sheet



Ethics Committee, Faculty of Computing and Mathematical Sciences

Project Title

Exploring a Mobile Platform for Community Social Support

Purpose

This research is conducted as partial requirement for *Emily Khong's Master's research project*. 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?

The aim of this research is to design and implement a software that promotes community and social support for families where a person suffers from long-term illness, such as Traumatic Brain Injury (TBI) and depression.

Our goal is to design, implement and evaluate a mobile software system that allows friend and family of people with TBI build a community contributing to memories of the person with TBI. The system would allow family members and friends to provide support and aid people with TBI, as well as the person with TBI to store and access records of their own and other people's memories relating to them. The goal is to help people with remembering past memories and helping them with integrating with the community.

What will you have to do and how long will it take?

You will be asked provide feedback to a mockup prototype application made for an android device. You may be ask to provide your preferred model choice and provide a reason for that choice. There may be a discussion between you and the researcher to identify the pros and cons of the mockup paper-prototype presented. Audio recordings may be use to record your responses. The user study may no longer than an hour for completion.

What will happen to the information collected?

The information collected will be used by the researcher to write a Masters 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, and audio recordings and the paper written. The audio recordings and all related data will be stored in the FCMS data archive for 5 years. Afterwards, notes, documents will be destroyed and audio recordings 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 will carry only a number. No participants will be named in the publications and every effort will be made to disguise 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:

Emily Khong

G2.06, Department of Computer Science,

The University of Waikato

Email: ebk4@students.waikato.ac.nz

Supervisors:

Dr Annika Hinze

*G2.26, Department of Computer
Science, The University of Waikato*

Email: hinze@cs.waikato.ac.nz

Research Consent Form



Ethics Committee, School of Computing and Mathematical Sciences

Exploring a Mobile Platform for Community Social Support

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**.

Signed: _____

Name: _____

Date: _____

- I agree / do not agree (please circle one) to my responses to be audio tape recorded.

Signed: _____

Name: _____

Date: _____

Researcher's Name and contact information:

*Emily Khong
G2.06, Department of Computer Science,
The University of Waikato
Email: ebk4@students.waikato.ac.nz*

Supervisor's Name and contact information:

*Dr Annika Hinze
G2.26, Department of Computer Science,
The University of Waikato
Phone: (07) 8384052
Email: hinze@cs.waikato.ac.nz*

7.4 Appendix II

Participant Information Sheet and Consent Form on Usability Study

Participant Information Sheet



Ethics Committee, Faculty of Computing and Mathematical Sciences

Project Title

Exploring a Mobile Platform for Community Social Support

Purpose

This research is conducted as partial requirement for *Emily Khong's Master's research project*. 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?

The aim of this research is to design and implement a software that promotes community and social support for families where a person suffers from long-term illness, such as Traumatic Brain Injury (TBI) and depression.

Our goal is to design, implement and evaluate a mobile software system that allows friend and family of people with TBI build a community contributing to memories of the person with TBI. The system would allow family members and friends to provide support and aid people with TBI, as well as the person with TBI to store and access records of their own and other people's memories relating to them. The goal is to help people with remembering past memories and helping them with integrating with the community.

What will you have to do and how long will it take?

You will be asked to test and provide feedback to a mobile prototype application made on an android device, provided by the University of Waikato. You will be provided with a task form and questionnaire to complete during the duration of the time of the user study. The user study may take up to 2 weeks for completion, however if the circumstances requires you may be given a longer period of time to complete this.

What will happen to the information collected?

The information collected will be used by the researcher to write a Masters 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, and audio recordings and the paper written. The audio recordings and all related data will be stored in the FCMS data archive for 5 years. Afterwards, notes, participants responds on questionnaire will be destroyed and audio recordings erased. The researcher will keep transcriptions of the recordings and a copy of the paper but will treat them with the strictest confidentiality. The participants responses on questionnaire will carry only a number. No participants will be named in the publications and every effort will be made to disguise 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:

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G2.06, Department of Computer Science,

The University of Waikato

Email: ebk4@students.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

Research Consent Form



Ethics Committee, School of Computing and Mathematical Sciences

Exploring a Mobile Platform for Community Social Support

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**.

Signed: _____

Name: _____

Date: _____

- I agree / do not agree (please circle one) to my responses to be audio tape recorded.

Signed: _____

Name: _____

Date: _____

Researcher's Name and contact information:

Emily Khong
G2.06, Department of Computer Science,
The University of Waikato
Email: ebk4@students.waikato.ac.nz

Supervisor's Name and contact information:

Dr Annika Hinze
G2.26, Department of Computer Science,
The University of Waikato
Phone: (07) 8384052
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7.5 Appendix III

Task Form for Usability Study

Task Form

Digital Memory Chest

The Digital Memory Chest is a mobile application with the purpose of promoting community and social support for families where a person suffers from long-term illness, such as Traumatic Brain Injury (TBI) and depression. For this study, you will be given examples of scenarios and personas of potential users. You will be asked to perform tasks related to that scenario. Please feel free to ask questions and give feedbacks.

Date:

ID:

Age:

Gender:

The following Scenarios are created to illustrate the two different personas that may be using this system; Sam who is suffering from TBI and have problem recalling some memories, and Joan who is a relative who wants to help (support) Sam with his inability to remember.

Scenario 1: Adding memories to the System (by Sam)

Sam has found a couple of pictures of himself dated back in his teens. One of them is a trip with his graduating class when he was 17. Sam would like to add these memories into his digital memory chest. Sam does not recall what year this took place, but he was sure this occurred at the end of the year, just before the school holidays (October -November). His cousin Joan was with him, and this was an overseas trip to Fiji.

Scenario 3: Adding memories to the System (for a friend)

Joan holds some pictures and videos of her sister's birthday party where both Sam and Joan's family were present. Joan would like to share this memory with Sam, who could not remember it very well. Joan entered her login details before gaining access to her own account, where she search for Sam under her friends list. Joan created a new event for Sam in his timeline, where she entered details related to that event, along with the pictures and videos she has on her computer.

Scenario 4: Looking / browsing for memories

Sam and Joan were talking about a trip to the zoo they went to as kids with their families. Sam and Joan could not remember the year they went to the zoo, but knew that Sam was around 10 years old, and it was a trip with their family in Australia. Using this information, they have decided to look up on pictures and videos related to this event through the Sam's timeline in the Digital memory chest app.

Scenario 5: Approving an Event / Revise or edit an event

Joan added some information of Sam's 21th birthday party into his Digital Memory Chest. Sam would like to review the information before approving it. Upon checking the details included, Sam found a spelling mistake in the event . Sam would like to make these changes before approving this event.

TASK 1

Using Scenario 1 as a guide, please **Add a memory** into your Digital Memory Chest.

Rate the level of difficulty you feel to complete this task.



TASK 2

You used the Add a Memory feature to add a piece of memory into your timeline. You were having a conversation with your family about something that happen in the past and you vaguely remember adding this memory into your Digital Memory Chest. Assuming that memory was a memory you have added in **Task 1**, search for this piece of memory from your Timeline.

How difficult was it to look up for this memory?



If applicable, provide a reason for your respond.

Task 3

Based on the information you obtain at the end of **Task 2**, how useful are the information kept in Memory Page with your own memory coping strategies?



Any suggestions about **Memory Page**?

TASK 4

Using the information you have added in Task 1, can you make modification to its details (For example, change the title of a memory)

How difficult was it to perform this task?



If you are not using this system as a support group, please skip to Feedbacks.

TASK 5

As Joan the user, you are browsing memory entries found on Sam's Timeline. You found one of Sam's memory under the "Child" phase, titled "Zoo with the Family". You remembered visiting the zoo with Sam when you were a child, and you remembered Sam made a friend with the Monkeys during one of the meet and greet sessions. You would like to include this information into Sam's Memory Chest.

How difficult was it to achieve Task 3?



TASK 6

As a user who is using this system to support someone with TBI, please add a memory into your friend's Memory Chest.

Rate the level of difficulty you feel to complete this task.



FEEDBACKS

1. How convenient would you think the Digital Memory Chest would be in your daily life?



2. Can you identify any potential cultural issues with this

Briefly provide a reason for this respond.

7.6 Appendix IV

User Manual for Usability Study

User Manual

Digital Memory Chest

The Digital Memory Chest is a mobile application with the purpose of promoting community and social support for families where a person suffers from long-term illness, such as Traumatic Brain Injury (TBI) and depression. For this study, you will be given examples of scenarios and personas of potential users. You will be asked to perform tasks related to that scenario. Please feel free to ask questions and give feedbacks.

Main Page

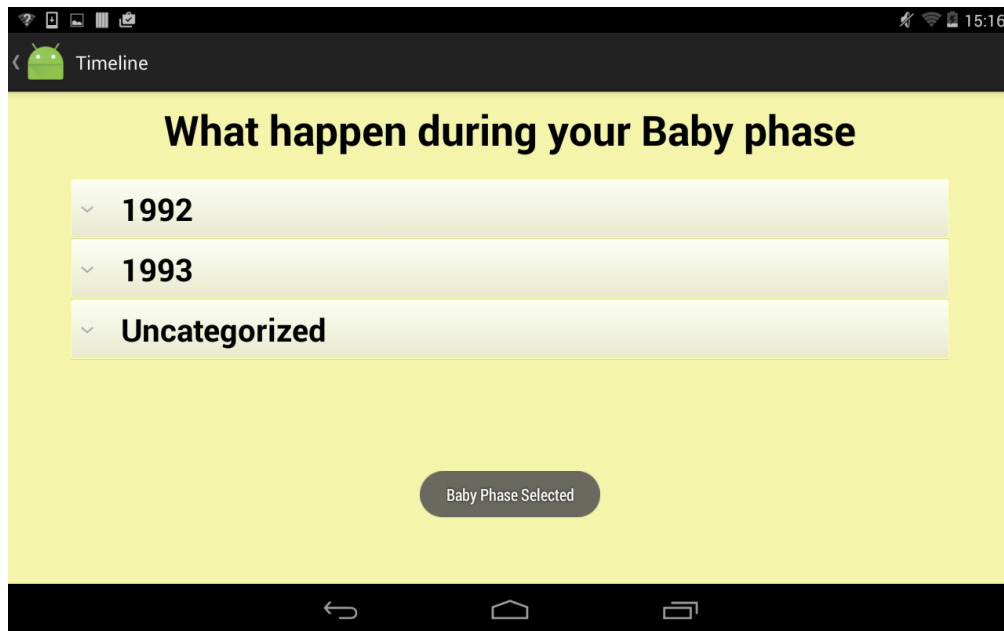
This is where you may navigate around the system in search for memories.

- a) Button to add an event (or a new memory) to the Chest
- b) To switch user, click on this button
- c) Navigate between phases using these buttons



Timeline Page.

After selecting on a phase, you will be redirected to this page. Each memories are organized based on the year, or if an event does not have a year registered to it, it would be labeled as “uncategorized”. Each time you select a phase, a notification (as shown at the bottom middle side of your tablet) would show up and display which phase you are currently at.



Create a New Memory Page

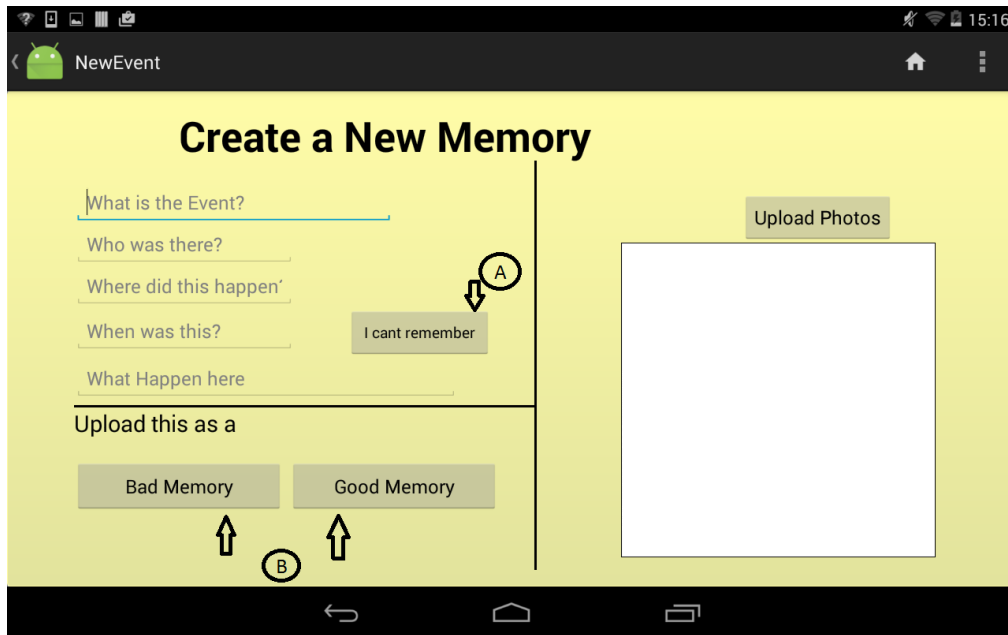
This is where a user may enter or create a new memory entries. These are the following possible entries to be entered : [Title, people's name, location, year, brief description]

Note:

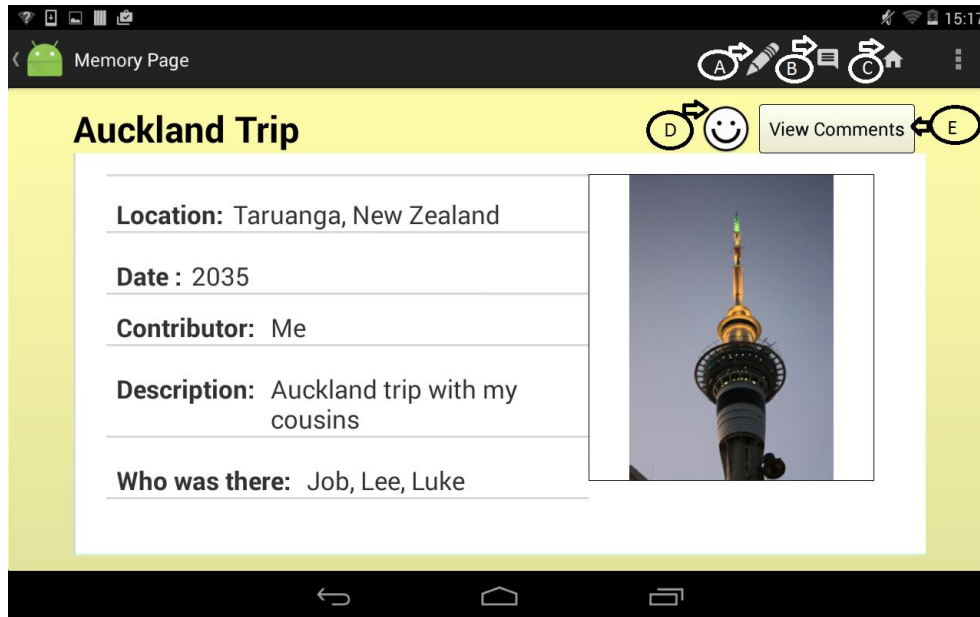
All entries/textbox/images needs to be filled.

Date entries "when did this happen" only accepts years, and not month and day.

- a) If you can't remember the exact year this event happen, use this button
- b) You may decide if this is a good memory or bad memory. An icon in the Memory Page would display what Memory Type the user picked



Memory Page



Comment Page

A user may access the Comment Page through the Memory Page interface “View Comments”. If you are a Secondary user, you may write a comment in the Main user, but the Main user may only view comments that are available to them.

