University of Dundee

DOCTOR OF PHILOSOPHY

Multimedia profiles as external personalities to support people with dementia and their carers

Webster, Gemma

Award date:
2011

Awarding institution:
University of Dundee

Link to publication

Multimedia profiles as external personalities to support people with dementia and their carers

Gemma Webster

2011

University of Dundee

Multimedia Profiles as External Personalities to Support People with Dementia and their Carers

Gemma Webster

Doctor of Philosophy

University of Dundee

2011

Contents

List of Tables

List of Figures

Acknowledgements

Declaration by the candidate

I declare that I am the author of this thesis; that, unless otherwise stated, all references cited have been consulted by me; the work which this thesis records is mine; and that it has not been previously presented or accepted for a higher degree.

Gemma Webster

2011

Declaration by the supervisor

I declare that Gemma Webster has satisfied all the terms and conditions of the regulations made under Ordinances 12 and 39; and has completed the required 9 terms of research to qualify in submitting this thesis in application for the degree of Doctor of Philosophy.

Prof. Vicki L. Hanson

2011

Abstract

Dementia is a growing problem with prevalence rapidly increasing. It is a progressive and eventually severe disease that affects many areas of the person's life. Often, as a result of this disease, individuals reside in care homes. Care staff can find it difficult to get to know a person with dementia as they have limited time to spend with each person. In addition, communication difficulties can make it difficult to learn important social information and preferences. This lack of knowledge about an individual with dementia can make social interactions very difficult and can often contribute to repetitive social interactions.

This research aimed to establish if technology could be used to support care staff within their care environment to get to know people with late-stage dementia. The goal was to develop software that can act as an external communication bridge between carers and people with dementia through the creation of simple but effective *'Portraits'*. This thesis investigates the creation and use of multimedia *'Portraits'* of individuals with dementia that are immediately and easily accessible to care staff.

This thesis describes the development of a software tool called *Portrait,* designed to help staff in care homes quickly get to know a person with dementia as a *person*. It is intended to be used by the staff in their care environment to gain an initial understanding of that person's life prior to entering care and to learn more personal information about their needs and habits. The *Portrait* system contains important but limited personal and social information about the people with dementia.

Five key studies were conducted during this research. The first study evaluated the usability of the *Portrait* system. The second and third were conducted with care managers and staff in the care home setting to assess usefulness and usability of the *Portrait* system and to compare it to current methods used in the care home environment. The fourth study conducted case studies with families of people with dementia to investigate the *Portrait* creation process and the final study investigated the placement of these *Portraits* in the care environment. The results of this research are promising, with *Portrait* being very positively received by care managers, care staff and the families of people with dementia. This research highlights the potential benefits of technology in the care environment to assist care staff. A number of key areas for future research have been identified including the possibility of expanding the use of the system and using alternative state of the art devices.

Associated publications

Webster, G., Fels, D. I., Gowans, G., Alm, N. (2010). Portrait: Portraying Individuality. In: Proceedings of the Computers Helping People with Special Needs Conference, Part II: 12th International Conference, *ICCHP 2010*, Vienna, Austria, July 14-16, 2010.

Webster, G., Fels, D. I., Gowans, G., Hanson, V. L. (2011). Portrait of Individuals with dementia: Views of Care Managers. In: Proceedings of the HCI 2011 Conference*, The 25th BCS Conference on Human-Computer Interaction.* Newcastle, UK, July 4-8.

Chapter 1: Introduction

Dementia is a growing concern worldwide with an estimated 35.6 million people living with dementia (Alzheimer's Disease International, 2010). As the population continues to age the prevalence of dementia is expected to continue to increase to an estimated 65.7 million people worldwide by 2030 and 115.4 million people having a form of dementia by 2050 (Alzheimer's Disease International, 2010). In the UK alone 700,000 people have some form of dementia with over a third of these people (244,000) living in care homes (Alzheimer's Society, 2007). Alzheimer's Society (2007) states that dementia is the strongest determinant of entry into residential care in over 65's, with 75% of people living in care homes having some form of dementia (Alzheimer's Society, 2003). Ward, *et al.* (2008) argue that dementia care can be considered the 'main business of care homes'.

Dementia is an umbrella term used to describe intellectual impairments in multiple areas of intellectual function including attention, orientation, memory, judgement, language, motor and spatial skills. These impairments most typically occur in older people and are produced by brain dysfunctions that are usually progressive and eventually severe (Alzheimer's Disease International, 2010). Alzheimer's disease is the most common form of dementia but there are over 100 different types of dementia each with unique causes and symptoms. Life history, personality and environment can potentially have a stronger effect on a person with dementia's experience of the disease than the dementia (Chapman, *et al.,* 2001).

People with late-stage dementia can be very difficult to get to know due to deterioration in their written or verbal communication skills. These communication difficulties can pose a problem when the person with dementia is introduced to a care environment. These individuals are unknown to care providers and are not able to easily communicate who they are and what they need. As a result, care functions can be limited to only dealing with the clinical care or daily living needs such as eating, bathing, toileting and sleeping (Ward *et al.* 2005, Ward *et al.* 2008, Caris-Verhallen *et al.* 1997, Armstrong-Esther *et al.* 1994). Thus, it is often the case that "*Dementia becomes a label behind which other needs were lost*" (Alzheimer's Society, 2007, p.8). A typical person in a care home can spend as little as two minutes interacting (not including care tasks) with staff and other residents over a six-hour period. This problem is particularly acute for those care home residents who have dementia, with relatives reporting residents left alone in their room with no social interactions for hours at a time (Ward *et al.* 2008, Alzheimer's Society, 2007).

The social environment in care homes is essential to the quality of care and life of residents with dementia and it is now widely accepted that the quality of this care can affect how a person with dementia copes with their situation. Although each care environment is run differently depending on size, management and area of specialty (i.e. Dementia Care, Frail Elderly), every person entering residential care in Scotland as in other countries must have a legally required care plan completed (The Social Care and Social Work Improvement Scotland (Requirements for Care Services) Regulations, 2011). Care plans focus on the clinical/medical care of the resident and are essential in meeting the daily living and medical care of residents. They have

little to no social information or preferences, however; their main focus is on physical care.

Each care home can use a different tool to communicate preferences and life history to care staff. From one care home to another there are large variations in the type and quantity of information contained in the tools as this information is considered best practice but is not legally required. Some care environments may use tools designed by other organisations such as the Alzheimer's Society '*This is me*' Booklet (Alzheimer's Society, 2010) others may develop their own Booklets. Although care homes purport to hold information on personal preferences and social needs, a recent study found that 42% of residents in care homes in Scotland had no recorded preferences of personal likes and dislikes, taste in food, music or interests. Only 24% of residents in care homes in Scotland had accurate recordings of their life history (Care Commission and Mental Welfare Commission, 2009).

There has been a lot of work that focuses on tools to aid the person with dementia from life story books/memory boxes for reminiscence, to simple pill boxes and 'cognitive prostheses' (Astell, *et al.,* 2009). For example, there are different tools available that are designed to be used as a communication or reminiscence support for the person with dementia, notably *CIRCA* (Alm *et al.* 2004, Alm *et al.* 2007) and *Multimedia Biographies* (Smith *et al.* 2009, Damianakis *et al.* 2009, Baecker and Marziali *et al.* 2006).

CIRCA (Computer Interactive Reminiscence and Conversation Aid) uses a touch-screen interface and randomly generated generic multimedia content (e.g. images, videos and music) to encourage people with short-term memory loss associated with dementia to draw on reminiscence to converse with relatives and care staff (Alm *et al.* 2004, Alm *et al.* 2007). There are three different topics (e.g. School Days, Working Life and Sports) of conversation available in each session within *CIRCA*.

Multimedia Biographies tell the life story of a person with mild cognitive impairments or Alzheimer's disease in a DVD format consisting of family photos, film clips, audio narration and music (Smith *et al.* 2009, Damianakis *et al.* 2009, Baecker and Marziali *et al.* 2006). This software was created to allow stories to be shown to the person with Alzheimer's disease on a regular basis to aid reminiscence and communication between the person and their families.

CIRCA and *Multimedia Biographies* are very good examples of some of the research being carried out to help the person with dementia and to aid reminiscence. However these tools were originally developed for use with people with dementia. While these could potentially be used by care staff, these tools did not target specific requirements for care staff. As a result, these tools can provide too much information or are too time consuming for care staff to sort through to learn the most salient personal information and preferences.

1.1   Thesis Aims

Given the importance of dementia care previously outlined, the main objective of this thesis work was to research and develop software that can act as an communication bridge between carers and people with dementia through the creation of simple but effective *'Portraits'*. This thesis will investigate the creation and use of multimedia *'Portraits'* of residents with dementia. The goal is software that allows immediate and effortless access to care staff. Consequently, the research questions proposed attempt to address the issue of creating such a system.

> *Question 1-*
>
> *How can technology be used to support care staff to get to know people with late-stage dementia within their working environment and what are the important considerations in developing such technology?*

This is the principle research question of the thesis. In answering this question information is collated throughout the thesis. The results will be discussed in Chapter 11.

> *Question 2-*
>
> *What information should be included in the profile of an individual with dementia?*

Motivated by the literature review and early research findings from Chapters $2 - 5$, a *Portrait* prototype system is developed and investigated in Chapters 7 and 9.

Question 3-

How do we get busy care staff to engage with the Portrait software, efficiently and effectively in their working environments?

This is motivated by early research findings from Chapters 4, and is dealt with in Chapters 7, 8 and 10, which focus on investigating and evaluating the *Portrait* systems use within care environments.

1.2   Contribution to Knowledge

Firstly, the literature review identifies a gap in knowledge with respect to the use of technology with care staff (not trained nurses) in the care environment. There is a finite area of research or studies conducted with care staff. A limited knowledge of this user group and the application of technology to aid in their working environment exist. This thesis describes the identification of this area and systematic processes involved in development and evaluation of a tool to meet the needs of care staff. Identification of key areas of information absent or sought after by care staff, investigation of the processes involved for families collecting this information and evaluation of usability of this technology by care staff in their working environment.

The contributions to knowledge of this thesis are:

- The investigation of care staff as a user group and application of technology within their working environment. This thesis identifies key factors of working with care staff within this environment. The main factor being an in-depth understanding of care staffs working routine and

their inability to exert control over their working routine, centring on the limited free time available to care staff.

- The exploration of the processes involved in the identification of the content of a *'Portrait'* of a person with dementia and investigating the gathering of such information by families. Focusing on the time and processes involved for families when gathering and producing the content of a *'Portrait'*.

- The evaluation of usability and usefulness of technology with care staff as a user group and also in relation to a care environment. It is possible for technology to be integrated into a care environment if a thorough investigation is conducted that fully evaluates the requirements of the technology, what is suitable for a care environment and what is currently available within the environment.

1.3 Thesis Structure

Chapters 2 and 3 form the literature review of this thesis. Having begun to set the agenda in Chapter 1, Chapter 2 contains an overview of dementia and dementia care. The chapter focuses on communication within the care environment, nurse-patient communication and communication in general with people with dementia. The chapter then goes on to describe person-centred care and its effect on people with dementia. Finally, current trends in dementia care are discussed, specifically reminiscence and care plans. This is further discussed in Chapter 3 which focuses on technology addressing dementia care. Considered in that chapter are key tools developed to aid reminiscence activities for people with dementia and also recent

advances in technology that help address the personal and cognitive needs of people with dementia.

Chapter 4 consists of the preliminary research conducted to fully understand the problem area. The chapter details observations made by the researcher in a specialist dementia unit of a care home and investigates information that is currently provided to care staff.

Chapter 5 introduces the *Portrait* software and describes the system design and development focussing on identifying the content of the *Portrait* system.

Chapter 6 details an initial usability study with the *Portrait* system (published in Webster, *et al.,* 2010).

Chapter 7 presents a study conducted with care managers to assess the usefulness and usability of *Portrait* from the standpoint of people working in dementia care environments (published in Webster, *et al.,* 2011).

Chapter 8 discusses a study carried out with care staff to evaluate the usefulness of the content of the *Portrait* system, to evaluate the usability of *Portrait* with care staff with no previous experience of the system and to consider *Portrait's* usefulness in

comparison to a paper equivalent (Booklet) of the information currently available to care staff within their care environment.

Chapter 9 describes case studies conducted with the families of people with dementia who live in a care environment. These case studies were conducted to address an issue that arose from the previous studies with respect to who would provide the information for the *Portrait* system and how this information would be gathered and entered into the system.

Chapter 10 begins to investigate the extended use of *Portrait* in the care environment.

Chapter 11 concludes the thesis and reflects on the research conducted in relation to the aims outlined. It also discusses these findings in terms of the implications on, and direction of future research.

Chapter 2: Dementia and Care

2.1 Dementia

Dementia is an umbrella term used to describe intellectual impairments produced by brain dysfunctions that are usually progressive and eventually severe. Dementia affects not only the patient but also their families and society. Although first described in 1906 by Alois Alzheimer, a German neuropathologist, "*it was not until 1970 that clinicians began to distinguish dementia from 'senility' attributed to aging.*" (Mendez and Cummings, 2003, p.2). Since the 1970's dementia has had extensive research and now there is a wide variety of knowledge and information available. More recent research has focused on caring for people with dementia producing an important understanding of the individuals' experiences of dementia and not simply being restricted to medical diagnosis and treatment. It is now widely accepted that quality care can affect how a person with dementia copes with daily life. "*The medical view that dementia is an impairment of brain function – which, over time, may rob the person of their ability to cope – is only part of the picture. The personal history, life experience, relationships, cultural identity, personality and environment of each individual exerts a potentially stronger influence than any dementia. Seeing the person first means that responses to the person with dementia require a heightened awareness, a sensitive approach and an insight concerning their life experience. No two people with dementia are the same.*"(Chapman, *et al.,* 2001, p. vii). People with dementia can continue their daily routines and activities and with the correct support premature dependency does not need to happen.

Dementia is a persistent impairment in multiple areas of intellectual function including attention, orientation, memory, judgment, language, motor and spatial

skills. Although typically associated with aging, it can occur to anyone at any age. It is commonly thought to affect all cognitive areas (Alzheimer's Disease International, 2010). This, however, is not true with some types of dementia impairing some cognitive functions and sparing others. These differences in affected intellectual function allow for the identification of different dementia syndromes. Each syndrome has its own characteristics. Not all dementias are progressive disorders and not all affect memory in the same way, with some relatively sparing memory and some dementias, in fact, being treatable or manageable, and a few even reversible.

2.1.1   Different types of Dementia

There are over 100 different types of dementia each with unique causes and symptoms. The most common types of dementia are Alzheimer's disease, Vascular disease, Dementia with Lewy Bodies and Fronto-temporal dementia. Figure 1 shows the relative distribution of the six main types of dementia.
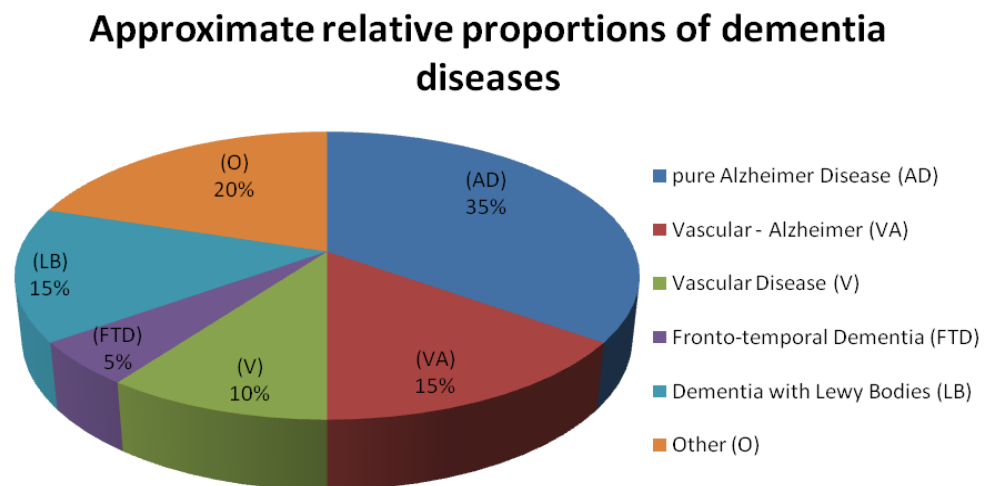
Figure 1 - Approximate relative proportions of dementia diseases. Source: Dementia a clinical approach (Mendez and Cummings, 2003).

Exactly how many people are affected by each specific type of dementia disease is unknown because of a variety of problems including misdiagnosis, non-diagnosis or the inability to diagnose until autopsy or damage to the brain from other conditions.

2.1.1.1 Alzheimer Disease

Alzheimer's disease is the most common form of dementia, with some experts estimating that up to 60% of people affected have this form of dementia. "*In 2006 the worldwide prevalence of Alzheimer's disease was 26.6 million. By 2050, prevalence is expected to quadruple by which time 1 in 85 persons worldwide will be living with the disease.*" (Brookmeyer, *et al.,* 2007, p.2). Alzheimer's disease causes the chemistry of the brain to change and during the course of the disease brain cells die due to amyloid plaques and neurofibrillary tangles that develop in the structure of the brain. As the disease progresses more of the brain is damaged causing greater impairments. The first symptom of Alzheimer's disease is usually mild difficulty with memory such as remembering recent events and forgetting the names of people (Mendez and Cummings, 2003). As Alzheimer's disease progresses the person might experience mood swings, have trouble finding the correct words, become frustrated at their incompetence, suffer depression and eventually will require help to carry out all daily activities.

2.1.1.2 Vascular Disease

Vascular disease is caused by problems in the supply of blood to the brain. The vascular system supplies blood to the body. If the vascular system in the brain is damaged it cannot deliver oxygen-bearing blood to the brain cells and without this oxygen supply brain cells will die (Mendez and Cummings, 2003). Vascular disease has many different causes and symptoms can happen suddenly or over a long period of time. The vascular system can become damaged suddenly following a stroke or

slowly through heart disease, high blood pressure, cholesterol, hypertension, diabetes and smoking. It is more common in men than women due to its association with heart disease. Any area of the brain can be affected meaning the symptoms can vary greatly with each person. Symptoms can include speech and communication problems, mood swings and depression, slight paralysis of one side of the body, memory problems, restlessness and hallucinations.

2.1.1.3 Dementia with Lewy Bodies (DLB)

Dementia with Lewy Bodies has many different names including Lewy body dementia, Lewy Bodies Disease and Lewy body variant of Alzheimer's disease, cortical Lewy body disease and senile dementia of Lewy body type. "*DLB shares mental symptoms, such as confusion and loss of memory, with Alzheimer's disease and motor symptoms, such as gait and slow movement, with Parkinson's disease. For that reason it is often misdiagnosed. Accurate diagnosis is essential for successful treatment of the disease: people with DLB are characteristically highly sensitive to certain drugs which can worsen unpleasant symptoms or even be fatal*" (The Lewy Body Society, 2007, p.2). This disease is caused by the presence of Lewy Bodies in the nerve cells of the brain. Lewy Bodies are tiny spherical protein deposits found in the nerve cells, they are named after the doctor who first identified them in 1912. It is not fully understood how Lewy Bodies form in the brain or how they cause damage. It is known they disrupt the brains normal functioning by interrupting the action of important chemical messengers. Dementia with Lewy Bodies can only be definitely diagnosed at autopsy but careful clinical evaluation of patient's symptoms can allow a reasonable diagnosis. It typically presents some of the symptoms of Alzheimer's and Parkinson's disease including attention and alertness, planning ahead, memory, slowness, muscle stiffness, trembling and loss of facial expression.

Additionally, symptoms can include hallucinations, 'funny turns', abilities may fluctuate daily and sleep may be disturbed at night. The core criteria for diagnosing Dementia with Lewy Bodies are spontaneous motor features of Parkinsonism, cognitive fluctuations and visual hallucinations. Two of these core symptoms are required for diagnosis of 'probably Dementia with Lewy Bodies' and one for 'possibly Dementia with Lewy Bodies'.

2.1.1.4 Fronto-temporal Dementia

Fronto-temporal dementia and Fronto-temporal lobar degeneration comprises a spectrum of dementia disorders with degeneration of the frontal lobes, anterior temporal lobes or both. Fronto-temporal dementia is the main syndrome and is characterised by personality and behaviour disturbances. All Fronto-temporal lobar degeneration syndromes are caused by damage to the frontal lobe or the temporal parts of the brain. Damage to these areas of the brain can cause a variety of symptoms including personality changes, language difficulties and changes in eating habits. In the later stages of the disease the symptoms begin to appear similar to that of Alzheimer's disease.

2.1.1.5 Other Forms of Dementia

Less common forms of dementia are caused by:

- Head Injury and Trauma

- Brain Tumours

- Infections and Toxins on the brain (e.g. Aids, CJD & Chronic Alcohol Dependency)

- Degenerative Conditions (e.g. Parkinson's Disease, Down's Syndromes & Pick's Disease)

While there are common symptoms of each type of dementia every person is an individual and will be affected differently. Therefore, no two people will experience dementia in the same way.

2.2   Communication

Communication is vital to our social identities (Kitwood, 1997). Levels of communication and social interaction affect a person's self-esteem and self-worth. Without meaningful communication our place in the social world is lost (Ward, 2002). Communication is a two-way process whereby individuals perceive the other person's response and act accordingly. This process becomes difficult when verbal communication is no longer possible. People with late-stage dementia often start to lose the ability to communicate verbally and this means that many people, including nurses, doctors and care providers, can presume that those with dementia are no longer able to communicate at all. Over the past thirty years there has been a growing body of research into communication within the nursing home environment, nurse-patient communication and communication in general with people with dementia. This research has informed us that people with dementia, despite people's judgments, have various means of communicating.

Many people with dementia were and still are considered unable to communicate. Studies however, have shown that this is not always true. Various different types of behaviour and expressions can be forms of communication (Kitwood 1997, Killick and Allan 2001, Ward *et al.* 2008).   Only 7% of communication is verbally communicated using words. Of the other 93%, non-verbal communication is facial expression and body language (55%) and vocal tone (38%). Despite the fact that

most communication is non-verbal, attempts at communication by people with dementia are often ignored by nursing staff and care providers as they have been labelled as 'unable to communicate'. Ward, *et al.* (2008) found people with late-stage dementia continued to try to communicate. These researchers argue that the most important information and insights into the experience and welfare of a person with dementia are contained in changes and adjustments of self-expression. They give the following example: *"One resident repeated the same two words throughout the day but variations in the tone of her voice signalled changes in her mood, wellbeing and need for assistance."* (p.14)

Many still treat people with any stage of dementia as unable to communicate, give opinions or have meaningful thoughts. This is demonstrated repeatedly in the study undertaken by Ward, *et al.* (2008):

> *"a social worker's assessment showed: '[The client is a] charming man; he discourses in a long and involved way and is talking total rubbish'."* (p.16)
>
> *"As one of the inspection reports noted: 'The inspector attempted to interview six service users. However, with one exception, all of them were unable to express an opinion because of their dementia. Three relatives were interviewed. The comments received were positive and indicated that they were satisfied with the care provided. (Commission for Social Care Inspection, Report of Announced Inspection, participating care home)'."* (p.7)

These comments make obvious the point that even some professionals who should understand the communication abilities of people with dementia presume these individuals cannot communicate at all.

Dementia care can follow a pattern of only dealing with the external care of a person, *are they hungry, do they need washed?* Ward (2005) describe this pattern as the 'mantra' of dementia care, *Out of bed – wash – dress – feed – toilet – back to bed.* In recent years many studies have focussed on the benefits of social interaction on the quality of care and life of residents in nursing homes (Ward *et al.* 2005, Ward *et al.* 2008, Caris-Verhallen *et al.* 1997, Burgio *et al.* 2001, Armstrong-Esther *et al.* 1994, Nolan *et al.* 1995). The belief sometimes held that people with dementia are unable to communicate their thoughts or feelings is echoed in the way staff and family members judge the well being of a resident with dementia. Ward, *et al.* (2008) describe bodies of residents as having 'symbolic value' in care homes. A resident's appearance can often be used to judge, not only the quality of care, but also the well being of a person. Well-presented, smartly dressed residents give family members the opinion that they are being well looked after. Producing clean and tidy bodies has become the focus of many homes, often at a cost to the psychological and social wellbeing of the resident.

The social environment in residential homes is essential to the quality of care and quality of life for residents. In many instances interaction with the care staff will be the only social contact for many residents. Despite this, there is considerable evidence showing the severe lack of staff-resident interaction. The issue of staff-resident interaction has been investigated since the 1970s, but current studies show that the levels of interaction are still the same despite 30 years of research. Residents with dementia spend an average of just 10% of the day in direct communication with others and 2.5% of the average day is direct contact with care workers. Of all carer-initiated interactions 77% are task-based encounters and only one-third of contact

between staff and residents in care homes involves verbal exchanges (Ward *et al.* 2008). As Ward, *et al.* (2008) note "*Thus, silence is the dominant mode of caring encounters.*". Armstrong-Esther, *et al.* (1994, p.8) found that patients with dementia spent 45% of their time engaged in solitary activities, and Ward (2005) reports that verbal input from residents was often not encouraged and rarely required. Furthermore, Caris-Verhallen, *et al.* (1997) state that the different agenda of staff and residents affects social interaction. Residents want to continue the interaction with social talk as opposed to the nurses' need to hurry up because they have work to do. Edberg, *et al.* (1995) mention the fact that, in some cases, it seems the patient continued their vocal interaction with the nurses even though they had left (unpublished observation). Despite this clear lack of social interaction Armstrong-Esther, *et al.* (1994) found that nurses of various grades ranked talking to elderly patients as enjoyable, important, rewarding and an objective for themselves. Most interaction between residents and care staff has a clear purpose and structure. Many studies have found three types of interaction: task-based, social-based or combination, with the majority of interactions being task-based, followed by a combination.

Ward, *et al.* (2005) discuss the fact that there is an identifiable structure to most resident-staff interactions: an opening, signal of intent, accomplishment of task and closing. The opening of an interaction is to alert the resident to the presence of care staff and the impending care encounter. The opening could be signalled to the resident through a brief greeting, use of the resident's name or through non-verbal input such as touching the resident's arm. The signal of intent is to communicate the purpose of the care encounter and is often done through a statement or command.

This signal of intent could also be carried out non-verbally through gestures towards the wheelchair or dinner table. Accomplishment of tasks is normally achieved through a series of directions from the care staff, and again, often through non-verbal gestures and touch. The closing of an interaction on completion of the care encounter is almost always by the care staff. Often a closing is indicated by a statement such as 'all done' or 'thank you', but the most frequently observed closing was the physical departure of the care staff without any spoken indication to the resident. Research suggests this standardised format of interaction and communication is due to the experience of completing certain tasks on such a regular basis that this leads to the accompanying communication becoming part of the standard routine also.

Many people with dementia and older people, in general, experience a contrast between their actual communication abilities and other people's judgement about their ability to communicate. Negative expectations lead to patronising or condescending speech or simply ignoring the older person. The Communication Predicament of Aging Model (Ryan, *et al.,* 1995) outlines the process by which communicators adapt their speech based on stereotypical views of an older person's dependency and incompetence (see Figure 2). It shows that when people recognise cues of old age and associate them with negative stereotypes. This negative feedback reinforces stereotypical behaviour such as being dependant and quiet, removes satisfying conversation and has a very negative effect on the older person's self-esteem and well being. Extensive exposure to this pattern of communication results in unnecessary dependency, isolation, depression and in some cases institutionalisation. This patronising communication conveys the sense of declining

abilities, loss of control and helplessness whether it occurs in a care home or family environment.
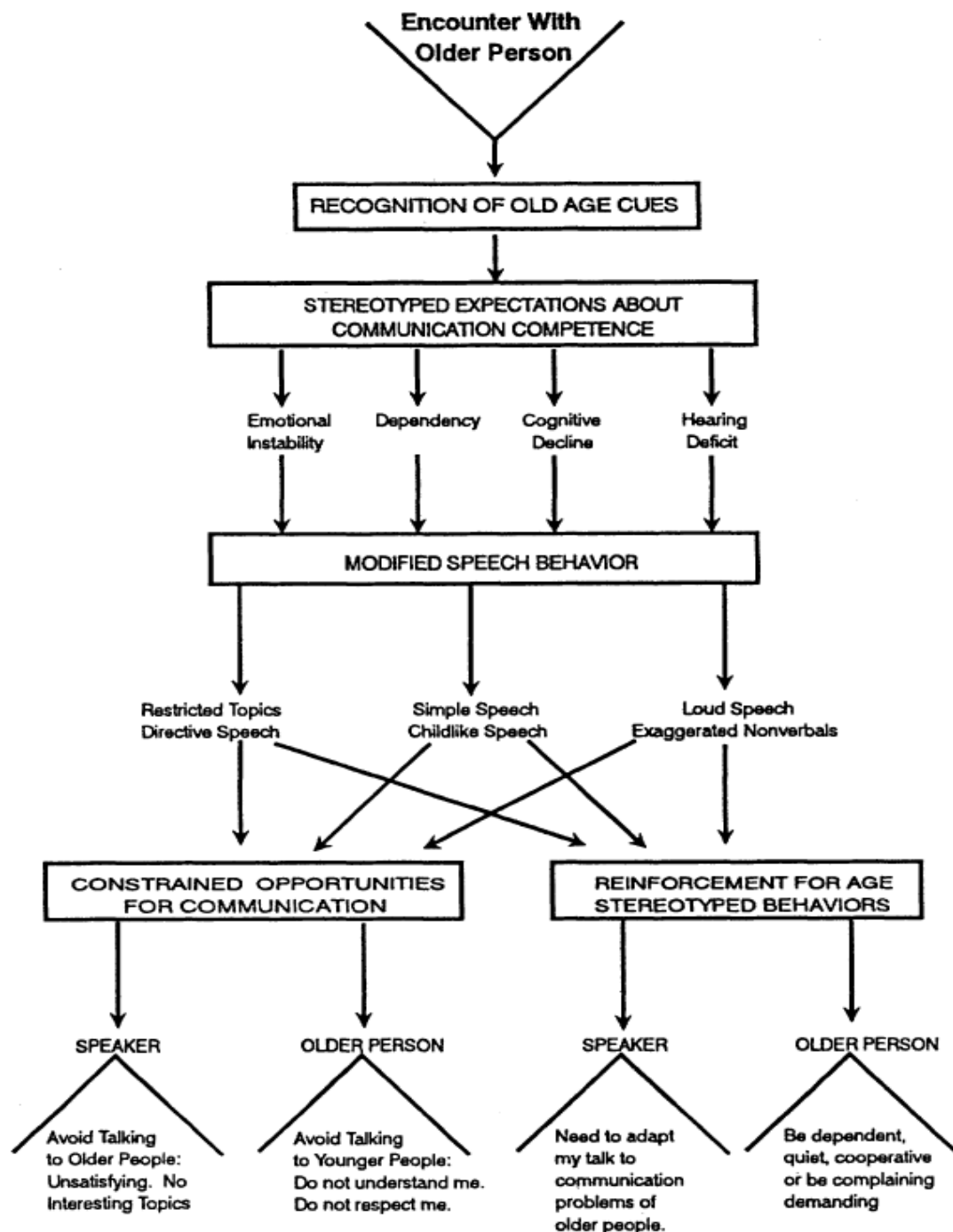
Figure 2 - Features and functions of patronising communication within the Communication Predicament of Aging Model (Ryan, *et al.,* 1995, p.4).

Speech Accommodation Theory proposes that people modify their speech in response to evaluations made of another person (Brown and Draper, 2003). Over-accommodation is the area within the speech accommodation theory that refers to the modifications that occur when communicating with an older person. Over-accommodation often results in the use of a simplified vocabulary, high-pitched tone of voice, relatively slow speech, exaggerated stress on certain words and increased use of questions and repetition (Brown and Draper, 2003). This type of speech modification is often associated with babytalk or 'elderspeak' as it has now been dubbed when used in relation to older people. Elderspeak is easily identified through the use of pet names, statements that sound like questions and the excessive use of words such as 'we' or 'our' i.e. '*Good morning <u>big guy</u>. Are <u>we</u> ready for <u>our</u> bath?'* as opposed to '*Good morning, <u>Mr Jones</u>. Are <u>you</u> ready for <u>your</u> bath?'*(Williams, *et al*., 2003, p.244). Many people believe elderspeak is used to make allowance for the natural decline in cognitive skills that happen with age, in order to convey nurturing or caring and the intention is not for it to be patronising or disrespectful. However, aspects of elderspeak actually make it more difficult for older adults to understand. It is difficult to understand a statement that sounds like a question, over-exaggerated words are confusing and talking too slowly reduces an older person's ability to focus on the main point and retain information. The use of over-accommodation or 'elderspeak' has been found to be common within care homes (Ryan, *et al*., 1994).

The type of language people use can depict power, particularly within relationships such as those between nurses and residents. The spoken word has a large effect on the social control of residents. The relationship between residents and nurses has a very uneven division of power. Interpersonal dominance is the idea that the language

used by nurses to address residents can control and limit independent actions and thoughts (Lanceley, 1985).
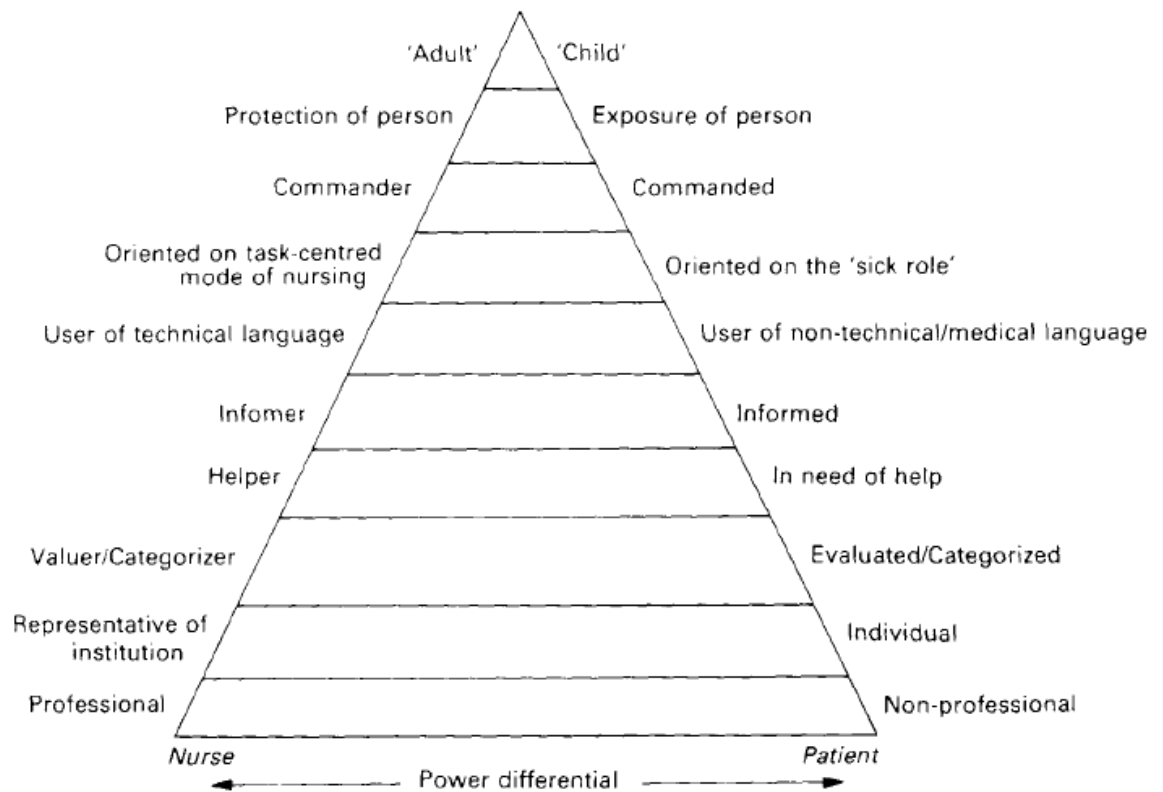
Figure 3 - Some features of the nurse-patient relationship (Lanceley, 1985, p.126).

Figure 3 demonstrates the very different roles and aims nurses and residents can have. Brown and Draper (2003) point out that there are very different and sometimes conflicting agendas between staff and residents in care homes with residents looking to converse, socialise and fulfil their need for friendship opposed to the desire of staff to complete the work as quickly and easily as possible. This attitude is demonstrated further by Nussbaum (1991) with a carer saying:

> *"Mrs_ wants to talk about her children, so I pretend to be interested, to get her into the dining room"* and *"I have my job and must not allow the residents to interfere, so sometimes I have to yell and force them to do what I want"*(p. 160).

Many papers discuss the task-based agenda that staff within care homes demonstrate but little consideration is given as to how much control the staff actually have over this style of working. Caring for residents in a care home is a very physically and emotionally demanding job, often for little thanks and poor pay. Many workers would be able to get equivalent pay from working in a supermarket with less emotional stress. Ward, *et al.* (2008) highlights the many emotional dimensions and personal costs to staff and the tensions they feel between the task-based instrumental care they feel under pressure to provide and their wish to spend time building relationships with residents. There are clear indications that the style and patterns of working are not within the control of individual staff but are shaped by the organisation and care system. For staff there is also an emotional effect of having a resident they cared for die or watching their health deteriorate.

Given that 'dementia care' is the 'main business of care homes', it has been argued that the focus of these 'businesses' needs to shift from task-based to person-based focus (Ward, *et al.,* 2008). For staff the challenge of dementia care is finding the balance between caring and showing respect, between expecting the most of a resident and making appropriate accommodation for difficulties, and between meeting the resident's social needs and completing the necessary care tasks.

2.3   Person-centred Care

Person-centred care is a term widely used within the community of dementia care. Tom Kitwood was the first person to use the term 'person-centred' in relation to the care of people with dementia (Brooker, 2004). Kitwood (1997) said that he used the term 'person-centred', to bring together ways of working with people with dementia,

to emphasise communication and relationships. Healthcare professionals have increasingly been encouraged to move away from traditional task-oriented models of care to person-centred care which emphasises the patient's perspective, experiences and needs (Timothy, 2003). The term person-centred care has become synonymous with good quality dementia care with any new approach having to 'claim to be p.c. (person-centred) in order to be p.c. (politically correct)' (Brooker, 2004).

Person-centred care is cited in policy documents, care plans, job descriptions, training courses and mission plans (Brooker, 2007). Despite the term being widely used and accepted within the care community there is no single accepted definition of what this term means (Brooker 2007, Timothy 2003, Packer 2000). The concepts in person-centred care are not easy to articulate in a straightforward manner, with it meaning individualised care to some while to others it is a value base. There are four major elements that have all been defined as person-centred care by different writers. Brooker (2004, 2007) defines these elements as:

1. Valuing people with dementia and those who care for them: promoting their citizenship rights and entitlements regardless of age or cognitive impairment.
2. Treating people as individuals: appreciating that all people with dementia have a unique history and personality, physical and mental health, and social and economic resources, and that these will affect their response to neurological impairments.
3. Looking at the world from the perspective of the person with dementia: recognising that each person's experience has its own psychological validity,

that people with dementia act from this perspective, and that empathy with this perspective has its own therapeutic potential.

4. Recognising that all human life, including that of people with dementia, is grounded in relationships, and that people with dementia need an enriched social environment which both compensates for their impairment and fosters opportunities for personal growth.

Timothy (2003) defines person-centred dementia care as:

1. Care that is centred on:

   a. The whole person, not on the diseased brain;

   b. Remaining abilities, emotions and cognitive abilities-not on losses;

   c. The person within the context of family, marriage, culture, ethnicity, gender.

2. Care that is centred within a wide society and its values

Both of these definitions demonstrate that an individual's life experience, unique personality and network of relationships should be valued and taken into account by the staff, in a care setting, seems to be the central principle of person-centred care (Timothy 2003).

Kitwood (1997) presents a person with dementia as a person in the fullest sense: he or she is still an agent, one who can make things happen in the world, a sentient, relational and historical being. Staff caring for people with dementia can face an impossible job, trying to provide a positive environment, with low staffing levels and large groups common practice in care homes. Staff can struggle to balance the social

needs of an individual with that of the person's physical needs and the group as a whole. Staff are often unaware of the latest thinking and practices in dementia care (Marshall 2001, Brooker 2004). Marshall (2001) discusses the difficulty involved in providing good quality dementia care with residents often having communication and interaction difficulties, high levels of incontinence, problems with eating and impaired abilities. These difficulties plus the fact that staff often do not have the time, or the energy, to provide more than the basic physical needs, means "*It is all too easy to blame the dementia for the extent to which patients spend their time sleeping or sitting apathetically around the walls of the communal areas. In a sense dementia lets staff at all levels and those responsible for quality of care, off the hook.*"(Marshall, 2001, p.2).

The umbrella term person-centred care can mean a number of different ways of working with people with dementia. The most tangible implication of person-centred care can become the whole definition, which is taking an individualised approach to the care of each unique person with dementia (Dawn, 2004). Clare, *et al.* (2003) discuss person-centred care as tailoring help and support to match individual's needs and understanding the experience of dementia in relation to the person's social context. There is a growing recognition that applying the concepts of person-centred dementia care in practice requires further work (Dewing 2004, McCormack 2004, Nolan *et al.* 2004). With the current haste to develop such care in practice it is now vital that the understanding and definition is finalised to ensure consistency in the frameworks developed (Dewing 2004, Dewing 2008).

Dewing (2008) states that person-centred care or person-centeredness, as an attribute to gerontological nursing, is based on the promotion of personhood. Kitwood (1997) defines personhood as:

> *"It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust."* (p.8)

Kitwood (1997) discusses the fears that a person with dementia can trigger in all people, about ageing, specifically becoming frail and highly dependent. A defensive tactic to deal with such fears can be to 'turn those who have dementia into a different species, not persons in the full sense'. A value-based hierarchy develops, with criteria or attributes for being or not being a person used, meaning not all humans maintain or ever attain the status of being a 'person' (Dewing, 2008). Kitwood (1997) argues the main psychological needs of a person with dementia are love, occupation, identity, comfort, attachment and inclusion which will only be met through maintaining personhood.

Kitwood's ideas of person-centred care and personhood have been embraced by some (see Brooker 2007, McCarthy 2006) or rejected by others as having limited relevance in practice (Dewing 2008, Nolan *et al*. 2004). Many argue that person-centred care does not exist and that 'only the language of care has been changing actual care delivery has failed to do so' (Packer, 2000). This attitude is demonstrated further by Packer (2000) who quotes a senior care worker:

> *"There's plenty of information and training that tells us what we should be doing; I really need something or somebody to show me how to achieve all these things in my current working environment"* (p.21)

This comment sums up the view that person-centred care is an ideal and too elusive to achieve (Dewing, 2008). Even those who unquestionably accept the idea of person-centred care discuss the difficulty that a method for staff engaging in person-centred care remains unclear (McCarthy, 2006). McCormack (2004) suggests that research into person-centred practice is poorly developed and that 'in reality there are few studies that identify the benefits'.

Although there is disagreement on whether or not person-centred care has been or is possible to achieve:

> *"there can be little doubt that Kitwood's ideas have provided a new sense of direction and purpose for practitioners."* (Nolan, *et al.,* 2004, p.2).

Person-centred care is about seeing all people as people and not just a set of needs. Hibbard, *et al.* (2003) show how some staff reactions changed to residents after implementing a project to encourage a shift from task-based care to person-centred care:

> *"it's about honouring who they are as persons… it takes the resident out of the passenger seat, and puts him behind the steering wheel"*,
> *"she didn't change, but my way of thinking changed"* and
> *"We developed more awareness of residents as persons… not just someone who wanted to go from A to B, or who was hungry… there is someone inside as well"* (p.13)

These reactions demonstrate that although there is no set definition or agreement on person-centred care it can still have a positive impact on the staff and residents and foster an environment that promotes relationships and personhood. However, it is in

the implementation stage that difficulties are encountered. For staff who are underpaid and overworked, and have few tangible resources, it is important to find ways to facilitate a change in the way care is provided by staff in institutional or home environments. One approach has been to examine ways in which to promote seeing people with dementia as individuals. Personal story telling, life histories to encourage reminiscence and care plans have been put forward as possible approaches. In this next section, I will review some of these new methods for providing a more person-centred approach to dementia care.

2.4 Current Trends in Dementia Care

Current practices that attempt to promote the person-centre approach to dementia care include reminiscence work, care plans, life stories and memory boxes.

2.4.1 Reminiscence

Reminiscence is the act of remembering or recalling past experiences and is an activity that is commonly undertaken in care homes. It takes advantage of the fact that the long-term memory of a person with dementia may be relatively intact even when their short-term memory is severely affected (Alm, *et al.,* 2004). Reminiscence can take many different forms. It can be carried out as a group activity with objects, photography or music to stimulate discussions about past events, traditions or places within the group. It can also involve life review stimulation and oral history (Bender, *et al.,* 1999). Regardless of how it is implemented, Bender, *et al*, 1999 showed that reminiscence can have positive effects for the person with dementia and the care staff as described in Table 1.

Table 1 - The major purposes of reminiscence (Bender, *et al.*, 1999, p.7).

The major purposes of reminiscence	
Purpose One	Reminiscence to encourage spontaneous conversation between clients
Purpose Two	Reminiscence to encourage informal conversation between staff and clients
Purpose Three	Reminiscence as fun
Purpose Four	Reminiscence to promote emotional and social stimulation
Purpose Five	Reminiscence to promote emotional and social stimulation with people who are severely disorientated
Purpose Six	Individual reminiscence work
Purpose Seven	Reminiscence to create group cohesion
Purpose Eight	Reminiscence to teach people how to use groups effectively
Purpose Nine	Reminiscence to re-use old skills or learn new ones
Purpose Ten	Reminiscence as oral history to maintain or improve skills
Purpose Eleven	Reminiscence to aid intergenerational communication
Purpose Twelve	Reminiscence to achieve cultural legacy
Purpose Thirteen	Reminiscence and spirituality
Purpose Fourteen	Reminiscence in the assessment process
Purpose Fifteen	Reminiscence for life review
Purpose Sixteen	Reminiscence to aid the creation of a positive identity
Purpose Seventeen	Reminiscence to aid communication between a person with a disability and their family
Purpose Eighteen	Reminiscence to train staff in groupwork or to improve staff groupwork skills
Purpose Nineteen	Reminiscence to improve staff understanding of the individual
Purpose Twenty	Reminiscence work as the working philosophy of the unit

2.4.1.1 Life Stories

Life stories, memory books, and scrap books are all documents that are produced with photos and stories relevant to the life of a person with dementia for the purpose of reminiscence. Life story books are filled with a person's experiences, achievements and life history. They can be used to help the person with dementia remember past events, to aid conversation with relatives and carers, to involve families in the care of a person with dementia in a positive way and to remind carers that the person had a full life before entering a home. Past life experiences and a person's history can help care staff to better understand current patterns of behaviour, to encourage interaction between care staff and residents and to help care staff see beyond the disease (Kennard, 2006).

Life stories usually contain written accounts of the important events in a person's life. They are often articulated in the person's own words, pictures of significant people and places and other personal documents. People with early stage dementia can be actively involved in the creation of the chronological account of their life (Haight, *et al.,* 2006). It has been found that care staff and the person with dementia both find the experience of creating a life story an enjoyable and rewarding experience (Kennard 2006, Haight *et al.* 2006).

2.4.2 Care Plans

Care plans or Personal plans tend to hold little information on the service user's personality or life, focusing instead on the physical care of a service user as opposed to their social needs. They are legally required documents created for each person who is entering a care home (The Social Care and Social Work Improvement Scotland (Requirements for Care Services) Regulations, 2011). The care plan contains information about medical history, hospital history, risk assessment (for lifting and handling, health and safety, infection control etc.), weight charts, fluid charts, blood pressure charts and daily nursing plans. These plans focus on actions designed to solve or minimise existing problems. They describe systematic processes to meet all the needs of the service user (see Appendix A – Care Plan).

Chapter 3: Technology Addressing Issues in Dementia

In contrast to care plans that focus on physical needs, recent advances in dementia care address personal and cognitive needs of person's with dementia.

3.1   Reminiscence Support for People with Dementia

The *Computer Interactive and Conversation Aid (CIRCA)* software (Alm *et al.* 2004, Alm *et al.* 2007) and *Multimedia Biographies* (Smith *et al.* 2009, Damianakis *et al.* 2009, Baecker and Marziali *et al.* 2006) allow people with short-term memory loss associated with dementia to draw on reminiscences to converse with relatives and carers.   Such memory loss can make ordinary conversation very difficult and eventually impossible. Conversation partners can become frustrated.   Despite such short-term memory losses, long-term memories of people with dementia are often well preserved.   Reminiscence activities capitalise on these intact long-term memories.

CIRCA and *Multimedia Biographies* are reminiscence tools designed to be used by a person with dementia and a carer or relative. The advantage of both is that these computer-based systems can incorporate various media such as music, video, text and pictures into one easily accessible device (Alm *et al.* 2004, Smith *et al.* 2009, Damianakis *et al.* 2009). *CIRCA* accomplished this through developing a hypermedia structure offering prompts to promote the conversation. It is a touch-screen application that randomly selects three themes out of a larger pool. Themes include topics such as childhood, working life, local area and sports.   This randomisation of content means that new and different conversations are generated each time the system is used. Users are not guided to the same content each time.

Unlike traditional reminiscence sessions, where the carer typically asks questions and the person with dementia simply answers, *CIRCA* sessions are conversational, with each person contributing equal amounts and sharing control of the conversation (Alm, *et al.,* 2007).

Alm, *et al.* (2007) illustrate this through an example of a memory recalled that had not been heard before:

> *"On one occasion, a street-scene photograph prompted a woman in her 80s to tell a vivid, and to her, amusing story of foiling an attempted robbery at the shop where she worked at age 18. When the woman's daughter saw the videotape of this, she asked for a copy, partly because it was such a pleasure to see her mother talking so freely again, and partly because this was the first time she'd heard this story from her mother's girlhood."*(p. 40).

CIRCA was found to be enjoyable and easy to use by both people with dementia and carers. Professional carers found that people with dementia could use the touch-screen with encouragement and thought the system got them talking more (Alm, *et al.,* 2007). Remarks that people with dementia made about *CIRCA* included:

> *"It takes you back and refreshes your memory."*
>
> *"This covers everything."*
>
> *"Good thing, this."*
>
> *"It's good to remember things."*
>
> *"That's entertainment."* (p.39)

Like *CIRCA*, *Multimedia Biographies* is designed for both carers and the person with dementia. *Multimedia Biographies* use reminiscence in DVD format to tell the life story of a person with mild cognitive impairments and Alzheimer's disease. Stories on the DVDs consist of family photos, film clips, audio narration and music.

Multimedia Biographies was created to allow stories to be shown to the person with Alzheimer's disease on a regular basis to aid reminiscence and communication between the person and their families. Persons with Mild Cognitive Impairment and Alzheimer's disease have been observed during the screenings of their *Multimedia Biographies* to record their responses and evaluate the psychosocial benefits (Damianakis, *et al.,* 2009). *Multimedia Biographies* aim was to capture a historical perspective of self through images. Although designed to support recollection for cognitively impaired individuals, *Multimedia Biographies* are also to form a legacy for family and friends of their relative before the onset of dementia (Damianakis, *et al.,* 2009).

Families whose relatives were in a care home or cared for by a private carer reported that they thought the *Multimedia Biographies* helped the carers see the person, not just an 'old lady with Alzheimer's disease'. These families reported that the carers enjoyed seeing how the person was before they had Alzheimer's disease and it helped them remember that they have not always been like this (Damianakis, *et al.,* 2009).

A potential downside of such reminiscence software is that it requires planning and gathering of materials as well as a lot of effort during the actual sessions. Due to the

required preparation time, carers do not use traditional reminiscence sessions as often as they would like (Alm, *et al.,* 2007). Reminiscence sessions are often done as a group activity. Due to the time investment it is difficult to devote the time to just one person (Alm *et al.* 2004, Alm *et al.* 2007, Damianakis *et al.* 2009, Baecker and Marziali *et al.* 2006). Smith *et al.* (2009) show that reminiscence is not that expensive if done by the family, Damianakis, *et al.* (2009) argue that reminiscence sessions are worth the investment.

3.2   Software for Other Types of Dementia Support

Biography Theatre is an in-home ambient display designed to be placed in the home of a person with Alzheimer's disease. *Biography Theatre* displays the person's digital life history in the form of music, photographs, movies, and narratives (Massimi, *et al.,* 2008). In a research study, this software was placed in a participant's kitchen in a similar role to that of a picture frame. The intent was to become part of the background environment of the person's home, focusing on engaging in the activity of reminiscence and social interaction rather than operating the display. The system allowed the participant to select a particular life event to view. If no selection is made within 5 minutes the biography will play from start to finish. *Biography Theatre* provided rehabilitative benefits to its participant with improved positive self-identity and apathy (Massimi, *et al.,* 2008).

Living in the moment (LIM) is a hypermedia system that is to be used alone by the person with dementia (Alm, *et al.,* 2006). It is intended to capitalise on the 'living in the moment' state of people with dementia making the most of their preserved skills. The system consists of three virtual environments that users can navigate: a pub, a garden and a museum. Users are encouraged to explore the environments and get lost

within the system to make the most of the material. This system is failure-free as wherever the user is in the environment is the right place to be.

LIM is intended as a virtual environment in which people with dementia can safely and independently engage in entertaining virtual activities. This provides the carers with, positive and safe, activities to occupy their relative, creating a well-earned respite from the demands of caring for a person with dementia.

ExPress Play is a prototype system designed to enable people with dementia to create music, regardless of any prior musical ability. It has a touch-screen interface to control the system which uses chords to make pleasant sounding music. The name *'ExPress Play'* encapsulates the whole purpose of the system to 'express' oneself through music and to 'press' to play (Riley, *et al.,* 2008). Participation in activities can improve quality of life for people with dementia, where the symptoms of the condition make it difficult to devise activities that are accessible. There are recognised benefits associated with musical activities but carers often lack the skills and resources to support music making sessions (Riley, *et al.,* 2008).

There is a growing body of research into *SenseCam* and how it could aid people with dementia. *SenseCam* is a digital camera that is designed to be worn by the user and take photographs passively without any intervention from the user. It is worn on the body and has a wide-angle lens that allows everything in the users view to be captured. There are a number of sensors within the camera that detect changes and trigger a photograph to be taken at pre-determined intervals (Microsoft Research 2007, Hodges *et al.* 2006). *"SenseCam is designed to capture a digital record of the*

wearer's day" (Hodges, *et al.,* 2006). The rationale being that having a digital record of an event it can be reviewed by the user to help trigger their memory (Hodges, *et al.,* 2006). Research into how *SenseCam* can aid autobiographical memory recall in people with early stage Alzheimer's disease is in its early stages but there are results reporting that participants enjoyed using the *SenseCam* and viewing the photographs (Microsoft Research, 2007).

A relevant project that does not focus on people with dementia is *Acting Up's* multimedia profiling for people who are at a disadvantage due to communication difficulties. This project provides multimedia training, support and profiling for people who are at a disadvantage because of communication difficulties, enabling people with profound and multiple disabilities to be involved in planning their life and self-advocacy (Ladle and Gibbons, 2004). It uses multimedia to enhance people's social contacts, well-being, learning opportunities and roles as active citizens (Acting Up, 2009). Its multimedia profiling supports people to represent themselves and to hopefully exercise more control over their lives. Information about an individual is stored and represented in an accessible format with situations being interpreted from the individual's point of view. Grove (2003) describes the multimedia profiling as a person-centred tool for people with profound disabilities.

The processes and techniques to develop the multimedia profiling foster user involvement through working in partnership with the service user, carers and practitioners. The system is a computer-based catalogue of an individual's daily activities and personal history (Downton and Ladle 2002, Grove 2003). Over time and as a joint activity the multimedia profile is created as a user centred resource

suitable for a range of purposes. Users and service provider's can work together to create and present multimedia reports with images and video selected from the catalogue that demonstrate individual needs and issues. Unlike traditional record and review systems that are text-based and use the language of professionals, the multimedia profiling is presented in a manner that is understandable to users and is in their control (Grove, 2003).

> *"It brings together all the different parts of a user's life in one accessible format. It reinforces "this is me!""* (Grove, 2003, p.6).

Ladle and Gibbons (2004) discuss how profiles can cause opinions to change with a care manager's opinion being used to demonstrate how dramatically these opinions can alter:

> *"'When I saw the profile I was blown away!' She described how a more detailed picture of Cathy has been emerging. 'Cathy has been perceived as small, cute, fragile, and that has affected the way people approach her. But she's 28 years old and has a tough side. Sometimes she's moody. She has a strong sense of humour. She likes to tease and likes to be teased back. She plays people up, pretending she can't hold her cup, but she can very well!'".* (p.14)

Involving the person is at the heart of multimedia profiling: using the 'language' of multimedia to engage and include someone in representing their situation. People gain a stronger sense of self and the opportunity, sometimes for the first time, to fully express their needs (Ladle and Gibbons, 2004). Grove (2003) states that multimedia profiling is viewed as a process rather than a product with its value being the use to which it is put. Four key principles inform the implementation of the

process: User involvement, Consent and Confidentiality, Positive images and Team Working.

Chapter 4: Preliminary Research

As a first step in exploring the domain of technology applied in dementia care, the researcher wanted to become more immersed in the culture of dementia care and the care staff jobs that were affected. Towards that end, the researcher volunteered at an Alzheimer Scotland day centre, in Dundee for one afternoon a week for the entire duration of the research (three years). While at, Alzheimer Scotland day centre the researcher would lead activities and take part in any that were being carried out, and also made informal observations of the people with dementia and the carers. Also, the researcher visited a specialist Dementia unit of a local care home for a day a week for approximately three months. These visits assisted the researcher in understanding what was involved in care staffs' daily routines and what the life of a person with late-stage dementia living in a care home consists of.

4.1   Care Home Observations

The following are observations gathered from the weekly visits to a local care home's specialist dementia units (four different units). This care home is designed to a very high standard for specialised dementia care and it incorporates the latest thinking in space design. Each unit has a maximum of 9 residents, with each having their own bedroom and bathroom that is personalised with pictures, familiar objects and furniture. Each unit has a communal living area that consists of a sitting room, dining and kitchen area, so residents (if able) can make themselves cups of tea or take part in daily living tasks such as doing the dishes. The sitting and dining room areas furniture is organised to promote communication between residents. The residents' bedroom doors have their names clearly on them and are decorated with individual memory cues for each resident. All bathroom/toilets have both written and

picture signs on the doors. Two of the units have secured outside gardens, which residents from any of the units are taken to, allowing access to an outside space for sitting in or gardening if the resident wishes and is able. The hallways are decorated in a homely manner and have 'tumble drawers' with different types of items, such as scarves and beads, tumbling out of them and are placed in the hallways to catch wandering residents attention.

Each unit houses individuals with different levels of dementia and abilities. There are advantages and disadvantages to this arrangement for the residents. In one of the units, there is only a single resident who was more able. This resident was aware of the other resident's inabilities but had no other able resident to communicate with or interact socially. The other residents' behaviour often can annoy the more able resident and cause frustration. With the other residents having a higher level of dependency, it also meant that the care staff are busier with care-based tasks and do not have as much free time to spend socially with the more able and aware resident. In another unit, some residents have formed friendships with someone of similar abilities and personality. Two of the women in one unit were talkative and they were able to understand the situation with other residents. They explained how one gentleman's wife had already visited but he had forgotten and how he will just constantly wander around the home. A woman who had been in hospital for a number of weeks, on returning, caused the two women to start pointing at the returning woman and telling the researcher 'it's her back, she hits'. They also commented on another woman who came in to the living area that they felt sorry because she had told them she was lonely.

Some residents have formed bonds with other residents of the opposite gender. In one unit, a man and woman have become close and on first meeting them, it is often presumed they are in a relationship. They spend all their time together holding hands and generally acting like a couple. In a different unit, another man and woman spend their time holding hands and always sitting together, the only exception being when the woman's husband comes in for his daily visit (Polley, 2006). These friendships and bonds appear to bring the residents who have them comfort and the social connectivity they need. Despite the clear comfort from these bonds, family members have shown distress at some of the residents' bonds, particularly where the resident's spouse has recently passed away. This has the potential to cause tension for staff between the families' wishes or unhappiness and the free will of the resident.

Certain residents' spouses and children visit on a very regular and sometimes daily basis. These relatives often spend time not only with their loved one but also take the time to speak to each resident in the unit. They bring sweets and treats for the residents and can speak to each on a personal level. The relatives often speak to the care staff about all residents' health and will try to help another resident if they become distressed or are looking for company. The relatives are able to tell you typical behaviour and can often help with the difficult behaviours that appear in some of the residents in the unit. In one unit, a gentleman and woman do not seem to like each other and often shout at each other. The visiting wife of another resident will often stop the argument by talking to or encouraging the shouting resident to come and sit beside her. The relatives will often answer other residents' questions such as when their husband will be visiting next or if they have already visited today.

The care staff's personal relationship and abilities varied greatly. Some knew every resident and visiting relative in great depth. Others seem to know nothing outside of the required care knowledge. Although no staff was ever observed to be negligent or cruel with a resident, the difference in the two extremes of care was very apparent. The care staff worked 12-hour shifts and, had many tasks to accomplish during that time. Each day the care staff must ensure that every resident was awake and appropriately dressed, tidy the care home as required, assist with all meals, and complete toileting and hygiene needs. It is not surprising, therefore that some care staff choose to have a seat or a cup of tea rather than socialising with the residents when they have 5 minutes free.

During the observations, some care staff stood out because of their exceptional attitudes and presence. One care staff member summed up her attitude to the residents in that she treats each as she would treat her own grandparent and how she would want to be treated. Staff similar to this person manage not only to complete all the required care tasks but also form and maintain positive relationships with the residents. One staff member, after completing all her required care tasks, would sit and speak to every resident in the unit, in turn ensuring that each was happy and had social interaction with her.

At the opposite end of the scale, when the researcher asked to be introduced to residents she had never met before, another care staff member gave the residents name, then provided her opinion on whether or not it was worth trying to talk to the residents. For one woman, the care staff member pronounced in front of the resident that she could not communicate and never made sense. This resident in fact, enjoyed

company and would often talk to visitors. For instance, during one visit this resident saw a baby on TV and then continued to talk about babies for some time after.

The researcher had a range of experiences during the weekly visits to the units, ranging from, very enjoyable, to upsetting, and sometimes even distressing visits. On one visit it was a man's 84th birthday, the care home chef baked a birthday cake and all the residents and staff sang Happy Birthday. The mini birthday party brought a lot of happiness to the whole unit but also had its sad points. When the man was asked how old he was today he said 46 years old. One of the care staff was joking with the man asking if he was not 21 today causing him to laugh and say no, he was 46. The man was very adamant about his age and he would accept nothing other than 46. On another visit when speaking to a woman about where she lived and what she had worked as, the woman was asked about where the researcher was from. On realising the researcher was from Dundee she started to talk about her friend who stayed in Dundee and even went to get her photo album and showed the researcher who her friend was and all her other photos.

Often during the visits, residents would ask for the researcher to help them get home with one man asking if he could get a lift home when the researcher left. Several other residents asked if the researcher could get out of the locked door to the unit or let them out. A man compared the unit to prison, actually stating that being there was like being in prison and that he just wanted to leave. He often thanked the researcher for talking to him as he thought no one liked speaking to him. The researcher found it very difficult and upsetting when the residents expressed their wish to leave or go home. The most distressing visit occurred when a woman, who was from Germany

and had reverted to mainly speaking German, started crying when the researcher was speaking to her. The woman often got upset and cried hysterically but the researcher could not understand why she was upset as she was speaking German. The researcher instinctively started to try and comfort her, which caused her to get more upset. The care staff told the researcher that she cries a lot without anything seeming to trigger it and that she cannot be comforted. They simply tell her, *"no crying"*, and to smile.

The visits to the specialist dementia units were key to fully understanding what it is like for people with late-stage dementia in care homes and also what difficult and demanding jobs care staff have. Although the researcher witnessed staff that in the researchers opinion were not skilled at promoting social relationships for the residents, it is understandable why they would choose to have a break rather than talking to the residents. It is very easy as an outsider who only has to deal with the demands of a care home once a week to expect every staff member to have the attitude and energy to provide 'perfect' care. It is also easy to forget that many of the care staff do not have extensive or formal training in dealing with every situation that arises but have developed their own techniques over time to adapt and cope with the different situations. The fact that the researcher could find 'faults' with some of the techniques or approaches care staff used in this home is not surprising as it is not a 'home' and the care staff were often over-stretched.

4.2 Current Information available in Care Homes

There are a lot of different types of information currently available to care staff. Each resident within the care home will have their own care plan or personal plan. Care plans contain a lot of information and although there are variations between care homes as to the order of the information and possibly the detail of information depending on if the home specialises in certain aspects of care (e.g. nursing, dementia beds). All care homes are required to store details on how to meet the residents' health, welfare and safety needs (The Social Care and Social Work Improvement Scotland (Requirements for Care Services) Regulations, 2011). In this section the researcher will discuss the information that was provided to care staff in the care home where the previous observations (see Section 4.1) were made. This information discussed is not only used for people with dementia it is used for all residents.

4.2.1 Care Plan

There are a total of nineteen different pages of information that need to be completed to form a new care plan (see Appendix A – Care Plan). The Front Sheet of the care plan contains information on the name of the care home, resident, date of admission, room number, team leader and key care worker. The care plan is then divided into seven subsections of different types of information:

[1] Consent Form

A single form to consent to service user's information being shared with health and social care professionals.

[2] Information Sheets / Practical Daily Living Tasks

There are a total of five pages of information within this section covering basic information to people's power of attorney.

    a. Personal Plan Information Sheet – contains name, date of birth, next of kin, medical history, allergies, power of attorney. This section also provides care staff with information about who should be involved in care reviews, when, and in what circumstances to contact friends or relatives. There is information on social, cultural and spiritual preferences, dietary needs (including likes and dislikes), any specialist equipment requirements and communication needs. This is all covered in four pages of A4.

    b. Practical Daily Living Tasks – provides care staff with instructions on what tasks people can complete independently, with prompting or require assistance as well as any specific details or actions. There are a total of 24 different tasks listed including getting up, hair care, public transport and whether their room should be locked at night. It is intended as a at a glance guide for staff in the day to day care of a resident.

[3] Specialist Assessments

    a. Moving and Handling risk assessment – must be completed for every resident and if there is a need a specific care plan created.

    b. Self-Medication Assessment – will be carried out on any resident wishing to self medicate.

    c. Any other specialist assessments will also be kept in this section e.g. Waterlow Pressure Sore Assessment.

[4] Risk Assessments

    a. Risk Assessment Index – quick reference of all risks and if they have been eliminated.

    b. Risk Assessment – details the resident's name, the risk, who is at risk and why, level of the risk, control measures in place, further actions, timescale and reviews.

[5] Specific Care Plans

    a. Specific Care Plan Index – quick reference of all specific care plans and if they have been resolved.

    b. Specific Care Plan – details the resident's name, the plan number, the problem, the goal and the action.

    c. Care Plan Reviews – any care plan reviews out with six monthly.

[6] Review Sheets

Formal reviews are carried out every six months but can be done more frequently if required by the resident.

    a. Review Index – quick reference of all reviews, designation and who held the review.

    b. Review of Personal Plan – details the resident's name, date of birth, review date, the reason for the review, if the resident wanted/had

anyone involved in the review, a list of areas to be addressed (e.g. Practical daily living tasks correct/ brought up to date), views of resident, views of staff, views of others and any actions and time scales.

[7] Specific Family / Representative Contact Sheet

Records all specific contact with family or representatives of residents and includes details of the contact.

There is a lot of very important physical care information contained within the care plan and these folders of information can become very large as resident's needs increase, particularly as the length of time in a care environment increases.

4.2.2   This is Me

In addition to a care plan, care environments often have personal information in the form of a booklet that can be kept with the care plan or separately. The booklet used within the care home discussed in the previous section (see Section 4.1) is the Alzheimer's Society's *'This is me'* leaflet (see Appendix B – *This is me*) that is designed for people with dementia who are going into hospital. *'This is me'* is intended as a simple tool to create and access. It consists of two A4 sheets of paper that someone with dementia going into hospital can give to staff to help them understand the needs of that individual. It provides *"a 'snapshot' of the person with dementia"* (Alzheimer's Society, 2010) by providing brief text-based information about the person with dementia. In the *'This is me'* package, 16 different questions are completed and provide information such as needs, preferences, likes, dislikes and interests (e.g. an example question is: My home and family, things that are important to me). Each question has four lines of space to fill in the necessary information

(Alzheimer's Society, 2010). Either the person with dementia's family members or care staff complete the booklet.

4.2.3   My Memories

In another care home visited during this research, additionally to a standard care plan the care home provided staff with a self made booklet called *'My Memories'* (see Appendix C – *My Memories*). *'My Memories'* was kept in each individual resident's room and could be used by both the resident and staff. It consisted of up to twelve A4 sheets of paper that contained information on that individual in the form of text and photographs about the person with dementia. Key life events are detailed such as birth details, married life and family with a photograph included when possible. The booklet also held information about the person's faith, things that make them happy or sad, hobbies, employment, special friends and important dates. Each point had only a few sentences to provide the information and care managers or key care staff completed the booklet.

There are no specific figures available that detail the use of My Memories or This is Me in care environments. This is Me however was not designed to be used in a long-term care environment its intended use is for hospital visits. Every care environment may have a unique way to portray personal and social preferences to staff or may have no information available.

Chapter 5: System design and development

The researcher's observations and the literature review indicated that support for care staff is not currently addressed by technology. Specifically, tools designed to help care staff learn important personal and social information and preferences about a person with dementia are lacking. To address this need a system called *Portrait* was developed. *Portrait* was specifically designed to only be used by care staff. The goal for this software tool is to help care staff get to know a person with dementia as a person within the care home environment's strict work schedules.

5.1   Target users

All staff that work in care homes have been included as possible users for the *Portrait* system as the researcher has observed that most staff working in care homes as well as most visitors interact with the residents. The range of possible users encompasses a large variety of roles, responsibilities, and levels of skill and training. It includes direct carers who are usually relatively unskilled as well as highly skilled visiting para-medical and medical personnel such as doctors, special activity personnel, and physiotherapists. It also includes management, nursing, gardening, maintenance and catering staff that may have more limited but important interactions with residents. There is thus a great variation in computer experience, age, literacy levels, and time available for training. For example, the main duty of a direct carer is to carry out the daily care tasks required for a person with dementia. These may include dressing, toileting, feeding and bathing activities but does not include computing tasks. The direct carer, therefore, does not typically use a computer as part of his or her job. In contrast, a visiting nurse may be required to interact with electronic patient records or to communicate through a fixed or mobile computing

device and thus uses technology as part of their work routine. A study conducted with care staff (see Chapter 8: Study 3 – Care Staff) found care staff's computer experience varied with computer use ranging from never to daily. The system must be intuitive, simple and easy to use, and require little or no training to suit this large range of users (Mulvenna, *et al.,* 2009).

5.2   Design strategy

The *Portrait* system is designed to provide care staff with important but limited personal and social information about people with late-stage dementia who are no longer able to live in the community and who often have communication difficulties. *Portrait* is designed to be accessed within three to five minutes so as to not interfere with care staff's busy work schedule. The purpose of this snap-shot of a person is to help care staff see the person behind the disease and to help them get to know that person. A multimedia *Portrait* about each person is presented using a combined computing system and touch-screen. Care staff can spend a small amount of time learning more personal information about each person in the care home in order to gain a better understanding and appreciation of those individuals. The use of multimedia can make the material more attractive and attention holding than a paper-based equivalent (Mulvenna, *et al.,* 2009).

The multimedia *Portraits* contain digital or digitized information on the person with dementia including key life events, family, preferences, important things to know, and hobbies and interests. A person's family or key care workers are anticipated to be the main creators of the *Portraits*. However, there is no limitation regarding who can develop the portrait information. If a person with dementia is able to contribute

or participate in the process, they would always be welcomed and encouraged to do so.

As the system is intended to be used for a short duration, the quantity of information is limited to either one or two screens per topic. *Portrait* is not intended to be a full and complete explanation of the person, nor is it intended for use with or by the person with dementia. The system would likely be located in a duty/work room so it is easily accessible by care staff, always available and not locked in an office or behind a desk.

5.3　Initial Considerations

5.3.1　Development Environment

The touch-screen interface has been found to be one of the most direct, and intuitive interfaces (Albinsson and Zhai, 2003). It has been shown to be one of the most direct forms of interaction as the information display and controls are the same (Mahmud and Kurniawan, 2005). For this reason, it is widely used by banks, museums and as information kiosks in public spaces (Albinsson and Zhai 2003, Mahmud and Kurniawan 2005). In addition, there is no need to learn how to use other hardware such as a mouse. The *Portrait* system has implemented a touch-screen hardware interface to take advantage of the ease of use features of this interface.

The software interface elements of the system were developed in Adobe Flex Builder 3 (recently renamed to Flash Builder) using the Adobe Air runtime to allow the system to run as a standalone client application without the requirement for a web browser. Adobe Flex builder was selected for the system development as it allows the possibility of migrating or developing a web based version of the system quickly and easily.

5.3.2 XML Documents vs. Database

A database was initially considered for storing all the individual portraits for the system. However, while visiting different care environments it was found that care homes may only have one or two computers located in the main office with no guarantee of a central system. Also, often there is no Internet access outside of the main office, which would restrict the possible locations for the *Portrait* system. The researcher did not want to add location and access barriers to acceptance of the *Portrait* system so decided it should be developed as a stand-alone system to ensure any care home environment could implement it quickly and easily. For these reasons it was decided that XML files instead of full-fledged database would be more appropriate. Further, an exact duplicate of the database would be required for every instance of the *Portrait* system placing restrictions on file type and sizes. Every individual portrait has a folder containing all the media and XML files so that if a person is moving to a new care environment they can easily export their folder and import it at the new care environment.

5.3.3 Identification of Content

There are six different categories of information available in the *Portrait* system. These six categories were derived from an informal survey 'Five Things about Me' (see 5.3.3.1), that the researcher conducted. The researcher asked individuals what they would like care home staff to know about them if they had to enter a care home situation.

5.3.3.1 'Five Things about Me' Questionnaire

The 'Five Things about Me' questionnaire was the first study undertaken in this research. It was designed to help fully understand what information people would want care staff in a care home to know about them as a person. The researcher

devised this questionnaire to get an initial sense of what different types of information people would want to convey about themselves if they were in a situation where they had care givers. There is a lot of medical and care information contained within the required care plan that is created when a person enters a care home (see Section 4.2.1). However, there is often a lack of personal information and preferences available to care staff. With every person being unique with different lifestyles, histories and personalities it is very difficult to know what different kind of information should be included for care staff.

The 'Five Things about Me' questionnaire (see Appendix D – 'Five Things about Me' Questionnaire) presented participants with the following scenario: 'Imagine that you are unable to communicate and that you will be moving to a place where you will be looked after, as far as the staff are able, but on your arrival they will not know you as a person'. The questionnaire then asked people their age group, gender and list to five things they considered would be important for the staff to know about them, so that the staff could learn what sort of person they were.

Participants were recruited through the questionnaire which was sent out to a local Bank and business employees, as well as to relatives of residents in a participating care home. Twenty three participants, 7 male and 16 female, responded to the questionnaire. Participants varied in age between under 30 and 60 years old, with 9 of the participants between 40-50 years old.

Filling out the questionnaire was approached in different ways. Some people simply listed what kind of person they are: Independent, Private, Friendly, Sociable and Active. Some gave general answers that covered a range of topics: What I did for a living, Who my family are, What hobbies/activities I enjoy, What my daily routine is and What I like and dislike to eat/drink. Finally, some answers were very detailed and personal. There was one that particularly stood out, with very interesting and vivid answers:

1. That I have been a carer myself and understand the difficulties and stresses involved and that my preference would be to be cared for by a mature, family oriented person.

2. I am a widower and have written a short story about my wife and our relationship. I would like staff to read this story to gain an insight into my personality.

3. I would like staff to have knowledge of my musical tastes, viewing habits and literature likes and dislikes.

4. My personal "Time-Line" which would depict events in my life, such as where I was born, my parentage, siblings, children, schools, colleges, university, military, jobs and marriage etc.

5. Family photographs and familiar items would be important to me e.g. I have a small 3" plastic tiger which my son and I used in our version of "hide and seek". We played this game throughout his childhood years. Some games lasted for weeks before the tiger was found. Memories are important to me.

It was surprising just how many questionnaires had more than five topics with people often stating two or three points for one answer i.e. you had a past, put your personal things around you photos etc.

An initial set of categories of answers were created from the questionnaire results. These categories were:

- Personal hygiene / Clothing -

    o 'Like to brush my teeth at least twice a day'

    o 'I like to have my hair and makeup done every day'

    o 'I prefer to wear trousers'

- Type of carer I would like / Dignity -

    o 'To be treated with dignity'

    o 'To be treated by people the way they would like to be treated'

    o 'To not have too many different carers'

- Routine -

    o 'I like long lies' (I like to sleep late in the morning)

    o 'When I like to get up and go to bed'

- Food / Drink -

    o 'I am a vegetarian'

    o 'I like to have a glass of wine'

    o 'I don't like …'

- Personal items / Photos -

    o 'Personal items around me'

    o 'Family photos and items'

- Family / Friends -

- o 'Who my family and friends are'

- o 'I like to talk to my family and friends every day'

- My Past -

  - o 'What I did for a living'

- Type of person I am -

  - o 'Private'

  - o 'Sociable'

- Personal Interests -

  - o 'Hobbies / activities I like'

  - o 'I like to read, do crosswords and listen to the radio'

  - o 'I like to watch sports on TV'

- How I like to spend my time and who with -

  - o 'Like to choose myself when I spend time alone and when I spend time with others'

  - o 'I don't like rude people'

  - o 'I like to be able to go outside'

  - o 'I don't like to be alone and enjoy company'

- Other

Occurrences of comments in the various topics were totalled and the percent contribution of each category to the total number of comments was then tabulated (see Table 2).

Table 2 - Percentage of times each category was mentioned.

Category	%
Type of person I am	20
Personal interests	14
How I like to spend my time and who with	14
Personal hygiene / clothing	12
Food / Drink	12
Family / Friends	7
Personal items / Photos	6
Type of carer I would like / Dignity	5
My past	4
Other	3
Routine	2

As shown in Table 2, the main topics that were listed by participants were the type of person they are, personal interests, how people like to spend their time and who with, food and drink preferences and finally personal hygiene and clothing preferences. It was surprising how little personal items and photos, their pasts and family and friends were mentioned. Although some categories were not mentioned as much as others the difference between each categories final results were not large enough to allow the results to be final and concise findings (see Table 2). The wide variety of answers suggests that the profiles will require flexibility. As every person has a unique life it is not feasible to identify a small number of topics that every person would find relevant. The researcher examined the categories of different topics from Table 2 and the percentage of times mentioned to devise a list of generic topics that could cover as much of these categories as possible. The topics found from this questionnaire that could possibly be covered in a profile are:

1. Type of Person I am.

2. Personal interests and hobbies including how I like to spend my time and the type of person with.

3. Who my family and friends are.

4. My past.

5. Personal Items and photos.

6. Likes and dislikes in terms of food and personal preferences.

Although this list of topics is not intended to be comprehensive or final, it allows a structure for sorting and adding information to portraits in a consistent manner. It was expected to identify new topics or overlapping topics during the usability and user studies. This questionnaire goal was to get an initial idea of topics to be included for further focused investigation.

5.3.4 Interface Design

5.3.4.1 Navigation

The overall design of the *Portrait* system orders the above six different categories of information along a linear main menu system located in the lower portion of the screen (see Figure 4). This main menu bar is consistently available in this position making it easy to locate at any time during system use.

5.3.4.2 Screen Layout, Content and Interaction

Above the main menu is the content area where information related to each menu item is displayed. Figure 4, through Figure 12 show examples from the 6 different categories.

The headings for each category in the menu are represented by icons and text labels to provide redundancy and to reduce literacy level requirements. To select a menu item the user would touch that item of interest on the screen. A new screen would appear containing a limited amount of additional information about the personal or social preferences of the person with dementia for that category. This information is presented in high-contrast text and image formats. The text format is organised in short sentences that are precise and concise to ensure the information can be read easily and quickly (see Figure 9 and Figure 12). In the first user study, the researcher considered substituting bullet points for the full sentences but users indicated the short, full sentences were preferable so the final design used full sentences. Where non-photo graphics or icons are used to represent a concept, a brief text description is also provided (see Figure 4 and Figure 12). In addition, text is used for instructions to users (see Figure 8).

A second content screen is available in three categories, 'Photo Album', 'Timeline', and 'Family Stories'. A "go back" button has been added to these second screens so that the user can easily return to the first content screen (see Figure 9). The other three categories contain only one screen of information (see Figure 10 - Figure 12). Finally, the name of the person whose portrait is currently being reviewed is consistently located in the top portion of the screen and a current picture is accessible through the 'see me now' button to remind the user/care worker which person is currently being reviewed (see Figure 7 and Figure 9).

5.3.4.3 Colour

Each main category and content area is represented by a unique primary colour (e.g., purple is the colour associated with the 'Photo Album' category), and a high-contrast text label so that the different topics are easily differentiated, also to help users keep

track of their location within the system. Colours were selected to be noticeably different from each other and to have good contrast with the images and text so that they were legible. To ensure people who were colour blind could successfully use the system no 'colour cueing' or instructions relied on the identification of a colour. Colours with a high degree of contrast and saturation were used to insure people who were colour blind could easily distinguish between the different colours (Hoffman, 1999). In the first user study, two colour choices were found to have poor contrast with the text and were changed as a result (see Section 6.2). The primary colour hues were also very positively received in this study (see Section 6.2) and considered eye-catching and bright.

5.3.4.4 Sound

Sound has not been included in the *Portrait* system because care homes are often noisy environments and the system may be located in a variety of spaces where that sound may distract people not using the system.

Figure 4 - Timeline topic showing meaningful icons and limited text descriptions that the user can select.
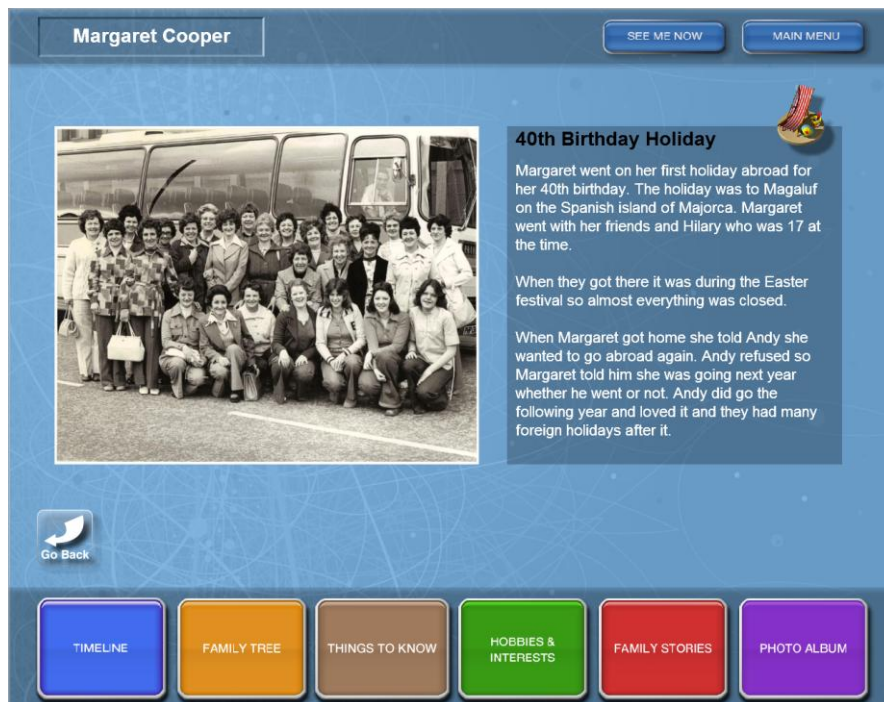
Figure 5 - Selected event from Timeline topic with photograph and text description.

Figure 6 - Selected story from Family Stories topic with photograph and text description.
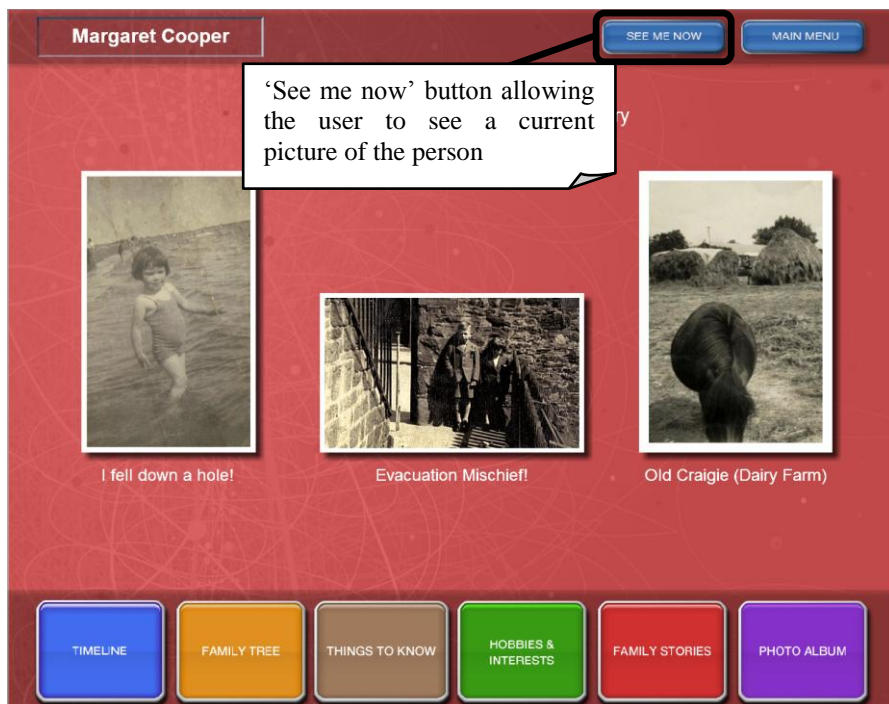
Figure 7 - Family Stories topic showing the 'see me now' button.

Figure 8 - Photo Album topic showing label indicating access to second level.
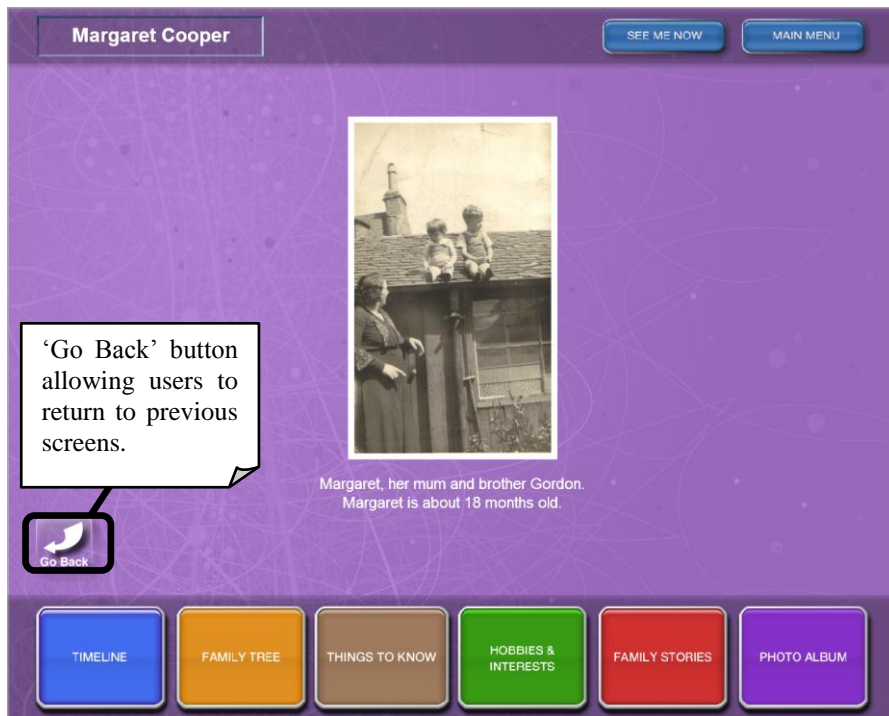
Figure 9 - Selected photo from Photo Album topic with short to the point text description.

Figure 10 - Family Tree topic showing the immediate family.
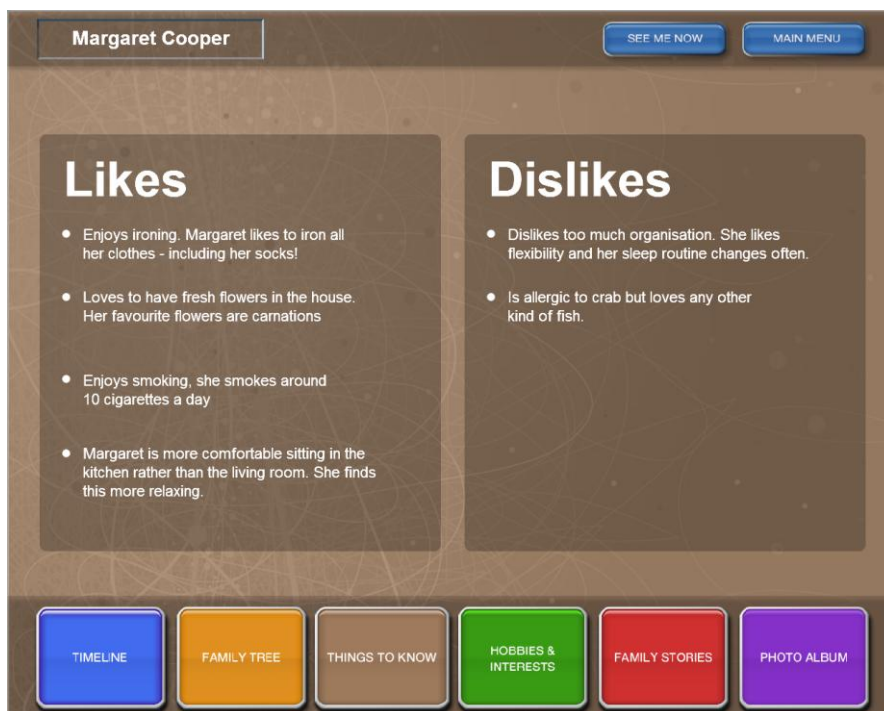
Figure 11 - Things To Know topic with bullet point text description.

Figure 12 - Hobbies & Interests topic with short to the point text description and meaningful icons.

Chapter 6: Study 1 – Usability of *Portrait* System

An initial usability study was carried out to evaluate the *Portrait* system with a range of different users. This study was carried out with novice *Portrait* users who were not care staff. As this evaluation was designed to evaluate the usability, not the usefulness, of *Portrait* it was not necessary for the participants to have any care experience.

6.1 Participants

Participants were recruited through family and friends to ensure a wide range of age and computer experience. None of the participants had experience of the *Portrait* system. The study was conducted in two iterations with five participants in each. Iteration 1 had 2 male and 3 female participants. Iteration 2 had 1 male and 4 female participants. Participants varied in age between 18 and 59 years. Most of the participants had never worked in a care environment but two had part-time experience for less than 5 years. Participants' average computer use was daily.

6.2 Method

Data were collected using a pre-study and post-study questionnaire. The pre-study questionnaire consisted of 5 questions and collected demographic data such as age and computer experience. The post-study questionnaire consisted of 17 questions all using a 5-point Likert scale with 1 as the most positive answer and 5 as the most negative answer. The questionnaire (see Appendix E – Usability of *Portrait* system) was designed to collect data on ease of use, preference of features, level of training required and how engaging *Portrait* was to use.

During the study audio and screen capture software was used to capture on-screen actions and commentary. This data were used to analyse positive and negative user experiences. For this study one female example portrait was used to populate the *Portrait* system. This example portrait was from an actual person. This person, however, was not known to the participants. Thus, the example portrait did not bias the participants. As the design of the system was intended to require little training to understand, each participant was only provided with a very brief introduction (see Appendix E – Usability of *Portrait* system) to the system (roughly 2 minutes). This introduction was designed to introduce the different topics of information available in the *Portrait* system (e.g., 'Timeline' can contain any significant events from a person's life up to a total of 8 and 'Family Tree' has an image of the person's immediate family). Participants were then asked to complete three simple training tasks to become familiar with using the system (e.g., Select a photo of Margaret from the 'Photo Album'). The participants were not given any further instructions during the training tasks unless they were unable to complete the task themselves. The only assistance required was when participants queried 'is this the back button'. This issue is addressed in the results (see Section 6.3). Once participants demonstrated they could complete the training tasks, they were asked to complete five representative tasks that involved finding specific information about the person profiled in the system (e.g., the names of her children and where she preferred to sit). The participants were asked to 'think aloud' while completing the tasks. After completing the tasks the participants were asked to complete the post-study questionnaire. Participants were involved in the study for approximately 15 minutes.

6.3   Results

The first iteration highlighted three usability issues: contrast between background colour and text, font size and the back button being unclear. Two people identified the text as difficult to read due to the lack of contrast between background colour and the text for two topics. Two people said that they would like the font size to be larger so the text would be easier to read. The final issue was elicited from observations made during the study where participants were confused by the back button icon (see Figure 13), unsure of its functionality.

Figure 13 - Original back button with X.   Figure 14 - New back button with arrow and label.
Changes to the system to address these issues were made and a second iteration of the study was carried out. The background colour of the 'Timeline' and 'Things To Know' topics was darkened to increase the contrast between the background and the text. The font size was increased from 16pt to 18pt bold for main text and 18pt bold to 20pt bold for headings. The back button icon was changed from the "X" (see Figure 13) to an arrow and label (see Figure 14).

Most questions had similar ratings between Iteration 1 and 2 for 5 of the 17 questions (see Table 3 – Q1, Q3.1, Q3.5, Q4.7 & Q5) and there were only slight difference (less than 0.5 reduction in mean) for 6 of the 17 questions (see Table 3 – Q3.2, Q3.3, Q3.6, Q4.1, Q4.2, Q4.6). These ratings were expected as these questions related to navigation and information available within the system and there were no usability issues highlighted in Iteration 1 and therefore no changes relating to

navigation or information carried out before Iteration 2 was conducted. The results for these 11 questions were essentially unchanged and had positive ratings with all means less than or equal to 1.4. For the remaining 6 questions (see Table 3 – Q2, Q3.4, Q4.3, Q4.4, Q4.5 & Q6), Iteration 2 consistently showed more positive ratings than Iteration 1 with all mean ratings reducing by a minimum of 0.6.

There were four questions where user ratings appeared higher in iteration 2 than iteration 1: Level of Training, Size of text, Text font/style and Colour of text (see Table 3 – Q2, Q4.3, Q4.4 & Q4.5). As the *Portrait* system was designed to require as little training as possible it was felt necessary to gauge user's opinions on how much if any training would be required to successfully use the *Portrait* system. As shown in Figure 15, the Level of Training ratings altered after the usability issues from Iteration 1 were addressed showing the issues addressed may have improved the usability of the *Portrait* system with ratings appearing higher. Participants indicated in the second iteration that they felt either no training or some training necessary (30 minutes was the lowest training option) where as in the first iteration participants ratings indicated between 30 minutes (lowest training option) and one hour (medium training option) of training necessary. Participants made comments such as that they would not require any training, although they offered that other people may need training. As seen in Figure 16, participants rated the size, colour and font style of text either with very high ratings or low ratings in Iteration 1. In Iteration 2, these attributes were all rated highly indicating that the changes made to the interface had a positive effect. All three of these questions had the same mean (M = 2.2) and standard deviation (SD = 1.64) (see Table 3 – Q4.3, Q4.4 & Q4.5) in Iteration 1 and Iteration 2 and therefore the same frequency diagram (see Figure 16).

Table 3 - Mean and standard deviation for post-study questionnaire on attitude towards *Portrait* (rated on a scale of 1 to 5 where 1 is very positive and 5 very negative) * indicates expected higher ratings in iteration 2 from the changes made after iteration 1.

| | Usability Study 1 | | Usability Study 2 | |
	Mean	SD	Mean	SD
Q1) How difficult it was to learn how to use the system	1.0	0.0	1.0	0.0
Q2) Level of training required to learn how to use the system	2.4	0.55	1.6	0.55
Q3.1) Knowing what to touch for more information	1.4	0.55	1.4	0.55
Q3.2) What information is available in the system	1.6	0.55	1.4	0.45
Q3.3) Reading information on the screen	1.6	0.89	1.2	0.45
Q3.4) Finding the information you wanted	1.8	0.45	1.2	0.45
Q3.5) Changing between topics	1.2	0.45	1.0	0.0
Q3.6) Using the system	1.2	0.45	1.0	0.0
Q4.1) Location of the menu buttons	1.4	0.55	1.0	0.0
Q4.2) Size of buttons	1.4	0.55	1.2	0.45
*Q4.3) Size of text	2.2	1.64	1.2	0.45
*Q4.4) Text font/style	2.2	1.64	1.2	0.45
*Q4.5) Colour of text	2.2	1.64	1.2	0.45
*Q4.6) Colour of screen	1.4	0.55	1.2	0.45
Q4.7) Match of the background colour to the button colour	1.4	0.55	1.4	0.55
Q5) Rate how clear the organisation of information was on the screen	1.4	0.55	1.4	0.55
Q6) How fun was the Profile system to use	1.8	0.45	1.2	0.45

Figure 15 - Frequency diagram of Level of training required to use the system for both iterations of the usability study.
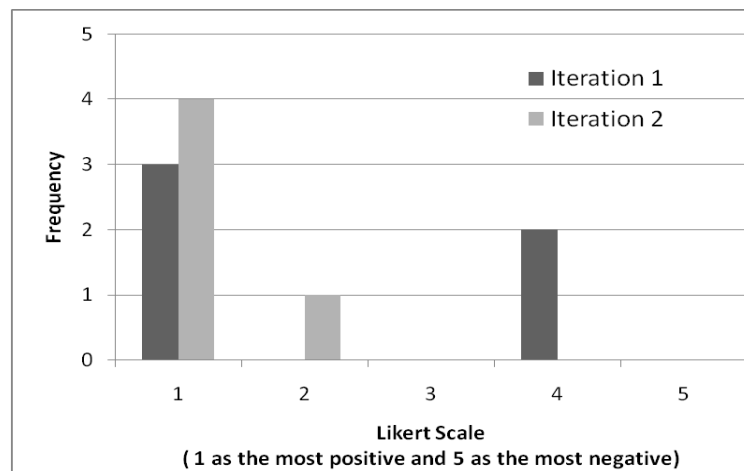
Figure 16 - Frequency diagram of size, colour and font style of text for both iterations of the usability study.

6.4 Discussion

The initial usability study carried out with novice *Portrait* users showed that the *Portrait* system seemed to be very easy to use and would require less than 30 minutes (30 minutes was the lowest training option) to no training. The researcher proposes that as no major usability issues arose during this study and participants were given only a brief introduction to the *Portrait* system (roughly 2 minutes) that rather than training users would require an introduction to the system and its content. The *Portrait* system had mostly positive outcomes from the first iteration of the

usability study with only three usability issues identified. These three issues were corrected for the second iteration and no new usability issues were identified during this second evaluation. These findings suggest that *Portrait* could be easily and quickly used by care staff with little computer experience. Overall *Portrait* was very positively received and all participants rated the system as either engaging or very engaging and fun to use. Given this positive rating of the usability of *Portrait* by these participants, the next step was to evaluate the system with people who actually worked in care homes to evaluate the content of the *Portrait* system and its usability in a care environment.

Chapter 7: Study 2 – Care Managers Initial Views

A study was conducted with carers to assess the usefulness and usability of *Portrait* from the standpoint of people working in dementia care environments. In particular this study used care home managers, all experienced carers, to assess the system.

7.1   Participants

Three care home managers were recruited with each being from a different 'style' of care home: a group care home, council-owned care home and a day centre for people with dementia. Four care managers were approached but only three responded in time to participate. Different types of care homes were selected to ensure that there was a range of opinion and possible use-case scenarios represented. The three study participants were female as is common in the care environment and they were aged between 30 and 49. All had been a carer and worked with people with dementia for over 11 years. They did, however, vary in experience as a manager of under 5 years to 15 years experience.

7.2   Method

Data were collected using a pre-study questionnaire (see see Appendix F – Care Managers Initial Views) and a post-study semi-structured interview. Participants were involved in the study for a maximum of 1 hour. During that hour, they answered a questionnaire, used *Portrait*, and engaged in a post-study interview. The pre-study questionnaire consisted of nine questions and collected demographic information such as age and experience. The pre-study questionnaire also gathered information about what information is normally received when managers first meet a person with dementia and how useful they find this information. There was a large variation in the quantity of information received by each care manager with only

medical history and information being reported as received by all care managers. There were nine other possible types of information including: family and personal history, social, cultural and spiritual preferences, and communication needs. All managers indicated that they would find all nine possible types of information (medical history, medication list, family & personal history, food likes & dislike, preferences for activities, risk assessment, personal hygiene needs, social, cultural & spiritual preferences, communication needs) either useful or very useful.

The *Portrait* system was then demonstrated to the care managers and they were asked to use the system in order to understand its functionality and user interface. As with the previous usability study (see Chapter 6: Study 1 − Usability of *Portrait* System), the same female example portrait was used to populate the *Portrait* system. This example portrait was from an actual person. This person, however, was not known to the care managers. Thus, the example portrait did not bias the participants. Each participant was only provided with a very brief introduction to the system (roughly 2 minutes) explaining what each different topic of information covered. Participants were then asked to complete three simple training tasks to become familiar with using the system. The care managers then spent more than six minutes trying the different aspects of the system and asking questions. They were asked to 'think aloud' while working through the training tasks and using the system. After completing the tasks, the participants were interviewed to gather their opinions of the system and its potential use in their facilities.

The post-study interview consisted of 13 guiding questions, as shown in Table 4. These questions were designed to gather information about the content, use and benefits of the system for care staff. During the study, audio and screen capture software was used to record on-screen actions and commentary.

The post-study interview was semi-structured, informal, and conversational in style, lasting between 20 and 35 minutes. The interview was held at each respective care home and focused on the manager's opinion and experience with *Portrait*.

Table 4 - Semi-structured Guiding Questions.

Questions
1   What information did you find most interesting? Why?
2   What information did you find least interesting? Why?
3   What information do you think you would find most relevant when you first meet a client?
4   What information do you think is missing?
5   What problems did you find with the system?
6   What benefits do you think staff would gain from using the system?
7   How much time do you think is needed to learn how to use the system?
8   What type of care giver do you think would benefit from using the system? (New staff, staff with a few years of experience, all staff, managers)?
9   How do you think that new staff would react if they were introduced to their clients using this software? (E.g. before they began work?)
10   When and how do you think existing staff would use this system?
11   What impact do you think the system would have on existing staff working with new or existing clients?
12   Where do you think that the system should be available (e.g., in staff room, in patient rooms, etc.).
13   Overall what do you think of the *Portrait* system?

7.3 Results

A qualitative thematic analysis of the interview data was carried out in order to examine common views on *Portrait* with a care home context. Also of interest was any specific issues related to care home type. Interviews were transcribed verbatim.

Ten thematic categories were derived by the researcher from a subset of this data in accordance with the method outlined by Miles and Huberman (2002). Two of the categories had positive and negative subcategories. Table 5 provides a definition and examples for each category. The researcher then categorised two of the three data sets (interview transcriptions) into the ten categories. To ensure there was no bias an independent researcher also categorised the two data sets into the ten categories. The two researcher's categorisation data was compared using Intraclass Correlation (ICC) statistic in SPSS v18 to describe how closely the categorisation data resembles each other. The ICC value for all ten categories was high, above 0.9 (1.0 is perfect agreement) meaning the two researcher's categorisation data was very similar. The final interview data set was then analysed by the researcher as the categories were already created.

Table 5 - Category Definitions and Examples.

Category	Description	Example
Communication	Any indication of starting, improving or increasing discussion or interaction with a client.	"will trigger a conversation with the individual"
Humanise	Seeing client as a person or individual rather than only medical or daily living needs (e.g. feeding, toileting).	"make the person a person"
Inform Others / Educate	Provide information so others can learn about the person.	"other health professionals who visit the unit"
Find Out More Details	To learn more or new information about a client, their life or experiences.	"find things"
Care Management	Improve or adjust a client's care to suit their individual needs.	"personalise things"
Data Entry	Any discussion or question regarding who or how the client's '*Portrait*' would be created or inputted to the computer.	"inputted by myself or senior staff"
Ease of Use	Any discussion or comments on how easy the system is to use.	"It's very user friendly isn't it"
Interface Suggestions	Any suggestions or discussions on how to improve the user interface.	"I would like a bigger picture of the resident"
Technical	Computer use, touch-screen or training for system.	
- Positive		"quite easy to follow"
- Negative		"is going to have to involve staff training or just the basic use of a computer as well"
Time	Any indication or discussion of how much time would be required to access and learn to use the system.	
- Positive		"it would enable staff to come in there at any time"
- Negative		"I can't believe you would get all the information in 3 minutes"

As the number of participants was small, a qualitative, rather than quantitative, treatment of data is presented.

The categories in Table 5 can be grouped into overarching categories: the first five categories are directly related to the impact of the information contained in the *Portrait* system on individuals with dementia and care givers, and the last five categories are related to the usability of the *Portrait* system and general computing issues.

7.3.1.1 Communication

Communication was one of the categories most discussed, with a total of nine comments. The comments about Communication included *"that's the talking point then"* and *"you're communicating, you're not just talking the weather."* These comments indicated that the participants recognised the value of the system for stimulating more meaningful conversations that could potentially be rewarding for both conversation partners, the care staff member and the person with dementia. Care staff could potentially use the information contained in *Portrait* as topics of conversation that could be more interesting for both conversation parties.

7.3.1.2 Humanise

There were five comments for the category Humanise with comments such as repeatedly mentioning 'empathise' and *"it is seeing the whole person…. not just the person as they are now that's especially important with people with dementia."* Managers indicated that the *Portrait* system would allow care staff to view the

person with dementia as a person who had lived a varied and interesting life and not simply an entity who needed *"looking after."*.

7.3.1.3 Inform Others/Educate

The Inform Others/Educate category was mentioned seven times. Example comments included *"we have district nurses coming in here who want to know a wee bit more"* and *"cover staff who are not with us on a contract basis all the time so they have been working on the 2nd January but are not back till the 3rd march. Things change, people change but Portrait can be updated ...I want to know for the afternoon as I am being left to do hobbies or arts and crafts with somebody; something about who I am actually with and that's the answer."* It was suggested that *Portrait* would be able to assist transient or intermittent staff such as doctors, physiotherapists, and temporary nursing/care staff to learn personal information about the residents quickly. This could then translate into a better understanding of the individual they came to see and again provide opportunities to stimulate meaningful conversations during their visit. In addition, the information may also provide reasons for some of the observed behaviour in people with dementia. One example provided was *"If somebody likes being in the kitchen, you would have to re-organise seating arrangements for that lady as she is not going to find it comfortable sitting in the living room with 9 or 10 other people. She is going to find it really quite irritating if she likes to be in the kitchen constantly boiling the kettle."* Each care manager also believed that the *Portrait* system would allow staff to find out more details about the people with dementia.

7.3.1.4 Find Out More Details

In the category Find Out More Details there were nine incidents. Comments such as *"get to know someone much quicker"* and *"the fact that they have got a wee bit*

more information that's basically there. It's in your face; it's there. You are taking it in" indicate that managers believe that the system could aid care staff in learning more information about the people with dementia under their care than is available from current sources such as the story book or the patient file/care plan. In addition, the important information about the person could be acquired quickly.

7.3.1.5 Care Management

Improving Care Management was discussed six times in relation to how knowing more information about a person could help personalise care and potentially improve quality of life for that person. This is demonstrated in the example with the woman who prefers to be in the kitchen and a care manager described *Portrait* as a *"care aid definitely."* It is important that management recognise the *Portrait* system as a care aid that is beneficial to the care home. As care staff have little control over their system of work (Ward, *et al.,* 2008), having *Portrait* recognised by management as important, may justify time being allocated for training and using it.

7.3.1.6 Technical Positive and Ease of Use

Examining the grouping of categories related to the use of the system, it is apparent that the majority of responses were positive. The Technical Positive and Ease of Use categories had 4 and 7 comments respectfully. Examples of the types of comments that were provided were *"I'm not very good on a computer and I would find that quite easy to use"*, *"quite easy to use"* and *"get to know someone much quicker."*

7.3.1.7 Time Positive

The responses to interview question 7 provided further evidence of this positive experience. The question asked how much time the participants thought would be necessary to learn how to use the system. All care managers reported that 'not very

much time' to 'no time at all' would be required and made comments regarding specific amounts of time *"You could learn it in the space of 5 minutes"* and *"you shouldn't need a whole day's training for it or anything like that, just 5 minutes/10 minutes max so you have time to read it all."* This indicates that the participants in the study believed the system was easy to use and learn, two key elements of usable interfaces (Preece, *et al.,* 2001). It also may indicate that the system may be acceptable to implement in care facilities where care staff are always busy and have relatively little time for learning new functions or tasks. Because the *Portrait* system would take little time to learn and the interface is simple, it may be feasible for use in care home situations.

7.3.1.8 Data Entry

Although the overwhelming impressions of the *Portrait* system were positive, managers did identify some important concerns particularly in the Data Entry and Technical categories. The most important concerns that arose in the Data Entry category related to who would enter the person with dementia's information, the time it would take to enter that information and the need for a simple data entry process. Comments such as *"so who enters all the information?"* were common among all three managers. Data entry was not shown to the care managers as the purpose of this study was to assess the usefulness and usability of the *Portrait* systems content and it was planned that families of people with dementia, not care staff, would be responsible for populating *Portrait.*

7.3.1.9 Time Negative

In the Time Negative category, the issue of data entry was also mentioned in relation to concerns regarding the amount of time that would be necessary to gather and enter the personal data and images for the individual *Portraits*. Example comments were:

"there would be a time factor that on top of their own written work and contact information that we need to have time to type that as well would be difficult." It is of most concern because additional data gathering and entry tasks would likely conflict with care staff's already busy schedule and the main task of caring for the people with dementia. It may also involve having the family collect the data and make it accessible to the care staff and/or the *Portrait* system. This is a key concern and one that requires considerable interface and process design consideration.

7.3.1.10 Technical Negative

The Technical Negative category had six comments but they were quite varied with no one clear issue in common to all managers. Examples of comments when asked if they experiences or could foresee any problems included *"I can't say I actually had any problems. I think I would like the print to be bigger because we have got staff who do wear glasses, and they might not have their glasses with them at the time for reading"* and *"it is going to have to involve staff training or just the basic use of a computer as well."* This is further reflected in the responses to question 4 on what information the care manager thought was missing with none selecting the same answer, one person saying "nothing", one person saying "other" and the third person saying that *"define each section clearer or the name of one of the sections was misleading."* This lack of any clear or common Technical Negative issue with the *Portrait* system suggests that the overall design of the system does not suffer from obvious usability issues.

7.3.1.11 Interface Suggestions

The categories Interface Suggestions and Time Negative were the least mentioned with only two comments in each category. Both comments in the Interface Suggestions category were related to the image of the resident at the top of the

screen e.g., *"would like a bigger picture of the resident."* It is not surprising that there were very few issues concerning the interface considering the positive results reported for the usability studies (see Chapter 6). As a result, no further interface modifications to the *Portrait* system were considered necessary before field trials began.

7.3.1.12 Portrait Content

Regarding specific comments on the actual content, all of the care managers mentioned that the 'Timeline' topic was the most interesting one. Reasons for this included that it highlights the most important parts of someone's life, as they lived it, providing an historical perspective in time whereas the other topics were overall summaries and had no pattern or relation to time.

No topic was identified as least interesting by the care home managers with one even stating *"I don't think that there is anything there that is least interesting. …. I think they are all relevant. I think they all have to be there."* It would appear that the topics selected during the initial interviews conducted at the beginning of this project were well identified and relevant to the care environment. However, further evaluation of the use and usefulness of each topic must be tracked when the system is in actual use.

7.4 Discussion

Overall, the system was very positively received by the care managers. These participants made closing comments such as *"I think it's great that everything is basically there - all of the key things,"*, *"I like it, I do like it a lot. I think it's got an awful lot of potential,"* and *"I think there is a huge amount of potential for it to*

personalise care." All three care managers thought that all staff could benefit from using the system *"I think all staff would benefit as there is so many changes around residents as you will have met someone new and you might not have seen Annie for a short while so you will have forgotten various things so you can just use this as a refresher."* These comments suggest that the *Portrait* system could be of benefit to care staff and people with dementia who live in care homes. There was no noticeable difference in the results from the different care managers resulting from the 'style' of care environment meaning the *Portrait* system could be of benefit to staff from all different types of care environments.

It was discussed that the *Portrait* system would allow care staff to quickly learn more information than is currently available about the person with dementia. This information could help care staff to have more natural and stimulating conversations with the person with dementia. It could enliven daily routines to include relevant and interesting interactions for both parties. Improvement to the social environment in a care home has been reported as vital to the social well being of residents and care staff alike (Ward *et al.* 2008, Armstrong-Esther *et al.* 1994).

The major concern with the system, however, was the data entry process, specifically who would gather, enter and manage the individuals and the time it would take to accomplish those tasks. These concerns and future directions for research will be discussed in Chapter 9: Study 4 – Family Case studies.

The small number of participants in this study is a clear limitation. The results were derived from three different care environments.   Despite this, the results, while suggestive, cannot be considered representative of the entire industry. However, this work does provide confirmatory evidence, together with the earlier work (see Chapter 6), for the usability of *Portrait*. Furthermore, the interviews with the care managers provide initial indications of the potential benefit of the *Portrait* system.

Given the overall positive reception to *Portrait* and the demonstrated usability, it was decided to proceed to the next level of research with actual care staff, people with dementia and families with the current system.

Chapter 8: Study 3 – Care Staff

This study was carried out with care staff to evaluate the usefulness of the content of the *Portrait* system, to evaluate the usability of *Portrait* with care staff with no previous experience of the system and to consider *Portrait's* usefulness in comparison to a paper equivalent (Booklet) of the information currently available to care staff within their care environment.

The study was conducted in three respective care homes: Two care homes from the same large care group (Care Home PB) and one from a smaller care group (Care Home D). The study was conducted using the same method in both care groups but results will be discussed separately due to the difference in the Booklet used by the two care groups. The aim of this study was not to compare different care home environments but to evaluate *Portrait* in different use-case scenarios.

8.1   Booklet

The paper Booklet is one of the commonly used tools within the care environment to introduce care staff to a person's life history and preferences.

8.1.1   Care Home PB Booklet

The booklet used within the Care Home PB is the Alzheimer's Society's *'This is me'* leaflet (see Section 4.2.2) that is designed for people with dementia who are going into hospital. *'This is me'* is intended as a simple tool to create and access. It consists of two A4 sheets of paper that someone with dementia going into hospital can give to staff to help them understand the needs of that individual.

8.1.2   Care Home D Booklet

The booklet used within the Care Home D is a self-made booklet called *'My Memories'* (see Section 4.2.3). *'My Memories'* was kept in each individual resident's room and could be used by both the resident and staff. It consisted of up to twelve A4 sheets of paper that contained information on that individual in the form of text and photographs about the person with dementia.

8.2   Method

The experimental session for each participant consisted of a pre-study questionnaire, familiarisation with *Portrait* and the appropriate Booklet, testing with *Portrait* and the Booklet, and finally a post-study questionnaire. Testing was conducted in individual sessions in a private office onsite at the respective care home where each participant worked. Sessions lasted approximately 25 minutes.

After completing the Informed Consent, participants were first asked to complete the pre-study questionnaire (see Appendix G – Study 3 – Care Staff). This questionnaire consisted of 9 questions and collected demographic data such as age and computer experience. The researcher devised this questionnaire to also gather information about participant's opinions of dementia and what information is important when getting to know a person with dementia and how useful they find this information.

Following the pre-study questionnaires, the Booklets and the *Portrait* software were introduced to the participants. For this study three individual's portraits (profile A, B and C) were used to populate separate entries into the *Portrait* system and the

equivalent paper Booklets. Two male and one female example portraits were used. These example portraits were from actual people. As with the previous studies (see Chapter 6: Study 1 – Usability of *Portrait* System and Chapter 7: Study 2 – Care Managers Initial Views), the same female example portrait was used to populate the *Portrait* system. These people, however, did not live in the participating care environments. Thus, these example portraits did not bias the care staff.

The information provided in the *Portrait* system and the Booklet was identical wherever possible. Due to the nature of the information contained in the different media, some differences, however, were unavoidable (see Table 6 - *Portrait* vs. Booklets differences). For example, the level of detail varied slightly (more in the *Portrait* system). In contrast, the *'This is Me'* Booklet contained some care information (about personal care, mobility, hearing, eyesight and medication) that the *Portrait* system did not cover. The initial needs analysis did not identify medical details as important personal information to know. This clinical/medical information is already currently available to care staff in the legally required care plan and is therefore not necessary in the *Portrait* system. The care plan has to be kept up-to-date with all medical needs to meet legal requirements. The *Portrait* system does not and the researcher was concerned that if this kind of information was contained in the *Portrait* system but care staff forgot to update it when changing medical information in the care plan people's health may be put at risk.

Table 6 - *Portrait* **vs. Booklets differences**

		Portrait
'This is Me'	• Only one photograph of the person • Contains care information (about personal care, mobility, hearing, eyesight and medication) • Handwritten • Limited to two A4 pages	• Multiple photographs • No care information. • Multimedia • Multiple screens of information
'My Memories'	• Printed Booklet	• Multimedia

Participants were provided with a brief introduction to the Booklet using profile A (approximately 2 minutes). Each participant was then provided with a brief introduction to the *Portrait* system also using profile A (approximately 2 minutes). The same profile A was used to provide an introduction to the *Portrait* system and the Booklet. Portraits B & C were counterbalanced and looped so that an even number of participants experienced the Booklet or *Portrait* system with the different profiles (see Table 7).

Table 7 - Study Structure.

Participant	First	Second
1	Booklet – profile B (Female)	Portrait System - profile C (Male)
2	Booklet – profile C (Male)	Portrait System - profile B (Female)
3	Portrait System - profile C (Male)	Booklet – profile B (Female)
4	Portrait System - profile B (Female)	Booklet – profile C (Male)
5	Booklet – profile C (Male)	Portrait System - profile B (Female)
6	Portrait System - profile B (Female)	Booklet – profile C (Male)
7	Portrait System - profile C (Male)	Booklet – profile B (Female)
8	Booklet – profile B (Female)	Portrait System - profile C (Male)
9	Portrait System - profile B (Female)	Booklet – profile C (Male)
10	Booklet – profile B (Female)	Portrait System - profile C (Male)
11	Portrait System - profile C (Male)	Booklet – profile B (Female)
12	Booklet – profile C (Male)	Portrait System - profile B (Female)

Participants were then navigated to profile B and asked to complete three simple training tasks (see Appendix G – Study 3 – Care Staff) to become familiar with using the system, either the Booklet or *Portrait*. They were then asked to complete five representative tasks that involved finding specific information about the person represented in the system (e.g., the names of her children and where she preferred to sit). Upon completion, they were then asked to find this information about the person described in profile C, this time using the other system (either Booklet or *Portrait*).

During the use of each system, participants were asked to think aloud their thoughts and opinions of each system. Audio and screen capture software (Camtasia™ version 7) were used to capture on-screen actions and commentary. This data were used to analyse positive and negative user experiences.

After completing the study tasks the participants were asked to complete the post-study questionnaire (see Appendix G − Study 3 − Care Staff). It consisted of 14 questions. Eleven of these questions used a 5-point Likert scale with 1 as the most positive answer and 5 as the most negative answer. One question asked participants to indicate their preference between two options. The remaining two questions were open ended and asked participants to answer questions based on the profiles they viewed (e.g. What was profile B/C's job?, What does profile B/C like to do in their spare time? and Does profile B/C have any children?). The questionnaire was designed to collect data on ease of use, preference of features, level of training required, how engaging each system was to use, and preference of system. The questionnaire also gathers information about participant's opinions of dementia but was not analysed given the brief examples of the study.

8.3   Participants

8.3.1   Care Home PB Participants

For the *'This is Me'* Booklet version of the study, the research was conducted in two different care homes but managed by the same large care group. The care group consists of a number of care homes throughout Scotland. The homes vary in terms of size and, thus, some operational details. All, however, use the *'This is Me'* Booklet described (see Section 8.1.1). Participants were recruited though the

management at the care home. All employees (day and night) in a care staff position at these homes were invited to participate. Due to scheduling conflicts, night shift and annual holidays, not all were able to take part in the study. The final group of care staff participants consisted of 20 care staff from one of the homes and 11 from the other. This was 47% of the total care staff (day and night staff) working at these two locations. It was 70.5% of the day staff.

Five of the participants were male and 26 were female, reflecting the gender balance in this occupation at the care homes. Participants varied in age between 18 and 60+ years. Their experience in the care environment varied from less than 6 months to over 5 years. Participants' computer use varied from 'never' to 'daily', the average computer use was a 'few days a week' demonstrating there is a wide variation in computer skills within the care environment. There were 24 of 31 participants with English as their first language. Fourteen had some personal experience with family members or friends with dementia beyond their professional contact with people with dementia.

8.3.2   Care Home D Participants

For the *'My Memories'* Booklet version, the study was conducted in a large care home (65 beds) from a different smaller care group. The care group consists of a number of care homes in the same area of Scotland. Care home D used the *'My Memories'* Booklet described (see Section 8.1.2). Participants were recruited though the management at the care home. All employees (day and night) in a care staff position at these homes were invited to participate. Due to scheduling conflicts, night shift and annual holidays, not all were able to take part in the study. The final group

of care staff participants consisted of 13 care staff. This was 26% of the total care staff (day and night staff) working at Care Home D. It was 39.4% of the day staff.

Three of the participants were male and 10 were female. Participants varied in age between 18 and 49 years-old. Their experience in the care environment varied from less than 6 months to over 5 years. Participants' computer use varied from 'Once every few months' to 'daily', the average computer use was again a 'few days a week'. There were 10 of 13 participants with English as their first language. Nine had some personal experience with family members or friends with dementia beyond their professional contact with people with dementia.

8.4   Results

The results of the study are discussed in this section without reference to the limitations of the study, which are discussed separately.

8.4.1   Care Home PB Results

8.4.2   Usefulness

Upon completion of both the *Portrait* and *'This is Me'* Booklet tasks, participants were asked to select "who do you feel you know better" (Q14): the person in the *Portrait* system or the person in the *'This is Me'* Booklet. This question showed a significant χ^2 result [χ^2 (1, 30) = 4.80, p<0.05] with 70% of participants selecting that they believed they knew the person in the *Portrait* system better regardless of order and profiles viewed. This was further confirmed with participant's response to "how well do you feel you know X" (Q3 & 12) with a one-way repeated measures ANOVA on condition (Booklet, *Portrait*) with Green-Geisser correction (correction

was used to correct for non-sphericity) showed that there was a significant effect of information presentation type on how well participants felt they knew the person in the *Portrait* and Booklet [F (1, 30) = 6.548, p<0.05].

Further tests were conducted to compare the effect of information presentation type on how engaged participants were (Q1 & 8), the amount of information presented (Q2 & 11) and how well participants retained information (Q4 & 13) in *'This is Me'* Booklet and *Portrait* system conditions. A one-way repeated measures ANOVA on condition (Booklet, *Portrait*) with Green-Geisser correction showed that there was a significant effect of information presentation type on how engaged participants were [F (1, 30) = 17.441, p<0.05]. These results indicate that information presentation type does have an effect on how engaged participants were and how well they thought they knew the person. Specifically, our results suggest participants from Care Homes PB found the *Portrait* system a more engaging method to view the example person's information than the paper-based *'This is Me'* Booklet equivalent and that they get to know the person with dementia more thoroughly using the *Portrait* system.

How well participants retained information (Q4 & 13) and the amount of information (Q2 & 11) presented had no statistical significance. A one-way repeated measures ANOVA on condition (Booklet, *Portrait*) with Green-Geisser correction showed that as with Care Home PB there was no significant effect of information presentation type on participants opinion of the amount of information contained (Q2 & 11) [F (1, 30) = 2.953, p=0.96]. There was also no significant effect of information

presentation type on how well participants retained information (Q4a, b, c & 13a, b, c) [F (1, 30) = 0.244, p=0.625], [F (1, 30) = 0.065, p=0.801], [F (1, 30) = 1.633, p=0.211].

8.4.3 Usability

A chi-square (χ^2) analysis was carried out on the five usability questions to examine whether there was any significant difference between responses and expected frequencies. All five usability questions (Q5, 6, 7, 9 & 10) showed significant differences (see Table 8 for all usability questions).

Table 8 - Usability Questions (1 is Very Easy, 5 is Very Difficult).

Usability Questions	
Q5	Rate how difficult it was for you to learn how to use the *Portrait* system?
Q6	What level of training do you think would be required to learn to use the *Portrait* system?
Q7	How confusing did you find the organisation of information on the *Portrait's* screens?
Q9	Rate how easy the following *Portrait* system features were to use (6 sub questions see Table 9)
Q10	Rate your level of preference for features (7 sub questions see Table 10)

Participants were asked to rate how difficult they found learning to use the *Portrait* system (Q5) and what level of training (Q6) they thought would be required. Both showed a significant χ^2 result [χ^2 (4, 30) = 37.33, p<0.05] and [χ^2 (4, 30) = 33.33, p<0.05] respectively. Twenty-nine of 31 participants (96%) rated the *Portrait* system as 'Very Easy' (1) or 'Easy' (2) to learn to use. Sixty percent of participants thought that it would take 'less than 30 minutes' (2) to learn how to use the *Portrait* system, 13.3% thought it would require 'no training' (1) and only 6.7% thought that it would take a maximum of 'half a day' (3) to learn to use. There was also a significant χ^2

result for the organisation of information on the screen (Q7) $[\chi^2(4, 30) = 64.33,$ p<0.05] with 76.7% participants rating the organisation of the screen as 'Very clear' (1) and no one selecting a negative rating for this question

A cross-tabulation correlation analysis was carried out with demographic factors of age and first language on the usability factors. There was no significant correlation between participant's age or first language and how easy they found learning to use the *Portrait* system or what level of training they thought would be required.

There was a significant χ^2 result to the level of p<0.05 for all of the ease of use factors (Q9) for the *Portrait* system as seen in Table 9. These questions asked participants to rate their level of agreement on a scale of 1 to 5, where 1 is 'Very Easy' and 5 is 'Very Difficult'. All of these features were rated as either 'Very Easy' (1) or 'Easy' (2) except for one participant who rated "knowing what to touch for more information" neutrally as 'not easy nor difficult' (3).

Table 9 - Rate how easy the *Portrait* system features were to use (1 is Very Easy, 5 is Very Difficult).

Question		χ^2(df)	M	SD
Q9.1	Knowing what to touch for more information	50.45(4)	1.61	.495
Q9.2	What information is available in the system	43.03(4)	1.61	.558
Q9.3	Reading information on the screen	50.45(4)	1.39	.495
Q9.4	Finding the information you wanted	47.23(4)	1.55	.506
Q9.5	Changing between topics	48.52(4)	1.42	.502
Q9.6	Using the system	46.58(4)	1.48	.508

Participants were asked to rate their preference for various features (Q10) of the *Portrait* system and there was a significant χ^2 results to a level of p< 0.05 for all factors (see Table 10). This question asked participants to rate their level of agreement on a scale of 1 to 5, where 1 is 'Like Very Much' and 5 is 'Dislike Very Much'. All of these features were rated positively.

Table 10 - Rate preference for features (1 is like very much, 5 is dislike very much).

Question		χ^2(df)	M	SD
Q10.1	Location of the menu buttons	47.23(4)	1.55	.506
Q10.2	Size of the buttons	47.23(4)	1.45	.506
Q10.3	Size of the text	46.58(4)	1.52	.508
Q10.4	Text font/style	48.52(4)	1.58	.502
Q10.5	Colour of the text	48.52(4)	1.58	.502
Q10.6	Colour of the screen	48.52(4)	1.58	.502
Q10.7	Match of the background colour to the button colour	48.52(4)	1.58	.502

8.4.4 Care Home D Results

8.4.5 Usefulness

As with the previous group, tests were conducted to compare the effect of information presentation type on how engaged participants were (Q1 & 8), the amount of information presented (Q2 & 11) and how well participants retained information (Q4 & 13) in *'My Memories'* Booklet and *Portrait* system conditions.

In contrast to the results from the other Care Home PB, participants from Care Home D did not show a clear preference for *Portrait* when selecting "who do you feel you

know better" (Q14): the person in the *Portrait* system or the person in the *'This is Me'* Booklet. This question showed no significant χ^2 difference for this group, with 53.9% of participants selecting that they believed they knew the person in the *Portrait* system better. There was however significance with participant's response to "how well do you feel you know X" (Q3 & 12) with participants rating that they felt they knew the person in the *Portrait* higher than the person in the Booklet. A one-way repeated measures ANOVA on condition (Booklet, *Portrait*) with Green-Geisser correction showed that as with Care Home PB there was a significant effect of information presentation type on how well participants felt they knew the person in the *Portrait* and Booklet [F (1, 13) = 11.739, p<0.05]. A possible reason for this difference between the two results is the level of detail in the example Booklet was better than the actual Booklets used within Care Home D. A number of care staff commented during the study that the example Booklet used had more pictures and was more complete than the ones they use in the care home. This happened as when the researcher was visiting Care Home D to investigate the Booklet used the care manager provided the 'best example' the care home had rather than an 'average' Booklet that more accurately demonstrated the amount of information provided to care staff.

A one-way repeated measures ANOVA on condition (Booklet, *Portrait*) with Green-Geisser correction showed that similarly to Care Home PB, there was a significant effect of information presentation type on how engaged participants were [F (1, 13) = 11.739, p<0.05]. These results indicate that again information presentation type does have an effect on how engaged participants were and how well they thought they knew the person. Specifically, the results suggest participants in this group

rated the *Portrait* system as a more engaging method to view the example person's information than the paper-based *'My Memories'* Booklet equivalent.

How well participants retained information (Q4 & 13) and the amount of information presented (Q2 & 11) again had no statistical significance in this study. A one-way repeated measures ANOVA on condition (Booklet, *Portrait*) with Green-Geisser correction showed that as with Care Home PB there was no significant effect of information presentation type on participants opinion of the amount of information contained (Q2 & 11) [F (1, 13) = 1.000, p=0.337]. There was also no significant effect of information presentation type on how well participants retained information (Q4a, b, c & 13a, b, c) [F (1, 13) = 1.929, p=0.190], [F (1, 13) = 0.187, p=0.673], [F (1, 13) = 2.182, p=0.165]. The care staffs limited time using the Booklet and *Portrait* within the study could have been the reason why there was no significance with how well information was retained.

8.4.6 Usability

Again with this care home data a chi-square (χ^2) analysis was carried out on the five usability questions (Q5, 6, 7, 9 & 10) to examine whether there was any significant difference between responses and expected frequencies. As with the previous group, participants were consistently positive about the ease of use of *Portrait*. All five usability questions again as with Care Home PB showed significant differences (see Table 11 for all usability questions).

Table 11 - Usability Questions (1 is Very Easy, 5 is Very Difficult).

Usability Questions	
Q5	Rate how difficult it was for you to learn how to use the *Portrait* system?
Q6	What level of training do you think would be required to learn to use the *Portrait* system?
Q7	How confusing did you find the organisation of information on the *Portrait's* screens?
Q9	Rate how easy the following *Portrait* system features were to use (6 sub questions see Table 12)
Q10	Rate your level of preference for features (7 sub questions see Table 13)

Participants were asked to rate how difficult they found learning to use the *Portrait* system (Q5) and what level of training (Q6) they thought would be required. Both showed a significant χ^2 result [χ^2 (4, 13) = 13.54, p<0.05] and [χ^2 (4, 13) = 28.92, p<0.05] respectfully. Eleven of 13 participants (84.6%) rated the *Portrait* system as 'Very Easy' (1) or 'Easy' (2) to learn to use. All 13 participants thought that it would take 'less than 30 minutes' (2) to learn how to use the *Portrait* system, 23% thought it would require 'no training' (1) to learn to use. There was also a significant χ^2 result for the organisation of information on the screen (Q7) [χ^2(4, 13) = 15.85, p<0.05] with 38.5% participants rating the organisation of the screen as 'Very clear' (1), 53.9% rating the organisation of the screen as 'Clear' (2) and again no one selected a negative rating for this question

A cross-tabulation correlation analysis was carried out with demographic factors of age and first language on the usability factors. In this study with Care Home D, there was also no significant correlation between participant's age or first language and

how easy they found learning to use the *Portrait* system or what level of training they thought would be required.

As with Care Home PB, there was a significant χ^2 result to the level of $p<0.05$ for all of the ease of use factors (Q9) for the *Portrait* system as seen in Table 12. These questions asked participants to rate their level of agreement on a scale of 1 to 5, where 1 is 'Very Easy' and 5 is 'Very Difficult'. One participants for each of the following question rated "knowing what to touch for more information", "finding the information you wanted", "changing between topics" and "using the system" neutrally as 'not easy nor difficult' (3), it was however not the same participant for any of the questions. All of the features otherwise were rated positively as either 'Very Easy' (1) or 'Easy' (2).

Table 12 - Care Home D - Rate how easy the *Portrait* system features were to use (1 is Very Easy, 5 is Very Difficult).

Question		χ^2(df)	M	SD
Q9.1	Knowing what to touch for more information	15.85(4)	1.54	.660
Q9.2	What information is available in the system	19.69(4)	1.46	.519
Q9.3	Reading information on the screen	24.31(4)	1.31	.480
Q9.4	Finding the information you wanted	15.85(4)	1.54	.660
Q9.5	Changing between topics	22.00(4)	1.38	.650
Q9.6	Using the system	18.15(4)	1.46	.660

Participants were asked to rate their preference for various features (Q10) of the *Portrait* system and there was a significant χ^2 results to a level of $p< 0.05$ for all factors (see Table 13) again as with Care Home PB. This question asked participants to rate their level of agreement on a scale of 1 to 5, where 1 is 'Like Very Much' and

5 is 'Dislike Very Much'. Unlike Care Home PB where all ratings were positive, a participant rated "text font/style" and "colour of the text" negatively as 'Dislike' (4), all other participants rated these two features positively with 'Like' (2) and 'Like Very Much' (1). Another participant rated "colour of the screen" neutrally with 'Don't Care' (3), otherwise all feature ratings were positive.

Table 13 - Care Home D - Rate preference for features (1 is like very much, 5 is dislike very much).

Question		χ^2(df)	M	SD
Q10.1	Location of the menu buttons	19.69(4)	1.46	.519
Q10.2	Size of the buttons	21.23(4)	1.38	.506
Q10.3	Size of the text	19.69(4)	1.46	.519
Q10.4	Text font/style	15.08(4)	1.69	.855
Q10.5	Colour of the text	15.08(4)	1.69	.855
Q10.6	Colour of the screen	15.08(4)	1.62	.650
Q10.7	Match of the background colour to the button colour	19.69(4)	1.54	.519

8.5   Discussion

8.5.1   Usefulness

In terms of *usefulness*, the *Portrait* system was overall rated more favourable by care staff in both studies than existing paper *'This is Me' and 'My Memories'* Booklets. The *Portrait* system was found to be more engaging to staff with care staff even asking the researchers if it was possible to have this system in their care environment. For example, comments such as *"The Portrait system is a lot more interesting and fun compared to the booklet"*, *"[the Portrait system is] easy to understand and quicker to get answers"*, *"It's quite difficult to remember and take in*

things from the booklet" were common. One participant even stated that *"I wish my Gran had this"*.

In terms of which participant they knew better, the person using the *Portrait* system or the Booklet showed mixed results from the two studies. There was a significant result of 70% of participants from Care Home PB preferring the *Portrait* system, whereas there was no significant result from Care Home D with 53.9% of participants selecting the *Portrait* system. This result was contradicted through the results of how well participants felt they knew the person in the *Portrait* and Booklet with both Care Home PB and Care Home D's results having significance and participants selecting that they felt they knew the person better via the *Portrait* system than via the Booklet. A possible reason for the difference between the two results is the difference in the Booklet used within each care home. The level of detail and amount of photographs in the *'My Memories'* Booklet used in Care Home D was higher than that of the *'This is Me'* Booklet used in Care Home PB. Another important issue to consider is the level of detail in the example *'My Memories'* Booklet used in the study was better than the actual *'My Memories'* Booklets used within Care Home D. When the researcher was visiting Care Home D to investigate the Booklet used the care manager provided the 'best example' the care home had rather than a 'average' Booklet that more accurately demonstrated the amount of information provided to care staff. A number of care staff from Care Home D commented on this difference during the study. The example *'My Memories'* Booklet used within the study having more detail than care staff from Care Home D were use to may be the reason why there was not a significant result for whom

participants felt they knew better but one for how well participants felt they knew the person in the *Portrait* and Booklet.

Neither Care Home PB nor Care Home D found a significant result in relation to how well participants retained information and the amount of information presented in the *Portrait* and *'This is Me'* or *'My Memories'* Booklets. The care staffs limited time using the Booklets and *Portrait* system within the study, care staff were only involved in the study for approximately 25 minutes, could have been the reason why there was no significance with how well information was retained.

8.5.2 Usability

In terms of usability, the *Portrait* system was very positively received by care staff with no usability issues being raised by participants. Earlier work on usability with managers of the care home thus successfully identified issues that would affect usability by the care staff (see Chapter 7: Study 2 – Care Managers Initial Views).

All care staff in Care Home PB rated the features of *Portrait* positively and there was only two care staff from Care Home D who did not rate the features of *Portrait* positively with one rating "colour of screen" neutrally and another rated "text font/style" and "colour of the text" negatively as 'Dislike'. All other participants from Care Home D rated these two features positively with 'Like' and 'Like Very Much' with 84.6% of participants from Care Home D and 93% of participants from Care Home PB rating the *Portrait* system as 'Very Easy' or 'Easy' to learn to use.

All participants from Care Home D and 60% from Care Home PB thought that the *Portrait* system would require 'less than 30 minutes' training (the lowest training option available) with 23.1% of participants from Care Home D and 13.3% from Care Home PB stating that it would require 'no training' to learn to use. One participant during the study stated *"I like the Portrait more 'cos it's easy and fast…it might need those people who's not very computer literate to have a short training."*. The researcher proposes that it may be an introduction to the *Portrait* system or computer-oriented training that is required rather than training specific to the *Portrait* system.

During the study the researcher observed that although no participants reported usability issues there were three minor issues. The name of two of the topics 'Timeline' and 'Things To Know' sometimes confused care staff. Some of the care staff were unsure which of these two topics would contain the information about life history or key life events and which topic would hold preferences and care related information. Changes were made to address this issue before placing the *Portrait* system in the care home (see Chapter 10: Study 5 – Care Home Study). The changes made were to use more meaningful labels for the two topics: 'My Life Events' (see Figure 17 - Timeline Topic Button and Figure 20 - Timeline Topic New Name) and 'Please Note' (see Figure 18 - Things To Know Topic Button and Figure 21 - Things To Know Topic New Name) that will make it more apparent what information is contained in each. To keep a consistence to the topic names 'Family Tree' was also re-named to 'My Family' (see Figure 22 - Family Tree New Name).

Figure 17 - Timeline Topic Button.

Figure 18 - Things To Know Topic Button.

Figure 19 - Family Tree Topic Button.

Figure 20 - Timeline Topic New Name.

Figure 21 - Things To Know Topic New Name.

Figure 22 - Family Tree New Name.

Within the 'Hobbies & Interests' and 'Family Tree' topic care staff sometimes tried to touch the screen for more information on these topics despite their being no instruction to do so. These are the only two topics that do not contain additional information (therefore, touching the screen results in no further action). It is proposed in future research to change the structure of the information in these two topics so that touching the screen will result in further information. Alternatively, a "further information" button could be added to the other screens and a label stating that there is no further information is available on screens where there is no further information. This may reduce the confusion, making it more obvious when touching the screen will result in further information being displayed. The last point of some confusion was within the 'Family Tree' topic where some care staff did not quickly identify where the person's spouse's name was located. As you can see in Figure 10 (page 66) it is the only entry not aligned to the left of the screen. When re-designing

this topic to add "further information" functionality, it will be essential to ensure all entries are aligned appropriately to allow for easier identification.

8.6 Limitations

Important limitations of this study were its relatively short time frame, the limited number of profiles available and that care staff had only one opportunity to work with either system. Participants were only involved in the study for approximately 25 minutes. This time frame was selected due to the busy schedule of care staff. The researchers did not want to prevent them from completing their duties but this also limited their use of the two systems. Care staff may have wanted to use the system longer but were prevented from doing so due to the potential interference with their normal duties. This limited time for use did not, therefore, allow us to collect data on information retention.

Finally, the care staff were only exposed to either system once. However, it should be noted that the paper-based Booklet system was more familiar to care staff as this was their existing system. The *Portrait* results could be a novelty effect and care staff may not be as positive with more regular or long term use. Longer term use with more profiles may provide improved opportunities to evaluate the long term effectiveness of the *Portrait* system.

A further limitation relates to the current practices at the care homes. When visiting the care environments to investigate their current paper method, we were shown the 'best' example of the information available to care staff. It was not until carrying out

the study that a large proportion of care staff mentioned that they had not seen these Booklets or that the example Booklets have more information than the ones currently being used. In future studies the researchers would randomly select resident's Booklets to fairly evaluate the level of information available to care staff.

The Booklets used in this study cannot be considered representative of the entire industry and should be considered as providing preliminary evidence of the benefit of the *Portrait* system compared to current paper-based methods.

8.7   Conclusion

Critically for usefulness, the data revealed that the care staff participants felt that they got to know the person with dementia better when using the *Portrait* system than when using the *'This is Me'* or *'My Memories'* Booklets. Participants from Care Home PB also selected that they knew the person in the *Portrait* more than the *'This is Me'* Booklet. Perhaps the more engaging presentation helped create this effect.

In terms of usability, the *Portrait* system was very positively received by care staff with no major usability issues being raised and only three minor issues observed. Participants rated the *Portrait* system highly with comments such as *"Portrait information is very easy to find"*, *"Booklet takes more time to find what you are looking for"*, and *"[the Portrait system is] easier and quicker"*.

Given the overall positive reception to *Portrait* by care staff and the demonstrated usability, it was decided to proceed to the next level of research involving the

families (see Chapter 9: Study 4 – Family Case studies) of people with dementia and placing the *Portrait* system in a care environment (see Chapter 10: Study 5 – Care Home Study).

Chapter 9: Study 4 – Family Case studies

An important issue arose during previous studies (see Chapter 7: Study 2 – Care Managers Initial Views) with respect to who would provide the information for the *Portrait* system and how would this information be gathered. A study with families of people with dementia who live in a care environment was carried out to examine:

a) How the information required for populating the *Portrait* system would be collected.

b) Who would be involved in this collection process?

c) How time consuming and difficult is populating *Portrait*?

d) What information would be included in the *Portrait*?

e) Is it possible for family's to create *Portrait's* of their relative?

The *Portrait* system is designed to help care staff get to know people with late-stage dementia who live in care environments, as such participant families for the study were recruited with the co-operation of two care homes from the same care group that had completed previous studies (Care Home PB from Chapter 8). As people with late-stage dementia can have communication difficulties and due to ethical issues, the researcher recruited the families to take part in the study rather than the people with dementia. To ensure there was no disruption to the person with dementia's daily activities or health care the researcher only interacted with the families.

As *Portrait* is for people with late-stage dementia living in care environments it is likely that in many (perhaps most) of the cases the *Portrait* of the person will be created not by them, but by a family member. While it could be hoped that the family's information about the person accurately represents the person's life and preferences, it can be imagined that if the person were writing their own portrait some of the information would be different. In this respect, future research should seek to have persons newly diagnosed with dementia involved, to begin capturing important information about their lives.

9.1 Method

Participants were recruited through their relative's respective care home. The researcher attended a 'Relatives Meeting' at each care home. The Relatives Meetings were held every three months for the care managers to let relatives know what was happening in the care home and to allow families to raise any concerns or issues. All relatives listed as the main contact for residents in the respective care homes were written to and informed that the researcher would be present at the meeting to demonstrate *Portrait* and recruit participants.

At each respective care home the Relatives Meetings were well attended and the researcher demonstrated the *Portrait* system using three example *Portraits* (see Appendix I – Example *Portrait*) to show families what type of information the system could contain. As with the previous studies (see Chapter 6: Study 1 – Usability of *Portrait* System, Chapter 7: Study 2 – Care Managers Initial Views and Chapter 8: Study 3 – Care Staff), the same three individual's portraits were used to populate separate entries into the *Portrait* system. Two male and one female

example portraits were used. These example portraits were from actual people. These people, however, did not live in the participating care environments. Thus, these example portraits did not bias the families. Families were then shown the 'Portrait Creation Pack' (see Appendix H – Portrait Creation Pack) which consisted of 6 forms to complete to help guide families while gathering the information required for the Portraits. The Portrait system was positively received by the families with many expressing an interest in the study. All families were made aware that the Portrait's created in this study were to be placed in the respective care home for the care staff to use (see Chapter 10: Study 5 – Care Home Study).

In the initial care home (Care Home P) visited, one family was recruited. Three families were recruited in Care Home B. Once families were recruited a meeting was arranged with each family either at the care home or their own home. At this meeting the Portrait system was again demonstrated to the families and they were allowed to use the system for as long as they wished. Once all questions were answered by the researcher, the families were given a verbal explanation of the study along with an information sheet and were asked for informed consent in compliance with the University of Dundee's ethical guidelines.

Data were collected using a pre-study questionnaire (see Appendix J – Study 4 - Family Case Studies) and observations. The pre-study questionnaire consisted of 13 questions and collected demographic data such as age, relationship to the person with dementia and time in care environment. The pre-study questionnaire also gathered information about participant's opinion of how long it would take to gather

the *Portrait* information, who they anticipated would help and how they would collect the information.

During the process of gathering the information for the portraits, the researcher kept in contact with the families having regular meetings to answer any questions and assist the families when needed. As one of the aims of this study was to see what type of information would be selected for inclusion by families in *Portrait,* the researcher did not help with identifying the content to include, only answering questions related to content length.

Once the families had gathered all the content for the *Portraits* the researcher manually entered the information into the *Portrait* system. The researcher directly transferred the data provided by the families in the '*Portrait* Creation Pack' forms to the corresponding XML files (see Chapter 5: System design and development: XML Documents vs. Database). When completed, the final *Portrait* was shown to the families. If the families required any changes these were addressed before the completed *Portraits* were placed in the respective care home for use testing (see Chapter 10: Study 5 – Care Home Study).

9.2   Participant 1

At the time of the study, Miss E was an 83-year-old Scottish female and had been living in the specialist dementia unit of Care Home P for 4 years. This was Miss E's only care environment. Prior to entry she was living independently in the community. Miss E had been diagnosed with dementia for over 5 years. Her family

described her as having late-stage dementia, stating that she no longer spoke, and rarely said random words. They stated that she enjoyed company and looking at her photo albums.

It was Miss E's niece-in-law (V) who consented to participate in the portrait creation and was the researcher's only contact from the family during the study. Miss E was never married and had no children but had been very actively involved in her two nephew's families. Her nephews and their wives were her main family carers and oversaw her care.

At the time of the study, V was a retired female over the age of 60. She intended to complete the information for the *Portrait* in two or three sittings, in under a week, with the help of her husband and his brother and sister-in-law (Miss E's nephew's and wife).

9.2.1   Portrait Creation Process

The researcher visited V a total of 4 times during the process of gathering the information. Due to the participants' holidays the follow up visit to evaluate the progress of the information gathering and to answer questions was two weeks after the initial visit to V. V provided the *Portrait* information in sections, completing one section completely before starting another. Two of the meetings with V lasted over an hour (first and final) and two were very brief lasting only ten minutes when the researcher collected the completed information. It was found that V wanted to discuss Miss E's standard of care and progression into the care home with the

researcher. When this occurred the researcher redirected the conversation back to the *Portrait*.

V took over two months to complete the *Portrait*. For this reason the completed *Portrait* was not able to be included in the Care Home Study (see Chapter 10: Study 5 – Care Home Study). V stated that she found gathering the information enjoyable but spent a long time waiting for other family members to provide her with the photographs she needed for the *Portrait*.

9.3 Participant 2

At the time of the study, Mrs MM was an 86-year-old Scottish female and had been living in Care Home B for 3 years. This was the only care environment Mrs MM had lived in. Prior to entry she was living with her husband at home. Mrs MM had been diagnosed with dementia for over 5 years. Her family stated that she sustained two strokes seven years ago, when she was 78. This was followed by the onset of dementia and the loss of mobility. Mrs MM's family visit her every other day, taking her out of the care home for the afternoon to go for a drive, picnic or dinner.

It was Mrs MM's son (D) that consented to participate and was the researcher's only contact from the family during the study. Mrs MM is married with her husband still living in the family home and she has two sons. D lived locally and visited every other day. Her other son visited regularly at the weekends.

At the time of the study, D was a male between the ages of 50-59. D was an author who worked from home. D intended to complete the information for the *Portrait* a section at a time, in 1 - 2 weeks, by himself. D was recruited to participate in the study by Care Home B's manager before the Relatives Meeting as the care manager felt this would be a project he would be very interested in. D keeps a regular blog about the experience of visiting his mother in the care home that was shortlisted for the Orwell Prize.

9.3.1 Portrait Creation Process

The researcher visited D three times throughout the *Portrait* creation process, once when the *Portrait* system was demonstrated to him, again at the Relatives Meeting and finally at the demonstration of the completed *Portrait*. D preferred to keep in touch with the researcher through email as he often had to travel for work.

D took over a month to complete the process but emailed all of the required content in one batch. When viewing the completed *Portrait* D stated that he only took a day to gather and complete the required information. It took over a month to complete the study, however, as although he rated gathering the information as an important task to complete he had many higher priorities so did not start the process for over three weeks. D stated that once he made the decision to make gathering the *Portrait* information his top priority he was able to complete it easily within one day.

D found gathering the information quite an easy task as Mrs MM had been exceptionally organised. Mrs MM kept detailed diaries and sorted all of her

photographs into albums with details of where the photographs were taken, when and with whom. For this reason D felt identifying what events/topics to include was easy and was very confident that the information he provided was accurate. The easily accessible photographs meant a very full and detailed *Portrait* of Mrs MM's life was created.

9.4   Participant 3

At the time of the study, Mrs Ma was a 95-year-old Scottish female and had been living in the Care Home B for 1 and a half years. This was Mrs Ma's only care environment. Prior to entry Mrs Ma was living on her own at home. Mrs Ma did not have dementia. As Care Home B was not a specialist dementia unit there were a wide variety of different care needs within the environment. Mrs Ma entered the Care Home B due to physical health needs including poor eyesight. Three members of Mrs Ma's family (Daughter, Son-in-law and Granddaughter) were present at the Relatives Meeting when the *Portrait* system was demonstrated and felt that although intended for people with late-stage dementia they would like to take part. The family believed helping care staff to know more information about any resident was a good idea.

It was Mrs Ma's granddaughter (T) who consented to participate and was the researcher's only contact from the family during the study. Mrs Ma had a large family with frequent visitors. Mrs Ma was married but her husband had passed away, she had 4 children, 10 grandchildren and 15 great-grandchildren.

At the time of the study, T was a female between the ages of 30-39 and was working away from home Monday to Friday. T intended to complete the required information for the *Portrait* a section at a time by identifying photographs first, in between 1 and 2 weeks, with the help of her Mother (Mrs Ma's Daughter) and Mrs Ma herself.

9.4.1   Portrait Creation Process

The researcher visited T three times throughout the *Portrait* creation process, once at the Relatives Meeting, again when the *Portrait* system was demonstrated to herself, and finally at the demonstration of the completed *Portrait*. T preferred to keep in touch with the researcher via email as she was away Monday to Friday most weeks.

T took two weeks to complete the process and emailed all of the required content in one batch. When viewing the completed *Portrait* T stated that she went through family photographs and identified the key points she wanted in the *Portrait*. Once these points were identified she discussed them with her Mother and Mrs Ma to confirm these were what Mrs Ma wanted covered and that the information was accurate.

T found collecting the information was quite an easy task and completed all of the information in one sitting. Having the help of T's Parents and Mrs Ma herself made the process of gathering the information simple and quick. T stated when demonstrated the final *Portrait* that she found the process enjoyable as it allowed her family to remember a lot of happy memories. T felt she would strongly recommend making a *Portrait* to other families.

9.5   Participant 4

At the time of the study, Mr P was an 83-year-old Scottish male and had been living in the Care Home B for 2 years. This was Mr P's only care environment, prior to entry he was living at home with his wife. Mr P also did not have dementia. Mr P entered Care Home B due to physical health needs resulting from Parkinson's disease. Mr P was recruited to participate in the study by Care Home B's manager, after the Relatives Meeting the care manager approached the researcher stating that Mr P would like to participate. The care manager stated that Mr P would be capable of participating in the project and that she would assist him if necessary.

It was Mr P that consented to participate and was the researchers only contact during the study as Mr P did not want his family's assistance. Mr P had regular visits from his wife and two sons. At the time of the study, Mr P was not able to write very easily due to his Parkinson's disease. Due to this he stated that he would much prefer to answer questions orally. Mr P did not complete the pre-study questionnaire. It was felt by the researcher too difficult for Mr P to physically complete and less relevant as it had been designed for the family of a person and he was participating in the study himself. Mr P was able to complete the consent form to participate in the study.

9.5.1   Portrait Creation Process

The researcher visited Mr P three times during the *Portrait* creation process, when the *Portrait* system was demonstrated to himself, to gather photographs and finally at the demonstration of the completed *Portrait*. All meetings took place in Mr P's room within the care home as he was most comfortable here.

During the initial demonstration of the example *Portraits* the researcher took detailed notes as Mr P stated what he could have in each section. During this meeting Mr P spent some time showing the researcher his personal photographs and explaining them. The initial meeting lasted approximately one hour. After the meeting the researcher gathered the information provided by Mr P into the appropriate topic. The researcher formed a list of questions to complete missing or gather more detailed information. The care home manager asked Mr P the questions and completed the answers on his behalf. With this additional information the researcher was able to identify which of Mr P's photographs would be required for the *Portrait.* The researcher asked Mr P for photographs he would like to show care staff that was relevant to each topic, once the photographs were identified they were copied at the home to ensure Mr P was not missing them for any length of time.

As Mr P did not have any photographs of his time spent in the Royal Observer Corps but it was a very important to him, the researcher gathered some generic photographs of the ensign and badge. At the final demonstration of the completed *Portrait* Mr P was delighted at seeing the generic photographs enquiring how the researcher managed to find them. Mr P was very happy with the final *Portrait* but was concerned that it stated his wife's name in the system and worried that she might not like being named in the system. The researcher reassured Mr P that it could be removed immediately and that the *Portrait* could be shown to his wife before any care staff used the system to ensure she was also happy with the content. Mr P

decided to leave his wife's name in the system as he felt it could be easily removed later if she wanted.

9.6 Discussion

Through this study involving different families it has become apparent that it is possible for families to create *Portrait's* of their relatives. An unexpected result from the study that will require more research in the future is the possibility of expanding the *Portrait* system to be used for all people who live in a care environment not just people with late-stage dementia. The family of a person who did not have dementia and a resident themselves requesting to participate in the study demonstrates that the information contained within the *Portraits* is not just relevant to people with late-stage dementia and could possibly have benefits to all residents within a care environment.

The information required for populating *Portrait* was gathered in different ways by each family with some selecting photographs and matching information and others identifying topics and matching photographs. A more structured process with immediate feedback as to how the *Portrait* will look could be of benefit to families in helping with motivation and identifying what still needs to be collected. It was noticed by the researcher when creating the *Portraits* that every family had provided additional or 'spare' photographs or information. If the family was creating the *Portrait* while gathering the information this would not happen as the instant feedback would allow them to see what topics of information were completed.

Previous studies such as *Multimedia Biographies* and *Biography Theatre* involving the families of people with dementia in the process of gathering information about their relatives life found similar results in that families found the process enjoyable, a good opportunity to reminisce about past memories and that it is feasible for families to develop a portrait of their relatives life (Massimi *et al.* 2008, Smith *et al.* 2009,) Damianakis *et al.* 2009, Baecker and Marziali *et al.* 2006). The process of gathering information for in the *Portrait* system did not take as long as in the previous studies conducted with the average process taking one month and the longest involvement in the study being two months. This may have been because the level of detail in the *Portrait* system was less than in *Multimedia Biographies* and *Biography Theatre* as the target user was not the person with dementia but care staff (Massimi *et al.* 2008 and Smith *et al.* 2009). Also the *Portrait* system in general did not actively involve the person with dementia as it was targeted at people with late-stage dementia who ethically could not consent to participate. Meaning the families were responsible for the collection of the information and there was not the issue of the person with dementia suffering 'fatigue' during the process and therefore postponing the collection until another session (Smith, *et al.,* 2009).

Who would be involved in the collection process will depend fully on the family's current situation and structure. There is no set answer to identify who would complete the *Portrait* with every family having a unique situation. The information included in the *Portraits* was all very different and unique in certain topics, such as 'Please Note' which contained preferences for some people and important family information for another. There was a similarity in other topics, such as 'My Life Events' where childhood, working life and family was often discussed. Further

research with families would possibly start to identify more common patterns as to the type of information contained in the *Portrait* system.

How time consuming and difficult families find populating *Portrait* again depends on the situation of each individual family. Families with access to organised photo albums or diaries can identify the information easily and quickly. Whereas families who have simply, a box full of photographs in no order may find it more time consuming. Although there was a large variation in the time taken by each participant to gather the information for the *Portrait,* none of the participants stated that they found it a particularly difficult process. Participants waiting for information from other family members or having more important tasks to complete had the largest effect on how long the gathering of the *Portrait* information took, rather than families finding it a difficult or time consuming process.

The participants described in these case studies successfully created unique portraits to be used in the *Portrait* system. Three of the *Portraits* developed during this study were then placed into Care Home B to evaluate the system with care staff in a care environment (see Chapter 10: Study 5 – Care Home Study).

Chapter 10: Study 5 – Care Home Study

This study was carried out with the portraits developed in the previous study (see Chapter 9: Study 4 – Family Case studies). Three of the portraits developed were placed in Care Home B to evaluate the use of the *Portrait* system with care staff within the care home. This study was conducted to examine the frequency of use of the *Portrait* system by care staff, the length of use of the *Portrait* system, to investigate the use of each topic ('My Life Events', 'My Family', 'Please Note', 'Hobbies & Interests', 'Family Stories' and 'Photo Album') by care staff and to examine the *Portrait* system in a care environment.

10.1 Participants

The study was conducted in Care Home B, a care home used in previous studies (see Chapter 8: Study 3 – Care Staff and Chapter 9: Study 4 – Family Case studies). Care Home B was a 32 bed facility on two levels with a total of 22 staff of which 15 were care staff. Twelve of the care staff had previously participated in a study using the *Portrait* system (see Chapter 8: Study 3 – Care Staff).

10.2 Method

The *Portrait* system with the three portraits was placed in a ground floor hallway beside the nurses' station, between the residents' bedrooms and the living rooms. All staff were given access to the system as the care home manager thought more than just the care staff could be interested in and benefit from using the system. All staff who worked at the home, therefore, were given a unique password for login. Only data for the 15 the care staff were analysed, however as the other 7 staff did not directly interact with the residents as part of their job.

No staff members were given any additional training to use the *Portrait* system. As almost all the care staff had previously been given a brief (approximately 2 minutes) introduction and subsequently used the *Portrait* system during a previous study (see Chapter 8: Study 3 – Care Staff), it was felt unnecessary to give a repeat introduction.

The *Portrait* system was placed in the care home and was left permanently switched on. Thus, the care staff required no setup to use the system, needing only their unique password to login. The researcher asked the care manager to inform all staff of their password and to encourage them to access the *Portrait* system.

The *Portrait* system logged the following data:

- user login by password, to track who was using the system;

- user login time, as measured from time of successful password entry to logout (by clicking the logout button);

- which portraits and length of time for each;

- which topics were viewed and length of time for each.

The post-study questionnaire consisted of 4 questions: One question asked participants to indicate their preference between two options, two questions used a 5-point Likert scale to rate how frequently the participants used *Portrait* and if they did not use *Portrait* why, and the fourth was an open-ended question asking participants

for any comments or recommendations. The questionnaire (see Appendix K – Study 5 – Care Home Study) was designed to collect data on participants' use of *Portrait*, if they did not use it, why, and their general opinions about it.

10.3 Results

The *Portrait* system was in the care home for four weeks (28 days). A total of 12 out of 15 care staff used the *Portrait* system at least once with 8 care staff repeatedly accessing the system (see Table 14 - Care Staffs individual use of *Portrait*). The system was viewed a total of 62 times during the 4 weeks (28 days) with 59.68% of these uses within 1 week (7 days) of being placed in the care home (see Figure 23 - Care Staff use of *Portrait* over time). Although Figure 23 shows a downward trend in the number of uses per day over the four weeks, the total number of viewings in weeks 2, 3 and 4 are very similar with 8, 9 and 8 uses respectively (see Figure 24 - Total *Portrait* Use (Week View)). This result needs further investigation to evaluate if the *Portrait* systems use by care staff may eventually plateau.
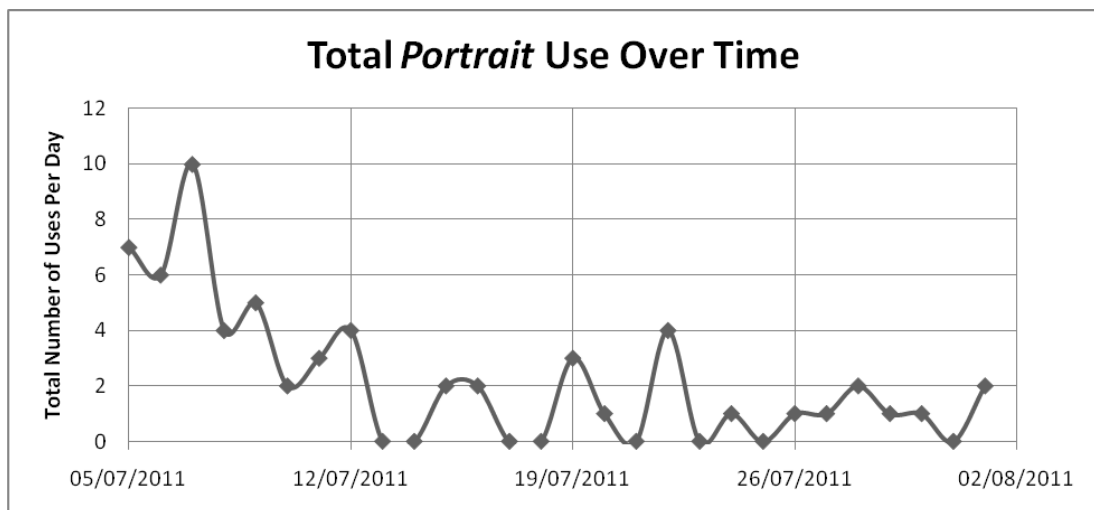
Figure 23 - Care Staff use of *Portrait* over time – showing the total number of logins per day.
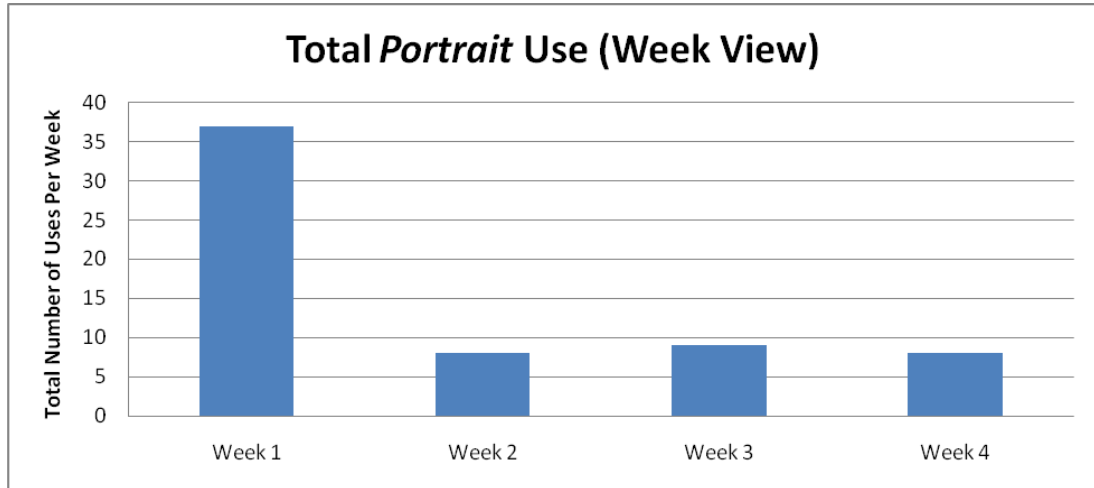
Figure 24 - Total *Portrait* Use (Week View) – showing the total number of logins per week.

There were 14 (22.58% of total logins) 'false' logins to the *Portrait* system (see Table 14 - Care Staffs individual use of *Portrait*) where a user logged in then logged back out having not selected a portrait to view or accessed any topics. It is presumed these short uses where care staff quickly logged out having not viewed any information were due to another task arising. Of the 62 times the *Portrait* system was accessed, 48 times care staff actually viewed information and 29.17% these 48 uses care staff looked at multiple portraits. This may mean that care staff do not access the *Portrait* system with the aim to find a specific fact or piece of information. Rather, they may be accessing to gain a fuller understanding of the people contained in the *Portrait* system.

Table 14 - Care Staffs individual use of *Portrait* - shown for each participant are the number of 'False' logins, the total of real logins (the total logins minus the false logins), the total time used for real logins and the percentage of time each looked at multiple portraits.

Participant	'False' Logins	Real Logins	Total Time Used (seconds)	% of Times Multiple Portraits Viewed
1111	2	16	5149	31.25
1112	0	2	513	50
1113	2	4	1697	25
1114	0	1	62	0
1115	0	1	97	0
1116	0	3	831	66.66
1118	2	12	1255	16.66
1119	1	2	608	50
1121	0	3	213	33.33
1123	4	1	39	0
1124	0	0	0	0
1125	1	2	396	0
1126	0	0	0	0
1134	0	0	0	0
1135	2	1	858	100

The *Portrait* system was accessed for a total of 3 hours 15 minutes and 18 seconds, with 'real' logins the mean length of use of *Portrait* being 244.12 seconds (4 minutes 4 seconds approximately). The 'false' logins are not being included in the final total use of the *Portrait* system as care staff did not actually access any information in the *Portrait* system during 'false' logins. 'false' logins were when the user logged in but then did not actually select any person to view. There was also an auto logout function. There were two prolific care staff users based on number of separate uses of *Portrait,* accessing the system 16 and 12 times for a total of approximately 1 hour

25 minutes 49 seconds and 20 minutes 55 seconds respectively (see Table 14 - Care Staffs individual use of *Portrait*). It was originally expected to see a longer initial use by care staff as they initially investigated and became familiar with the resident's in the *Portrait* system, then the length of time viewing *Portrait* would decrease as care staff became familiar. This however was not the case with there being no apparent pattern to how long care staff accessed the *Portrait* system. As the number of visits to the *Portrait* system increased the length of each use did not necessarily decrease (see Figure 25 - Length of use of *Portrait* Over Time – showing the total length of each login over time).

Figure 25 - Length of use of *Portrait* Over Time – showing the total length of each login over time.

Table 15 shows that the different topics of information were viewed a total of 241 times in the total 48 'real' uses of the *Portrait* system. The 'My Life Events' (Timeline) topic was the most accessed by care staff being viewed a total of 52 times, 21.58% of total number of topic viewings for 13 minutes 20 seconds. Different care staff preferred different topics of information each viewing different topics more or less frequently depending on their personal interests. The least viewed topic was 'Please Note' (Things To Know) with only 11.62% of the total viewings. 'My Family' (Family Tree) although not viewed as frequently as 'My Life Events'

(Timeline) or 'Photo Album' had the longest time spent actually viewing the information in the topic, this could be because although not visited as frequently by care staff they possibly spent more time reading the information contained in the topic therefore not needing to repeatedly visiting the topic.

Table 15 - Care Staffs use of individual Topics.

Topic	Total Uses	Total Time (seconds)
My Life Events (Timeline)	52	800
My Family (Family Tree)	37	1392
Please Note (Things To Know)	28	573
Hobbies & Interests	37	537
Family Stories	40	1027
Photo Album	47	1029

Of the eight participants who completed the post-study questionnaire all indicated that they had used the *Portrait* system as is consistent with the data. No participant selected the highest rating of using *Portrait* 'a lot', with three participants selecting 'several times'. It is of interest that the two prolific users, with over 10 viewings each, selected this category. Two participants selected that they had only used *Portrait* 'once' with one of these participants selecting that they 'forgot to look at it' as their reason for only viewing the *Portrait* system once. A participant selected that they used *Portrait* 'infrequently', stating in the open-ended question that they 'already know the resident well.' This participant commented that *"I thought that the Portrait system was to give details of all the residents not just three"* this comment was also mirrored in comments made to the researcher during the follow up visit to the care home where care staff commented that *"it would have been nice*

to have more people". It was anticipated that care staff would comment on only having three portraits, as with only three portraits to view using the *Portrait* system could become repetitive. Two participants selected that they used the *Portrait* system 'occasionally' with one of these participants stating that they found *Portrait* *"Quite helpful as I am a new member of staff here. I think this is a good idea knowing and seeing a client as a person, an individual who used to have a good job, a good life not a person with an illness"*. This comment is a very positive result as the aim of *Portrait* was to assist care staff to get to know residents as people and to help them focus on more than the physical care of a person. None of the three care staff that did not use the *Portrait* system completed the post-study questionnaire.

10.4 Discussion

This study investigated the use of the *Portrait* system by care staff within their care environment. The results of this study showed that the *Portrait* system could be integrated into a care environment and successfully used by care staff. A participant commented *"In the short time that I have used the system I have found it to be very useful and would ask other clients to participate, which would help staff with vital information"* demonstrating that *Portrait* could be of benefit to care staff by helping them to learn some important information. The researcher proposes that the *Portrait* system could be used by care staff with a limited introduction to the system's content and no long-term training. This is supported by the findings that care staff successfully used *Portrait* during this study and no care staff had any lengthy training or had even seen *Portrait* for approximately two months.

The total number of times each different topic was accessed may be explained by the quantity of information available in each. 'My Life Events' (Timeline) has the most detail and was viewed the most frequently where as 'Please Note' (Things To Know) is limited to a maximum of six bullet points of information. This variation in level of detail may mean care staff are more quickly able to access and retain the information in 'Please Note' (Things To Know) than that of other more detailed topic. A further long-term study with care staff is required to fully understand the use and benefits of each individual topic.

Future research is needed to fully investigate the long-term use of the *Portrait* system in a care environment, specifically with more residents in the *Portrait* system. The limited number in this study will have affected care staff's use of the system due to repetitiveness. Care staffs holidays and working hours were not investigated in this study and could have affected the use of the *Portrait* system and also needs further analysis. Investigating the use of the *Portrait* system when a new resident enters the care environment or integration in new care staffs training is also vital to evaluate *Portraits* full potential and benefits to a care environment.

Chapter 11: Conclusions

This chapter discusses the overall contribution to knowledge of this thesis and summarises the thesis work, referring to each specific research question as outlined in Chapter 1. Finally the chapter concludes by discussing possible areas of future research and an overall summary of the thesis.

11.1 Contribution to Knowledge

This thesis directly investigated care staff as a user group and the application of technology within their working environment. It identified key factors of care staff as a user group and implications of conducting research within a care environment. It examined the processes involved in the identification of the content of a *'Portrait'* of a person with dementia and investigated the gathering of information by families to create such a portrait. In doing so, *Portrait*, a software tool was systematically developed and evaluated in care environments by care staff for usability and usefulness of this technology in their working environment. Thus the studies reported in this thesis have not only examined and identified care staff as a user group and explored how families would gather information for and create portraits of their relatives, but have also identified approaches to integrating technology into care environments. New application areas for technology are constantly being sought. In particular, areas where such applications of technology could be of benefit or could improve people's lives, specifically focussing on new or under represented user groups.

Firstly, the literature review identified a gap in knowledge with respect to the use of technology with care staff (not trained nurses) in the care environment. There is a finite area of research or studies conducted with care staff. A limited knowledge of this user group and the application of technology to aid in their working environment exist. This thesis describes the identification of this area and systematic processes involved in development and evaluation of a tool to meet the needs of care staff. It identified key areas of information absent or sought after by care staff, investigated the processes involved for families collecting this information and evaluated the usability of this technology by care staff in their working environment.

11.2 Technology Integration in Care Environments

The principle research question of this thesis was identified firstly by a gap in knowledge found through the initial literature review with respect to the use of technology within a care environment by care staff.

Question 1-

How can technology be used to support care staff to get to know people with late-stage dementia within their working environment and what are the important considerations in developing such technology?

This thesis has illustrated through the development and evaluation of the *Portrait* software that innovative, simple and novice applications of technology can be used to support care staff in their working environment.

11.2.1 Discussion

11.2.1.1 Care Environments

Care Environments pose a number of different issues when integrating technology within them. The first issue is a physical consideration when designing technology that is to be placed in a care environment, mainly health and safety. A care environment's principle function is to provide a safe environment for its residents. Therefore, any technology used must not affect this requirement. There must be careful consideration when identifying any physical hardware for use within such an environment focusing on the questions: Where is the technology going to be located? Who are going to be the principal users? Who will have access to the technology? Any hardware placed in a public or communal area of a care environment must be durable as more than the intended users may investigate the device. There cannot be wires or leads which pose a risk to health and safety. The inclusion of sound requires careful consideration as care environments can be noisy and if the technology is to be placed in a communal area it could disturb the residents or be inaccessible to care staff. Will the technology require any set-up to use or maintenance to continue use and, if so, how will this be done and by whom? Care staff have very busy routines with little free time to set-up or maintain technology every time they wish to use it. The availability of technology considered commonplace must also be considered as older care environments may not have such technologies readily available (i.e. Internet outside the office), but more modern care environments may have more advanced technology than expected (i.e. integrated networks throughout with monitors outside every bedroom). Thorough initial requirements gathering must be conducted to fully understand the technology's target environment.

The studies involving care staff were easily conducted in their care environment. The length of time each care staff member could be involved, however, was limited by the strict schedule of care environments. Time is a major issue within a care environment. Care staff have very strict routines and there was only a short window of time in mid-morning and again mid-afternoon when care staff had time to work with the researcher. This strict schedule meant there was approximately 3-4 hours spread out over a day when care staff could be involved in the studies. This available time is also often when care staff breaks are taken due to it being the quiet time in the care environment. This limited time was only available if there were no problems such as care staff or resident illness. Each care staff member was also only able to be away from their set of duties for a restricted length of time. All this meant that the study designs used when working with care staff has to be carefully considered to not affect their routine. This, therefore, limited how long each participant could be involved. A possible solution to this problem would be to fund additional care staff during the studies to ensure there is always cover for study participants.

Ethically, it is not possible to completely monitor or shadow care staff's daily routine or working environment due to the sensitive nature of their jobs. This can pose a problem to conducting investigations or evaluations in care staff's full care environment. Thus it can be difficult to get an accurate study conducted within their 'real' routine. In the present case, research could only be conducted in the communal areas of a care environment, missing vital social and task-based encounters that happen in care staff's daily working environment in residents' private rooms.

11.2.1.2 Care Staff as a User Group

The carer does not typically use a computer as part of his or her job. There is a wide variation in age, literacy levels, first language and experience in care staff. Although it was presumed that care staff would not have any physical disabilities due to the physical nature of their jobs, care staff often required reading glasses but did not carry them when conducting the physical care tasks. It was also observed that care staff may have hearing impairments. The use of any technology with this user group must take into consideration these different user requirements.

The studies reported in this thesis found that many care staff are experienced computer users and all seemed to be open to the use of technology within their working environment. However the researcher still recommends that any technology for use by care staff is designed for novice users to ensure all care staff can easily use the technology. Technology for care staff should require little or no training, so that it does not add any barriers to acceptance. Technology that is intuitive, simple and easy to use is required to suit the varied ability of the large range of users.

11.2.2 Future Research

Overall, while the results discussed in this thesis are very promising, further research is required to fully explore the use of the *Portrait* system in care environments. A long-term study investigating the use of *Portrait* by care staff could help fully understand the long-term use of such technology in the care environment. Further research should also focus on benefits of the *Portrait* system could for care staff and potentially residents.

11.3 Profile of an Individual

The second research question was also directly motivated by the literature review and early research findings focussing on identifying the content of the *Portrait* system and methods used to populate such portraits.

> *Question 2-*
>
> *What information should be included in the profile of an individual with dementia?*

This thesis identified key topics of information through analysis of the information currently available to care staff, the literature review, and through the initial research questionnaire. The list of topics identified through the initial 'Five Things about Me' questionnaire were designed to allow a structure for sorting and adding information to the *Portrait* system in a consistent manner. This was not designed to be used as a comprehensive or final list. No two people have lived the same life or had the same personal experiences. As such a final list of what exactly should be included in a profile of an individual with dementia is not possible. A guide to what type of information and the level of detail instead is presented as it allows for personalisation to each individual.

11.3.1 Discussion

11.3.1.1 Portrait Content

Care plans contain a lot of important and vital information regarding a resident's physical and medical care. In contrast, the *Portrait* system focuses on personal and social information. The *Portrait* system was very positively received by care staff and managers with comments such as *"...all the key things"* and *"...potential for it to personalise care"*. Care managers thought the *Portrait* system could be of benefit

to care staff and people with dementia who live in care environments. Regarding the actual specific topics of information available, all were found to be relevant to the care environment by care managers with 'My Life Events' (Timeline) being selected as the most interesting as it highlighted the most important part of someone's life. This preference for 'My Life Events' (Timeline) was also mirrored by care staff, with it being the most accessed topic when the *Portrait* system was placed in a care home.

This thesis discussed and demonstrated through the studies conducted how the *Portrait* system could allow care staff to quickly learn more information than is currently available. The information identified to be included in the topics of *Portrait* was found to previously not be easily available to care staff and thought to have the potential to help care staff stimulate more natural conversations and enliven daily routines by including interesting interactions.

11.3.1.2 Populating Portrait

Through investigations with families it was found to be possible for families to create *Portraits* of their relatives lives using the topics of information identified in this thesis. Unexpectedly it was found that these topics of information potentially could also be of benefit to people without dementia who live in care environments.

There was not found to be a set method for gathering the information to populate *Portrait,* with different families applying different methods. However all four participant families were able to complete the process with the average process

taking one month. None of the families felt it was a difficult or time consuming process, but balancing the time for this with other events in their lives resulted in the one month average time to completion. Families found the process enjoyable and a good trigger to reminisce about previous events and past memories.

11.3.2 Future Research

Further case studies involving families of people with dementia are required to quantify if there are set processes that could be followed to help families when gathering the information for the portraits. This information could then be used to aid in the development of the input system. A *Portrait* creation system that allows families to independently create the portraits is required if the *Portrait* system is to become a marketable product. The *Portrait* creation system would be a very interesting project again due to its wide range of possible users: key care workers, spouse/partners, children and grandchildren. There are also a wide variety of different hardware and software considerations to investigate to find the best medium for creating such an input system: web page, desktop application, touch-screen or tablets are all possible use-case scenarios. It is estimated it would take between three to six months to fully develop the *Portrait* creation system. The most important requirements of the *Portrait* creation system are:

1. A structured process to follow to complete the *Portrait*.

2. Ability to easily upload and carry out basic photograph manipulation (i.e. cropping, straightening, borders, red-eye correction).

3. Easy data entry and selection of appropriate icons / graphics.

Another consideration for the development of the *Portrait* creation system would be the level of skill / computer experience the people creating the *Portraits* would have. The *Portrait* creation system would require being very easy and simple to use as there could be a wide variation in skill levels depending on which family members were completing the data entry. It is anticipated that the *Portrait* creation system could be targeted at people with some basic computer skill / experience as it is likely within families that there would be a family member who would have enough experience to complete the data entry process successfully. Further investigation is required to fully understand and identify all possible markets that *Portrait* may be of benefit to.

11.4 Efficient and Effective Technology

Having already established the need for technology to support care workers and having developed content for the *Portrait* system, the final research question directly addresses how to efficiently and effectively engage care staff with the *Portrait* system.

> *Question 3-*
>
> *How do we get busy care staff to engage with the Portrait software, efficiently and effectively in their working environments?*

Getting care staff to use the *Portrait* system efficiently and effectively is not an easy task. As discussed previously, care staff have very busy schedules and little free time in their work routine. For technology to be successfully adopted by care staff it needs to seamlessly fit into to their routine or require very little time to access and gain the necessary information.

11.4.1 Discussion

11.4.1.1 Portrait Usefulness

In terms of usefulness both care staff and care mangers rated the *Portrait* system and its content positively. For both of these separate groups, acceptance of the possible benefits of the *Portrait* system was essential. The *Portrait* system was found to be engaging, with care staff requesting *Portrait* during the early studies of this thesis. Care staff found the system easy to understand and quick to get answers. Thus, they were able to successfully engage with the system. These findings are reflected in the use of *Portrait* when placed in Care Home B, through the voluntary use of the system by the majority of care staff. Critically for usefulness, care staff felt they got to know the person in the *Portrait* system better than through conventional previously used paper Booklets. The engaging presentation of the information in *Portrait* may have helped care staff to get to know the person better.

11.4.1.2 Portrait Usability

The *Portrait* system was very positively received by care staff from initial studies and had no major usability issues during any studies, with comments such as *"Portrait information is very easy to find"*. This ease of use may have had a positive effect on care staff's acceptance of *Portrait* into their work environment and their ability to efficiently use the system. *Portrait* was able to be used by care staff after only a limited introduction to the system's content. The researcher proposes no long-term training is necessary. The high usability of the *Portrait* system, the successful use of *Portrait* during studies with care staff and care managers, and acceptance of the tool showed that the *Portrait* system could be integrated into a care environment and successfully used. Care environments openness to adopt the

Portrait tool demonstrates the possibility for effectively and efficiently integrating technology into the working environment of care staff and care environments.

11.4.2 Future Research

Research is needed with more residents in the *Portrait* system as the limited number used in this thesis will have affected care staff's use of the system. Investigating the use of the *Portrait* system when a new resident enters the care environment or integration in new care staffs training is also vital to evaluate *Portraits* full potential and benefits to a care environment.

11.5 Limitations

Important limitations of this thesis were the study's relatively short time frame for the care home use, the limited number of portraits available for care staff to use, and the length of time care staff were available to participate in the studies.

The small number of participants in this thesis is a clear limitation. The results were derived from four different care environments. Despite this, the results, while suggestive, cannot be considered representative of the entire industry. However, this thesis work does provide support for the usability of *Portrait*. Furthermore, the results of the interviews with the care managers, usability and usefulness evaluation with care staff and the case studies with families provide initial indications of the potential benefit of the *Portrait* system and technology in care environments.

The Booklets used in this study cannot be considered representative of the entire industry and should be considered as providing preliminary evidence of the benefit of the *Portrait* system compared to current paper-based methods. When visiting the

care environments to investigate their current paper method, the researcher was shown the 'best' example of the paper-based information available to care staff. It was not until carrying out the study that a large proportion of care staff mentioned that they had not seen these Booklets or that the example Booklets had more information than the ones currently being used. In future studies, the researcher would randomly select resident's Booklets to fairly evaluate the *Portrait* system against the level of information currently available to care staff.

Also, one specific aspect of *Portrait* deserves consideration. It is likely that in many (perhaps most) of the cases the *Portrait* of a person with dementia will be created not by them, but by a family member. While it could be hoped that the family's information about the person accurately represents their life and preferences, it can be imagined that if the person were writing their own portrait some of the information would be different. In this respect, work that seeks to have persons newly diagnosed with dementia begin capturing important information about their lives is critical work and an important area for further research.

11.6 Conclusion

As the use of technology spreads into more aspects of everyday life, new and novel uses of technology are constantly being identified. There are only limited studies conducted with care staff as a user group or the application of technology in their working environment. The literature review in this thesis identified a gap in knowledge in relation to care staff as a user group and the use of technology with this group in a care environment. This thesis described the identification of this area and the systematic development and evaluation of *Portrait* a tool to aid care staff

within their working environment. Discussed in this thesis is the identification of key areas of information absent or sought after by care staff, investigation of the processes involved for families collecting this information and evaluation of usability of this technology by care staff in their working environment. A number of studies were conducted throughout this thesis to aid in answering the research questions identified at the outset. This thesis identified key factors of working with care staff within care environments. The results illustrate care staff's ability to use technology within their work routine and the care environment. Care staff are open and accepting of new technology and its possible benefits to them, the care environments, and importantly the residents themselves.

References

Acting Up (2009). Acting Up [Website]. Available at: <.http://www.acting-up.org.uk/> [Accessed: 23rd February 2009].

Albinsson, P. and Zhai, S. (2003). High precision touch screen interaction. *In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Ft. Lauderdale, Florida, USA, April 05 - 10, 2003). CHI '03. ACM, New York, NY, 105-112.

Alm, N., Ellis, M., Astell, A., Dye, R., Gowans, G., Campbell, J. (2004). A cognitive prosthesis and communication support for people with dementia. *Neuropsychological Rehabilitation*, 14 (1/2), 117-134.

Alm, N., Dye, R., Gowans, G., Vaughan, P., Astell, A., Ellis, M. (2006). Living in the Moment: An interactive entertainment system for people with dementia. *International Workshop on Cognitive Prostheses and Assisted Communication (CPAC2006) at the Intelligent User Interfaces Conference (IUI2006)*, Sydney, Australia 29 January 2006, 16-19.

Alm, N., Dye, R., Gowans, G., Campbell, J., Astell, A., Ellis, M. (2007). A communication support system for older people with dementia. *IEEE Computer*, 40 (5), 35-41.

Alzheimer's Disease International. (2010). *World Alzheimer Report 2010, The Global Economic Impact Of Dementia*, UK, ADI.

Alzheimer's Society. (2003). Alzheimer's Society welcomes statement on long term care. [press release] Available at:

<http://www.alzheimers.org.uk/site/scripts/press_article.php?pressReleaseID
=25 >[Accessed: 2nd June 2011].

Alzheimer's Society. (2007). *Home from home*. London, Alzheimer's Society.

Alzheimer's Society. (2010). *This is me*. [online] Available at:

<http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1290
> [Accessed: 5th May 2011].

Armstrong-Esther, C.A., Browne, K.D. and McAfee, J.G. (1994). Elderly patients:
still clean and sitting quietly. *Journal of Advanced Nursing* 19, 264—271.

Astell, A., Alm, N., Gowans, G., Ellis, M., Dye, R., and Vaughan, P. (2009).
Involving older people with dementia and their carers in designing computer
based support systems: some methodological considerations. *Univers. Access
Inf. Soc*. 8 (1), 49-58.

Baecker, R.M., Marziali, E., Chatland, S., Easley, K., Crete, M., and Yeung, M.
(2006). Multimedia biographies for individuals with Alzheimer's disease and
their families. *In Proceedings of the World Congress on Internet in Medicine
(MEDNET).*

Bender, M., Bauckham, P., and Norris, A. (1999). *The Therapeutic Purposes of
Reminiscence.* London: SAGE Publications.

Brooker, D. (2004). What is person-centred care in dementia? *Reviews in Clinical
Gerontology* 13, 215–222.

Brooker, D. (2007). *Person-centred dementia care: making services better*. London:
Kingsley Publishers.

Brown, A. Draper, P. (2003). Accommodative speech and terms of endearment: elements of a language mode often experienced by older adults. *Journal of Advanced Nursing*, 41 (1), 15-21.

Brookmeyer, R., Johnson, E., Ziegler-Graham, K., and Arrighi, H. M. (2007). *Forecasting the global burden of Alzheimer's disease.* Johns Hopkins University, Dept. of Biostatistics Working Papers.

Burgio, L., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., Jackson, E., and Bankester, L. (2000). Come Talk With Me: Improving Communication Between Nursing Assistants and Nursing Home Residents During Care Routines. *The Gerontological Society of America*, 41(4), 449-460.

Camp, C. J., Cohen-Mansfield, J., and Capezuti, E. A. (2002).Use of Nonpharmacologic Interventions Among Nursing Home Residents with Dementia. *Psychiatric Services,* 53(11), 1397-1401.

Care Commission and Mental Welfare Commission. (2009). *Remember, I'm still me*. Scotland, Care Commission and the Mental Welfare Commission.

Caris-Verhallen, W. Kerkstra, A. Bensing, J. (1997). The role of communication in nursing care for elderly people: a review of the literature. *Journal of Advanced Nursing*, 25, 915-933.

Chapman, A., Gilmour, D., McIntosh, I. (2001). *Dementia care: A Professional Handbook.* 2nd Edition. London: Age Concern England.

Clare, L., Baddeley, A., Moniz-Cook, E. and Woods, B. (2003). A quiet revolution. *The Psychologist,* 16(5), 250 -254.

Cohen-Mansfield, J. (2004). /Nonpharmacologic Interventions for Inappropriate

Behaviors in Dementia: A Review, Summary, and Critique. *The Journal of*

Lifelong Learning in Psychiatry, 11(2), 288-308.

Damianakis, T., Crete-Nishihata, M., Smith, K. L., Baecker, R. M., and Marziali, E.

(2009). The Psychosocial Impacts of Multimedia Biographies on Persons

With Cognitive Impairments. *The Gerontologist*, 50(1), 23-35.

Dewing, J. (2004). Concerns relating to the application of frameworks to promote

person-centredness in nursing with older people. *Journal of Clinical Nursing*,

13 (3a), 39-44.

Dewing, J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas.

International Journal of Older People Nursing, 3, 3-13.

Douglas, S., James, I., and Ballard, C. (2004). Non-pharmacological interventions in

dementia. *Advances in Psychiatric Treatment,* 10, 171-179.

Downton, K. and Ladle, J. (2002). Representing, Quality and 'Small Things' [PDF].

Available at: < http://www.acting-up.org.uk/> [Accessed: 24th February

2009].

Edberg, A. K., Sandgren, A. N. and Hallberg, I. R. (1995). Initiating and terminating

verbal interaction between nurses and severely demented patients regarded as

vocally disruptive. *Journal of Psychiatric and Mental Health Nursing*, 2 (3),

159–67.

Grove, N. (2003). Multimedia Profiling: a person centred tool for people with

profound disabilities [PDF]. Available at: < http://www.acting-up.org.uk/>

[Accessed: 24th February 2009].

Hoffman, P. (1999). *Accommodating Color Blindness*. [online] Available at:

    <http://www.stcsig.org/usability/newsletter/9910-color-blindness.html>

    [Accessed: 3rd July 2011].

Haight, B., Gibson, F., Michel, Y. (2006). The Northern Ireland life review/life

    storybook project for people with dementia. *Alzheimer's & Dementia,* 2, 56–

    58.

Hampson, S. (1993). *The Construction of Personality.* 2nd Edition. London:

    Routledge.

Hibbard, J., Jansen, D. and McFarling, L. (2003). Behind the steering wheel. *Journal*

    of Dementia Care, 11, 12–3.

Hjelle, L. and Ziegler D. (1976). *Personality Theories: Basic Assumptions, Research*

    and Applications. London: McGraw-Hill Book Company.

Hodges, S., Williams, L., Berry, E., Izadi, S., Srinivasan, J., Butler, A., Smyth, G.,

    Kapur, N., and Wood, K. (2006). SenseCam: A Retrospective Memory Aid.

    In Proceedings of the 8th International Conference on Ubiquitous

    Computing, *UbiComp'06*. Springer, 177-193.

Huberman, A. M. and Miles, M. B. (2002). *The Qualitative Researcher's*

    Companion. London, Sage.

Kennard, C. (2006) Life Stories. About Inc. [Website]. Available at:

    <http://alzheimers.about.com/od/professionalresources/a/life_stories.htm>

    [Accessed: 3rd September 2008]

Killick, J. and Allan, K. (2001). *Communication and the Care of People with Dementia*. Buckingham: Open University Press.

Kitwood, T. (1997). *Dementia Reconsidered: the person comes first*. Buckingham: Open University Press.

Ladle, J. and Gibbons, L. (2004). Multimedia profiling: a tool for inclusion. *Living Well*, 4(1), 13-15.

Lanceley, A. (1985). Use of controlling language in the rehabilitation of the elderly. *Journal of Advanced Nursing*, 10 (2), 125–35.

Mahmud, M. and Kurniawan, H. (2005). Involving psychometric tests for input device evaluation with older people. *In Proceedings of the 17th Australia Conference on Computer-Human interaction: Citizens online: Considerations For Today and the Future* (Canberra, Australia, November 21 - 25, 2005). OZCHI, vol. 122. Computer-Human Interaction Special Interest Group (CHISIG) of Australia, Narrabundah, Australia, 1-10.

Marshall, M. (2001). The challenge of looking after people with dementia. *BMJ*, 323, 410–11.

Massimi, M., Berry, E., Browne, G., Smyth, G., Watson, P., and Baecker, R., M. (2008). An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease. *Neuropsychological Rehabilitation,* 18, 742–765.

McCarthy, B. (2006). Translating person-centred care: a case study of preceptor nurses and their teaching practices in acute care areas. *Journal of Clinical Nursing*, 15, 629-638.

McCormack, B. (2004). Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing*, 13 (3a), 31-38.

McCrae, R. and Costa, P. (1997). Conceptions and Correlates of Openness to Experience. *In* Hogan, R., Johnson, J., and Briggs, S. (eds.) *Handbook of Personality Psychology.* California: Academic Press.

Mendez , M., Cummings, J. (2003). *Dementia a clinical approach.* 3rd Edition. Philadelphia: Butterworth-Heinemann.

Microsoft Research (2007). Introduction to SenseCam. [Website] Available at: <http://research.microsoft.com/en-us/um/cambridge/projects/sensecam/default.htm> [Accessed: 18 July 2011].

Mulvenna, M., Zheng, H. and Wright, T.(2009). Reminiscence Systems. *In Proceedings of the HCI'09* (Cambridge, UK, September 1-5, 2009).

Nettle, D. (2008). It takes all sorts. *New Scientist*, 2642, 36-39.

Nussbaum J.F. (1991). Communication, language and the institutionalised elderly. *Ageing and Society*, 11, 149–165.

Nolan, M., Grant, G. and Nolan, J. (1995). Busy doing nothing: activity and interaction levels amongst differing populations of elderly patients. *Journal of Advanced Nursing*, 22 (3), 528–38.

Nolan, M., Davies, S., Brown, J., Keady, J., and Nolan, J. (2004). Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing*, 13 (3a), 45-53.

Packer, T. (2000). Does person-centred care exist? *Journal of Dementia Care*, 8, 19–21.

Away From Her (2006). [Film] Directed By Sarah Polley. Canada: Capri.

Preece, J., Rogers, Y., and Sharp, H. (2001). *Beyond Interaction Design: Beyond Human-Computer Interaction*. John Wiley & Sons, Inc.

Riley, P., Alm, N., and Newell, A. (2008). An interactive tool to promote musical creativity in people with dementia. *Computers in Human Behavior*, doi:10.1016/j.chb.2008.08.014

Ryan, E. B., Hummert, M. L. and Boich, L. H. (1986). Psycholinguistic and Social Psychological Components of Communication by and with the Elderly. *Language & Communication,*6, 1-24.

Ryan E. B., Hamilton J.M. and See S.K.(1994). Patronising the old: how do younger and older adults respond to baby talk in the nursing home? *International Journal of Ageing and Human Development*, 39 (1), 21-32

Ryan, E. Hummert, M. and Boich, L. (1995). Communication Predicaments of Aging Patronizing Behavior Towards Older Adults. *Journal of Language and Social Psychology*, 14, 144-166.

Smith, K. L., Crete-Nishihata, M., Damianakis, T., Baecker, R. M., and Marziali, E. (2009). Multimedia Biographies: A Reminiscence and Social Stimulus Tool for Persons with Cognitive Impairment. *Journal of Technology in Human Services*, 27(4), 287 - 306.

The Lewy Body Society (2007). *The Lewy Body Society* [Website]. Available at: <http://www.lewybody.org/ > [Accessed: 8th September 2008].

The Social Care and Social Work Improvement Scotland (Requirements for Care Services) Regulations. (2011). SI 2011/210, UK, Crown.

Timothy, D. (2003). Person-centred Dementia Care: A Vision to be Refined. *The Canadian Alzheimer Disease Review.*

Ward, R., Vass, A. A., Aggarwal, N., Cybyk, B. and Garfield, C. (2002). Communication and care. Part 1 : Expanding our understanding. *Journal of Dementia Care*, 10 (5), 33–6.

Ward, R., Vass, A. A., Aggarwal, N., Garfield, C. and Cybyk, B. (2005). What is dementia care? Dementia is communication. *Journal of Dementia Care*, 13 (6), 16–9.

Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., and Cybyk, B. (2008). A different story: exploring patterns of communication in residential dementia care. *Aging & Society*, 28, 629-651

Webster, G., Fels, D. I., Gowans, G., Alm, N. (2010). Portrait: Portraying Individuality. In: Proceedings of the Computers Helping People with Special Needs, Part II: 12th International Conference, *Icchp 2010*. Vienna, Austria, July 14-16, 2010.

Webster, G., Fels, D. I., Gowans, G., Hanson, V. L. (2011). Portrait of Individuals with dementia: Views of Care Managers. In: Proceedings of the HCI 2011 Conference, *The 25th BCS Conference on Human-Computer Interactions.* Newcastle, UK, July 4-8.

Williams, K., Kemper, S. and Hummert, M. L. (2003). Improving Nursing Home

    Communication: An Intervention to Reduce Elderspeak. *The Gerontologist*,

    43, 242-247.

Appendices

Appendix A – Care Plan

RESIDENT PERSONAL PLAN

NAME OF HOME	_____
NAME OF RESIDENT	_____
DATE OF ADMISSION	_____
UNIT & ROOM NO	_____
TEAM LEADER	_____
KEY WORKER	_____

Sharing the care with you…….

CONSENT FORM	1
INFORMATION SHEETS / PRACTICAL DAILY LIVING TASKS	2
SPECIALIST ASSESSMENTS	3
RISK ASSESSMENTS	4
SPECIFIC CARE PLANS	5
REVIEW SHEETS	6
SPECIFIC FAMILY / REPRESENTATIVE CONTACT SHEET	7
	8
	9
	10

CONSENT FORM
SHARING OF INFORMATION

DATA PROTECTION ACT 1998

The information obtained from you and from any third party, will be used in connection with the provision of Health and Social Care Services for you and may be shared between Health & Social Care Professionals.

NAME OF HOME: _____

NAME OF RESIDENT: _____

DELETE AS APPROPRIATE:

1. I consent to the sharing of information obtained in connection with my Health and Social Care needs between Health and Social Care Professionals.

2. I do not consent to the sharing of information obtained in connection with my Health and Social Care needs between Health and Social Care Professionals.

RESIDENT SIGNATURE: _____

DATE: _____

PERSONAL PLAN INFORMATION SHEETS

NAME: **URN NO:**

DOB: **CHI NO:**

LIKES TO BE CALLED:

GP NAME:
ADDRESS:

TEL NO:

N.O.K. NAME: **2ND CONTACT**
ADDRESS: **NAME:**
                                           ADDRESS:

TEL. HOME: **TEL. HOME:**
TEL. WORK: **TEL. WORK:**

RELATIONSHIP: **RELATIONSHIP:**

FOR HOLIDAY DATES AND CONTACTS SEE OVERLEAF

CARE MANAGER NAME:

ADDRESS:

TEL NO:

TEMPORARY/HOLIDAY CONTACT DETAILS

NAME:

KNOWN MEDICAL HISTORY:
                  MEDICATION NEEDS:

ANY KNOWN ALLERGIES:
                  SELF MEDICATES – YES/NO
If yes see assessment/ if no will be dealt with by staff in accordance with medication policy)

POWER OF ATTORNEY ON FILE:

FINANCIAL YES / NO
                  WELFARE   YES / NO

DO YOU WANT ANYONE INVOLVED IN REVIEWS OF YOUR CARE?

YES/NO (If yes please complete the following details)

NAME:
ADDRESS:
                  TEL HOME:
                  TEL WORK:
                  MOBILE:

RELATIONSHIP:

WHEN, AND IN WHAT CIRCUMSTANCES DO YOU WANT FRIENDS, RELATIVES AND CARERS TO BE CONTACTED (Please include if you need replacement personal items,if you become unwell at night or if you want an independent person to help you raise a concern or make a complaint.

NAME:

SOCIAL, CULTURAL AND SPIRITUAL PREFERENCES:

DIETARY NEEDS:

SPECIAL DIET REQUIRED - YES/NO (if yes please specify)

PERSONAL LIKES   PERSONAL DISLIKES

ANY SPECIAL FURNITURE, EQUIPMENT AND ADAPTATIONS YOU NEED:

ANY COMMUNICATION NEEDS YOU HAVE:

PRACTICAL DAILY LIVING TASKS FOR:

ACTIVITY	INDEP-ENDANT	PROMP-TING	ASSISTANCE 1/2	FURTHER DETAILS/ACTION
GETTING UP				
WASH SELF am				
BATH /SHOWER am				
ORAL/DENTURE CARE				
SHAVING				
DRESS TOP HALF				
DRESS BOTTOM HALF				
APPLY MAKE UP				
HAIR CARE				
FINGER NAIL CARE				
USE OF TOILET DAY				
GET IN/OUT OF CHAIR				
MOBILITY IN HOME	IF NOT FULLY INDEPENDENT SEE INDIVIDUAL MOVING & HANDLING CARE PLAN			
EATING/DRINKING				
COMMUNICATION				
CHIROPODY CARE				
GOING OUT OF HOME				
PUBLIC TRANSPORT				
BATH /SHOWER pm				
GOING TO BED				
USE OF TOILET NIGHT				

LEISURE INTERESTS/CLUBS/DAY CENTRES	

ROOM LOCKED / UNLOCKED AT NIGHT	
STAFF CHECKS AT NIGHT	

MOVING & HANDLING ASSESSMENT

RESIDENTS NAME: **DATE:**

BUILD: Above average ☐   Average ☐   Below average ☐   Weight

HEIGHT: Tall ☐   Medium ☐   Small ☐

RISK OF FALLS: High ☐ Moderate ☐   Low ☐

MOBILITY AIDS CURRENTLY USED:

IDENTIFY ANY PROBLEMS DUE TO MENTAL OR PHYSICAL HEALTH:

IDENTIFY ANY PROBLEM WITH:

ACTIVITY	SPECIFY PROBLEM OR WRITE NONE
STANDING	
WALKING	
SITTING	
TRANSFERING	
MOVEMENT IN BED	

INDEPENDENT IN ALL ASPECTS WITHOUT AIDS: YES ☐ NO ☐

(IF NO COMPLETE DETAILED CARE PLAN)

SELF ADMINISTRATION OF MEDICATION ASSESSMENT

RESIDENTS NAME: **DATE:**

WHAT DOES THE RESIDENT WISH TO SELF MEDICATE:

Internal medication   ☐

External preparations   ☐

Respiratory aids   ☐

Other (please specify)   ☐ _____

QUESTIONS FOR RESIDENT	YES	NO
Do you know what the medications are for?		
Do you know not to give your medication to anyone else?		
Are you clear about directions for use?		
Can you open and close the containers?		
Do you agree to keep medication in your locked drawer?		
Do you agree to your medication being ordered by senior staff on a monthly basis?		

Is this resident assessed as able to self medicate?		

IF YES COMPLETE CARE PLAN/RISK ASSESSMENT AS REQUIRED

STAFF SIGNATURE: DESIGNATION:

Waterlow Pressure Sore Assessment

Resident's Name_____

BUILD/HEIGHT FOR WEIGHT		SKIN TYPE/VISUAL RISK AREAS		SEX AGE		SPECIAL RISKS
Average	0	Healthy	0	Male	1	**Tissue Malnutrition**
Above average	1	Tissue paper	1	Female	2	Terminal Cachexia
Obese	2	Dry	1	14-49	1	8
Below average	3	Oedematous	1	50-64	2	Cardiac Failure
CONTINENCE		Clammy (temp)	1	65-74	3	5
Complete/Catheterised	0	Discoloured	2	75-80	4	Peripheral Vascular Disease
Occasional incontinent	1	Broken/spot	3	81+	5	5
Cath/incont. of faeces	2	**MOBILITY**		**APPETITE**		Anaemia
Doubly incont.	3	Fully	0	Average	0	2
		Restless/Fidgety	1	Poor	1	Smoking
		Apathetic	2	N.G. Tube	2	1
		Restricted	3	Fluids only		**Neurological Deficit**
		Inert/Traction	4	NBM/anorexic	3	Diabetes, MS, CVA, Advanced Parkinsons, Motor Sensory Paraplegia
		Chairbound	5			
						4 – 6
						Major Surgery/Trauma
						Orthopaedic below Waist or spinal
						5
						On table > 2 hours
						5
						Medication
						Steroids, Cytotoxics, High dose anti-inflammatory.
						4

SCORE: **10+ AT RISK**   **15+ HIGH RISK**   **20+ VERY HIGH RISK**

DATE	WATERLOW SCORE	ACTION TAKEN	SIGNATURE

RISK ASSESSMENT INDEX

RESIDENTS NAME:		SHEET NO:	

RISK NO	SPECIFIC RISK	DATE RISK ELIMINATED	SIGNED BY

RISK ASSESSMENT

RESIDENTS NAME:	RISK NO:

WHAT IS THE RISK:

WHO MAY BE HARMED AND WHY:

WHAT IS THE LEVEL OF RISK:

High ☐   Moderate ☐   Low ☐

CONTROL MEASURES IN PLACE:

FURTHER ACTION / COMMENTS:	TIMESCALE:	BY WHOM:

STAFF SIGNATURE:	DESIGNATION:
RESIDENT SIGNATURE:	DATE:

REVIEW:

Date	Outcome	Signed	Designation	Next review

SPECIFIC CARE PLAN INDEX

RESIDENTS NAME:		SHEET NO:	

PLAN NO	SPECIFIC PROBLEM	DATE RESOLVED	SIGNED BY

SPECIFIC CARE PLAN

RESIDENTS NAME:	PLAN NO:

PROBLEM:

GOAL:

ACTION:

STAFF SIGNATURE:	DESIGNATION:
RESIDENT SIGNATURE:	DATE:

For reviews out-with 6 monthly – see overleaf

CARE PLAN REVIEWS OUTWITH 6 MONTHLY

REVIEW:

Date	Outcome	Signed	Designation	Next review

REVIEW INDEX

RESIDENTS NAME: **SHEET NO:**

DATE	REVIEW / DISCUSSION (STATE FULL REVIEW OR NAMED WORKER / CARE TEAM DISCUSSION)	REVIEW HELD BY	DESIGNATION	SIGNATURE

REVIEW OF PERSONAL PLAN

Name: Review Date:

D.O.B:

Reason for review:

Did you want anyone involved in your review?   Yes/No

If yes are they attending?   Yes/No

Names of those attending: Relationship:

The following areas are to be addressed at review:	Met	Unmet
Front Sheet/Consent Form/Information Sheets correct/signed	☐	☐
Practical daily living tasks correct/brought up to date	☐	☐
Specialist assessments are current and have been reviewed	☐	☐
Risk assessments are current and reviewed individually and timorously	☐	☐
Specific care plans are current and reviewed individually and timorously	☐	☐
Contact sheets are being used/completed appropriately	☐	☐
Update on Team Leader/Key Worker status	☐	☐
Make sure all aware of informal/formal complaints procedure	☐	☐

Views of Resident:
My care plan fully meets my needs yes/no if no identify unmet need:

Action by & timescale:

Views of Staff:
Your care plan fully meets your needs yes/no if no identify unmet need:

Action by & timescale:

Views of Others:

Action by & timescale:

I have been given the opportunity to discuss all aspects of my care and have been given a current information sheet for my self/my representative.

Signed Resident/Representative: _____

Signed Staff: _____ Designation: _____

SPECIFIC FAMILY/REPRESENTATIVE CONTACT SHEET

RESIDENTS NAME:		SHEET NO:	

DATE	CONTACT WITH	DETAILS	SIGNED BY

Appendix B – *This is me*

Royal College of Nursing

Leading the fight against dementia
Alzheimer's Society

This is me

This leaflet will help you support me in an unfamiliar place

Please place a photograph of yourself in the space provided.

My name

photo
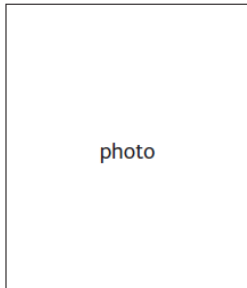
This is me is about the person at the time the document is completed and will need to be updated as necessary.

This is me should be completed by the person or persons who know the patient best and wherever possible with the person themselves.

Please refer to the back page for guidance notes to help you complete **This is me**.

My name: full name and the name I prefer to be known by

I currently live

Carer/the person who knows me best

I would like you to know

My home and family, things that are important to me

My life so far

My hobbies and interests

Things which may worry or upset me

I like to relax by

_____

_____

_____

_____

My hearing and eyesight

_____

_____

My communication

_____

_____

My mobility

_____

_____

My sleep

_____

_____

My personal care

_____

_____

My eating and drinking

_____

_____

_____

My medication

_____

_____

_____

Date completed: _____   By whom: _____

Relationship to patient: _____

In signing this document, I agree that the information in this leaflet may be shared with health and care workers.

Appendix C – *My Memories*

My Memories

By

Margaret Cooper

Birth Details

I was born on the 23ʳᵈ of January 1936. I grew up in Rosebank Street in Dundee.

My Gran lived with us and I often got up to mischief with my brother Gordon to annoy my Gran. I had two brothers Gordon and Billy and two sisters Dorothy and Nancy. I was the second oldest.

Here is a photo of me with my Mum and brother Gordon I am about 18 months old.

School Years

I went to Rosebank Primary School and Rockwell Secondary School.

Here is a school photo of me.

Married Life

I was married in 1957 at 21 years old. I married Andrew Cooper who was my older brother's best friend, I had known him since childhood.

This is Andy and I on our wedding day.

Family

I have two children:

Hilary - the eldest

Andrew (Drew)

Hilary and Drew in a School photo.

Old Craigie

My Uncle Dave ran the Old Craigie dairy farm. I loved visiting the farm as a child. I had a pony to play with and my uncle would pay me half a crown to collect geese eggs.

Family Holidays

We got our first caravan in 1965 and had many family holidays in it travelling all over Scotland. When Andy and I retired we continued to travel around Scotland and England in a caravan for our holidays.

Andy and I with our first caravan.

40th Birthday Holiday

I went on my first holiday abroad for my 40th birthday. I went to Majorca with my friends and daughter Hilary who was 17 at the time.

This is everyone who went. I am in the middle of the back row.

Holidays

I travelled around Europe in 1981 and again in 1982 with my family. We visited France, Germany, Austria, Italy, Switzerland, Luxemburg, Monaco and Liechtenstein.

Andy, Me and Hilary on one of the trips.

Things that make me Happy

I like to have fresh flowers in my room.

I like to be able to go for a cigarette.

Things that make me sad

I dislike too much organisation I like to be able to change my sleep routine.

Hobbies when I was young

I use to enjoy knitting and cross stitch. I liked playing card games and puzzle. I still enjoy reading and baking.

Employment

I worked as a Nursery Nurse when I left school. I was a training instructor in Timex until 1985 when I moved to the 'Keep Dundee Tidy' campaign going round schools and nurseries until I retired.

Special Friends

I am very close to my brother Gordon and sister-in-law Jenny.

Important Dates

My birthday is the 23rd of January 1936 and my wedding anniversary is the 14th September 1957.

Appendix D – 'Five Things about Me' Questionnaire

University of Dundee
School of Computing

Code of Practice for Research involving Human Participants

External Personalities

Informed Consent

Dear Participant

Thank you for your interest in the 'External Personalities' Project. This page describes what you will be asked to do for the questionnaire. Please read through it and then sign at the bottom to say that you understand and accept the conditions of this study. If you have questions, please feel free to ask the researcher.

'Multimedia Profiles as External Personalities to Support People with Dementia and their Carers' is a research project being carried out by, Gemma Webster a PhD student at the University of Dundee, who can be contacted by phone at (01382) 386528 or by email at gwebster@computing.dundee.ac.uk..

Background

People with dementia who are living in a care/nursing home are very difficult for staff to get to know as people because their communication is limited, sometimes almost nonexistent. Yet without exception these people all have had lives full of incident and relationships, jobs, hobbies, awards, and interesting experiences. Establishing communication between carers and people with dementia is an important issue with vital implications for their welfare.

Proposed project

The project aims to research and develop software that can act as an external communications bridge between carers and people with dementia through the creation of simple but effective 'external personalities'. These will take the form of an interactive multimedia presentation that will contain biographical and personal information relevant to a particular person with dementia. If even a flavour of

information like this could be made available quickly and easily to busy staff it would help immensely in the quality of care they could give.

What is involved?

You can help this project by completing the '5 things about me' questionnaire. The questionnaire is designed to help get an idea of what kind of information people might like care staff to know about themselves as people, as appose to just as a resident. The questionnaire is completely anonymous and voluntary, if you do not want to complete the questionnaire or there are any questions you do not want to answer you are not obliged to do so.

Your participation in this study is voluntary and you can leave the study at any time without penalty or giving reasons. No undue risk arises from the participation in this study.

All the information which you give us will be stored safely and kept separate from information about your identity. Access to your data is minimised to the people involved in this research. If information about you is used for publications or presentation, we will ensure that no reference to your identity is made.

Please date and sign the page below to indicate that you understand and accept the conditions of this study. Thank you.

If you would like to know more about this project and/or you have questions that cannot be answered by the researcher, please feel free to contact the Project Supervisor, Dr. Norman Alm, School of Computing, University of Dundee, Dundee DD1 4HN. He can be contacted by phone at (01382) 385596 or by email at nalm@computing.dundee.ac.uk.

I have read the project Information (above), & I consent to completing the questionnaire.

Print Name	Signature	Date

5 things about me

Please tick your gender:

Male ☐   Female ☐

Please tick your age group:

Under 30 ☐   30-40 ☐   40-50 ☐   50-60 ☐   60-70 ☐   Over   70 ☐

Imagine that you are unable to communicate and that you will be moving to a place where you will be well looked after, as far as the staff are able, but on your arrival they will not know you as a person.

What 5 things do you think it would be important for the staff to know about you, so they can get an impression of the sort of person you are?

1.

2.

3.

4.

5.

Appendix E – Study 1 – Usability of *Portrait* System

University of Dundee
School of Computing

Code of Practice for Research involving Human Participants

Multimedia Profiles as External Personalities to Support People with Dementia and their Carers

Information Sheet

'Multimedia Profiles as External Personalities to Support People with Dementia and their Carers' is a research project being carried out by me, Gemma Webster a PhD student at the University of Dundee. The project is being funded by the School of Computing, University of Dundee and the Balhousie Care Group – it begun in September 2008 and will continue until September 2011.

Background

People with dementia who are living in a care/nursing home are very difficult for staff to get to know as people because their communication is limited, sometimes almost nonexistent. Yet without exception these people all have had lives full of incident and relationships, jobs, hobbies, awards, and interesting experiences. Establishing communication between carers and people with dementia is an important issue with vital implications for their welfare. People with dementia have serious problems with working (short-term) memory while their long-term memory can remain relatively intact. It would not be inaccurate to say that they "live in the past", while only fleetingly knowing the present. In order to establish communication, carers must know about the past histories of the people under their care, which can be very difficult to achieve.

Proposed project

The project aims to research and develop software that can act as an external communications bridge between carers and people with dementia through the creation of simple but effective 'external personalities'. These will take the form of an interactive multimedia presentation that will contain biographical and personal information relevant to a particular person with dementia. If even a flavour of

information like this could be made available quickly and easily to busy staff it would help immensely in the quality of care they could give.

What is involved?

You can help this project by allowing me to learn from you. I am new to this field and have never cared for someone with dementia before. Allowing me to talk to you about your job and experiences of working with people with dementia I will be able to develop a better understanding of good practice and what exactly is involved in caring for someone with dementia. This will take place at the care home and will not affect your work. In order for me to develop a thorough understanding of what is involved I may ask you to allow me to shadow you when you are working, complete a questionnaire or I may simply want to talk to you.

Participants will be asked to sign a form saying that they are willing to participate in the research. The consent form will explain what will be asked and what will happen to any information which is collected. The participants will be given a copy of this form to keep.

If you would like to know more about this research and/or you have questions that cannot be answered by the researcher, please feel free to contact the Project Supervisor, Dr. Norman Alm, School of Computing, University of Dundee, Dundee DD1 4HN. He can be contacted by phone at (01382) 385596 or by email at nalm@computing.dundee.ac.uk.

University of Dundee
School of Computing

Code of Practice for Research involving Human Participants

Multimedia Profiles as External Personalities to Support People with Dementia and their Carers

Staff Consent Form

As part of my PhD, I am researching and developing software that can act as an external communications bridge between carers and people with dementia through the creation of simple but effective 'external personalities'.

This page describes what you will be asked to do for the study. Please read through it and then sign at the bottom to say that you understand and accept the conditions of this study. If you have questions, please feel free to ask the researcher.

The Researcher will begin by asking some general information about yourself and your job within the care home. You will be asked your opinion and thoughts to gain a better understanding of what it is like to care for someone with dementia in a care home setting. These thoughts and opinions may be elicited through interviews and questionnaires. You may be asked to talk about what you think of your personal job, the care home environment and also your feelings and experiences within the care home. Also to gain a better understanding of all the duties you carry out in your day to day routine the researcher may request to shadow or observe you working.

Your participation in this study is voluntary and you can leave the study at any time without penalty or giving reasons. No undue risk arises from the participation in this study.

All the information which you give will be stored safely and kept separate from information about your identity. Access to your data is minimised to the people involved in this research. If information about you is used for publications or presentation, no reference to your identity will be made.

Please note that you are helping the researchers to develop an understanding of what it is like to care for a person with dementia. You are not being tested and your job is not being evaluated. There are therefore no right or wrong answers to the questions you will be asked. The researcher is very grateful for your help.

If you are willing to take part, please sign the consent form below

I have read the project Information (above), & I consent to taking part in this exercise.

Signed: _____

Printed Name: _____

Date: _____

Witness by the Researcher: _____

Printed Name: _____

Date: _____

Usability Evaluations: Pre-study Questionnaire

This survey will gather background information data about you and you experience in the care environment. The survey will take about 5 minutes to complete. Thank you in advance for your time and effort.

Background Information

1.) Gender

☐ Male   ☐ Female

2.) Age (please check one)

☐ 18-29   ☐ 30-39   ☐ 40-49   ☐ 50-59   ☐ 60+

3.) What positions have you worked in the care environment (check all that apply)

☐ I have never worked in a care environment
☐ I have worked as a full-time first line care worker
☐ I have worked as a part-time first line care worker
☐ I have worked as a manager in a care environment

4.) In total how long did you work in the care environment (please check one)?

☐ never   ☐ less than 5 years   ☐ 5-10 years   ☐ 11-15 years   ☐ 16+ years

5.) How often do you use a computer (Please circle one)?

| Never | Once every few months | Once a month | Weekly | A few days per week | Daily |

Usability Evaluations: Prototype Questions

The purpose of this questionnaire is to gather your opinion about learning and using the system. It should take about 10 minutes to complete.

1.) Rate how difficult it was for you to learn how to use the Profile system (please circle one).

Very difficult   Difficult   Not difficult   Easy   Very easy
nor easy

2.) What level of training do you think would be required to learn how to use the Profile system (please circle one)?

No   training   Less than 30   About one   Half of a day   One day
necessary   minutes   hour

3.) Rate how easy you found the following features to use.

	Very easy	Easy	Not easy nor difficult	Difficult	Very difficult
Knowing what to touch for more information					
What information is available in the system					
Reading information on the screen					
Finding the information you wanted					
Changing between topics					
Using the system					

4.) Rate your level of preference for the following features

	Like Very Much	Like	Don't Care	Dislike	Dislike Very Much
Location of the menu buttons					
Size of the buttons					
Size of the text					
Text font/style					
Colour of the text					
Colour of screen					
Match of the background colour to the button colour					

5.) Rate how confusing did you find the organisation of information on the Profile's screens to be (please circle one)?

Very clear   Clear   Not confusing nor clear   Confusing   Very confusing

6.) How fun was the Profile system to use (Please circle one)?

Very engaging and fun to use   Engaging   Don't care   Boring   Very boring

What did you like least about using the Profile system:

1.

2.

3.

What did you like most about using the Profile system:

1.

2.

3.

Any Recommendations:

Appendix F – Study 2 – Care Managers Initial Views

Portrait Introduction and Tasks

- Introduce the general topics and explain what each is :

  o Time Line :

    - Time line can contain any significant events from a person's life up to a total of 8.

    - For example this profile has information on Margaret's childhood, first job, wedding/marriage, children, job at Timex, her 40th birthday, a holiday around Europe and retirement.

  o Family Tree :

    - Family Tree has an image of the person's immediate family.

    - Family Tree is included so if a carer notices Margaret talks about 'Gordon and Jenny' a lot they can see who this person is in relation to Margaret.

  o Things To Know:

    - Things to know can contain any facts that would be important to know about a person up to a total of 6.

    - For example Margaret prefers to sit in the kitchen at the table than in a sitting room or she is allergic to crab but loves all other types of fish.

  o Hobbies & Interests:

- - Hobbies and interests can contain any information on how the person likes to spend their free time. What they enjoy doing. Up to a maximum of 4 different interests / hobbies.

  - Family Stories

    - Family stories can contain up to 3 different stories about the person.

    - Family stories were included to allow the family to share some information about the person that might not fit into any of the other categories. To help show the person they love.

  - Photo Album

    - Photo Album contains up to 12 photos of the person during their life. This is included to help staff see what this person was like during their life and how they liked to spend their time.

Allow people to try the system for about 10 minutes

Next ask them to try to:

1.) Select a photo of Margaret from the 'Photo Album'.

2.) Go to 'Family Stories' and read the story 'Evacuation Mischief!'.

3.) Go to 'Time Line' and read the event 'Europe'.

Portrait Questions

The purpose of this interview is to gather your feedback and opinion on the Profile system and how you think it might be used by care staff.

1. What information did you find most interesting? Why?

2. What information did you find least interesting? Why?

3. What information do you think you would find most relevant when you first meet a client?

4. What information do you think is missing?

5. What problems did you find with the system?

6. What benefits do you think staff would gain from using the system?

7. How much time do you think is needed to learn how to use the system?

8. What type of care giver do you think would benefit from using the system? (new staff, staff with a few years of experience, all staff, managers)?

9. How do you think that new staff would react if they were introduced to their clients using this software? (e.g., before they began work?)

10. When and how do you think existing staff would use this system?

11. What impact do you think the system would have on existing staff working with new or existing clients?

12. Where do you think that the system should be available (e.g., in staff room, in patient rooms, etc.).

13. Overall what do you think of the Profile system?

Informal Evaluations: Pre-study Questionnaire

This survey will gather background information data about you and you experience in the care environment. The survey will take about 5 minutes to complete. Thank you in advance for your time and effort.

Background Information

1.) Gender

☐ Male   ☐ Female

2.) Age (please check one)

☐ 18-29   ☐ 30-39   ☐ 40-49   ☐ 50-59   ☐ 60+

3.) How often to you use a computer?

Never	Once every few months	Once a month	Weekly	A few days per week	Daily

4.) In total how long have you worked in the care environment/ been a carer?

☐ less than 5 years   ☐ 5-10 years   ☐ 11-15 years   ☐ 16+ years

5.) How long have you worked with people with dementia?

☐ less than 5 years   ☐ 5-10 years   ☐ 11-15 years   ☐ 16+ years

6.) How long have you been a care manager?

☐ less than 5 years   ☐ 5-10 years   ☐ 11-15 years   ☐ 16+ years

7.) What information do you normally receive when you first meet a person with dementia? Please check all that apply.

- ❑ Medical history and information
- ❑ Medication list
- ❑ Family & personal history
- ❑ Food likes and dislikes
- ❑ Preferences for activities
- ❑ Risk assessments
- ❑ Personal hygiene and toileting needs
- ❑ Social, cultural or spiritual preferences
- ❑ Communication needs
- ❑ Other, please specify _____-

8.) How useful do you find this information for working with individuals with dementia?

Information Type	Not useful at all	Not very useful	Don't care	Useful	Very useful	N/A
Medical history and information						
Medication list						
Family & personal history						
Food likes and dislikes						
Preferences for activities						
Risk assessments						
Personal hygiene and toileting needs						

Information Type (continued)	Not useful at all	Not very useful	Don't care	Useful	Very useful	N/A
Social, cultural or spiritual preferences						
Communication needs						
Other						

9.) What other information that is currently not accessible to you would you like to know or have about that person? Please list.

Appendix G – Study 3 – Care Staff

Portrait – Staff Information Sheet

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Once you have read the information below you can decide if you would like to take part in the study. If you do wish to take part you should sign the consent form.

Portrait - 'Multimedia Profiles as External Personalities to Support People with Dementia and their Carers' is a research project being carried at the University of Dundee. It started in September 2008 and will continue until September 2011.

Background

It can be very difficult for staff working in care/nursing homes to get to know and learn about the individuals with dementia living in that care home because people with dementia can have limited or no ability to communicate. Yet, without exception all of these individuals have had lives full of incident and relationships, jobs, hobbies, awards, and interesting experiences. Establishing some form of communication between carers and people with dementia can have vital implications for everyone's health and well-being. Learning about a person's past history may assist a care giver by providing interesting and important information from which to stimulate discussion and communication. However, this information is rarely available and can be difficult to obtain through patient records or discussions with family especially when the health or medical situation often takes priority.

Overall Project and Purpose of this Study

The project aims to develop software that can act as an external communications bridge between carers and people with dementia through the creation of 'Portraits'. These will take the form of an interactive multimedia presentation containing brief biographical and personal information relevant to a particular person with dementia. It is intended to be used by care staff working with that individual to learn about some interesting aspects of his or her past in a relatively short time. The purpose of this study is to gather feedback and opinion of the Portrait system by care staff.

Why have I been invited?

You have been identified as care staff that work with people with dementia that live in a care home. I am inviting you to help evaluate the Portrait system.

Do I have to take part?

Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your work.

What is involved?

You can help this project by telling me your thoughts and opinions of the Portrait system. This will take place at the care home and will not affect your work. In order for me to develop a thorough understanding of what is involved I may ask you to complete a questionnaire or I may simply want to talk to you.

You will be asked to sign a form saying that you are willing to participate in the research. The consent form will explain what will be asked and what will happen to any information which is collected. You will be given a copy of this form to keep.

If you would like to know more about this research please contact the researcher, Gemma Webster, on (01382) 385509 or if you have questions that cannot be answered by the researcher, please feel free to contact the Project Supervisor, Prof. Vicki Hanson, School of Computing, University of Dundee, Dundee DD1 4HN. She can be contacted by phone at (01382) 385509 or by email at vlh@computing.dundee.ac.uk.

School of Computing
UNIVERSITY OF DUNDEE

Gemma Webster, *PhD Student*
School of Computing, University Of Dundee, Dundee, DD1 4HN
t +44 (0)1382 388528   f +44 (0)1382 385509
e gwebster@computing.dundee.ac.uk www.computing.dundee.ac.uk

 School of Computing

Portrait - Staff Consent Form

As part of a PhD, software is being researched and developed that can act as an external communications bridge between carers and people with dementia through the creation of simple but effective 'external personalities'.

This page describes what you will be asked to do for the study. Please read through it and then sign at the bottom to say that you understand and accept the conditions of this study. If you have questions, please feel free to ask the researcher.

The Researcher will begin by asking some general information about yourself and your job within the care home. You will be asked your opinion and thoughts to gain a better understanding of what it is like to care for someone with dementia in a care home setting. These thoughts and opinions may be elicited through interviews and questionnaires. You may be asked to talk about what you think of your personal job, the care home environment and also your feelings and experiences within the care home. Also to gain a better understanding of all the duties you carry out in your day to day routine the researcher may request to shadow or observe you working.

The feedback sessions may be recorded using a voice recorder or screen capture (recording the computer screen), as this will allow the researcher to incorporate your feedback into the design of the system. Some recordings that show an important point may be used in presentations at future research conferences and meetings.

Your participation in this study is voluntary and you can omit any questions in any questionnaires or you can leave the study at any time without penalty or giving reasons. No undue risk arises from the participation in this study.

All the information which you give and the recordings (that is all data) will be stored safely and kept separate from information about your identity. Access to your data is minimised to the people involved in this research. If information about you is used for publications or presentation, no reference to your identity will be made.

Please note that you are helping the researchers to develop an understanding of what it is like to care for a person with dementia. You are not being tested and your job is not being evaluated. There are therefore no right or wrong answers to the questions you will be asked. The researcher is very grateful for your help. If you are willing to take part, please sign the consent form below.

I have read the project Information (above), & I consent to taking part in this exercise.

Signed: _____

Printed Name: _____

Date: _____

Witness by the Researcher: _____

Printed Name: _____

Date: _____

Gemma Webster, *PhD Student*
School of Computing, University Of Dundee, Dundee, DD1 4HN
t +44 (0)1382 386528   *f* +44 (0)1382 385509
e gwebster@computing.dundee.ac.uk www.computing.dundee.ac.uk

School of Computing

UNIVERSITY OF DUNDEE

Portrait Checklist

1.) Information Sheet ☐

2.) Consent Form ☐

3.) Pre-Study Questionnaire ☐

4.) Introduce Booklet Practice profile Vic ☐

5.) Introduce Portrait System profile Vic ☐

6.) Change to Booklet profile Margaret – use practice tasks ☐

7.) Change to profile Booklet profile Margaret – use trial tasks ☐

8.) Change to Portrait profile Alex – use practice tasks ☐

9.) Change to Portrait profile Alex – use trial tasks ☐

10.) Post-Study Questionnaire ☐

11.) Any questions and debriefing ☐

School of Computing

UNIVERSITY OF
DUNDEE

Portrait
User Study 1: Pre-study Questionnaire

This survey will gather background information data about you and your experience in the care environment. The survey will take about 5 minutes to complete. Thank you in advance for your time and effort.

Background Information

1.) Gender (please tick one)

☐ Male ☐ Female

2.) Age (please tick one)

☐ 18-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ 60+

3.) How often to you use a computer? (please circle one)

| Never | Once every few months | Once a month | Weekly | A few days per week | Daily |

4.) In total how long have you worked in the care environment/ been a carer? (please tick one)

☐ less than 6 months ☐ 6 months - 1 year ☐ 1 - 5 years ☐ 5+ years

5.) Have you any personal experience of dementia? (please tick one)

☐ No ☐ Family Member ☐ Friend ☐ Other

6.) What is your first language? Please tick one.

❏	English	❏	French	❏	Romanian
❏	Scottish Gaelic	❏	German	❏	Russian
❏	Irish	❏	Greek	❏	Serbian
❏	Welsh	❏	Gujerati	❏	Slovak
❏	Albanian/Kosovan	❏	Hindi	❏	Slovenian
❏	Arabic	❏	Hungarian	❏	Somali
❏	Bengali	❏	Italian	❏	Spanish
❏	Bulgarian	❏	Japanese	❏	Swahili
❏	Chinese	❏	Latvian	❏	Tamil
❏	Croatian	❏	Lithuanian	❏	Turkish
❏	Czech	❏	Polish	❏	Urdu
❏	Estonian	❏	Portuguese	❏	Vietnamese
❏	Farsi /Persian	❏	Punjabi	❏	Other, please specify _____ -

7.) What do you think of when you first hear that a resident has dementia? Please tick all that apply.

❏ Quiet
❏ Obedient
❏ Affectionate
❏ Awkward
❏ Emotional
❏ Unresponsive
❏ Detached
❏ Friendly
❏ Communication Problems
❏ Other, please specify _____ -

8.) Rate your level of agreement with these statements? Please tick relevant box.

	Agree	Slightly Agree	Neutral	Disagree	Strongly Disagree
People who have dementia are not aware they have it.					
People with dementia have interesting memories and stories I enjoy hearing.					
Dementia does not make a person incompetent; they are still able to make decisions and choices.					
It is rewarding when you talk to a resident with dementia about something they are interested in and you get a response.					
People with dementia are unaware of what is going on.					
I feel I know the residents with dementia as much as any other resident.					
Residents that have dementia make carrying out our work duties more difficult.					
I find it upsetting when a resident who has dementia is upset.					
People with dementia become childlike.					
Having dementia means your life is over and you can no longer contribute to society.					

9.) What information do you think is important when getting to know someone and should be included in the Portrait? Please tick relevant box.

	Very Important	Important	Neutral	Irrelevant	Strongly Irrelevant
A person's childhood					
A person's siblings and parents					
A person's education					
A person's marriage and spouse					
A person's children					
A person's working life					
How someone likes to spend their free time					
What someone likes and dislikes					
An important or significant event in someone's life					
Interests or hobbies					
No Information					
Other					

Portrait Introduction

Portrait Tasks (Participant 1)

Booklet (Female)-

Trial Tasks:

1.) What is Margaret's sleep routine?
2.) What was Margaret's husband called?
3.) What was Margaret's first job?
4.) Can you find out what Margret likes to spend her spare time doing?
5.) Can you find who Margaret's children are?

Portrait (Male)-

Training Tasks:

1.) Select a photo of Alex from the 'Photo Album'.
2.) Go to 'Family Stories' and read the story 'The Berries'.
3.) Find one of Alex's favourite hobbies.

Trial Tasks:

1.) What did Alex look like as a young man?
2.) What was Alex's wife called?
3.) What was Alex's first job?
4.) Can you find out what Alex likes to spend her spare time doing?
5.) Can you find who Alex's children are?

School of Computing

DUNDEE

Portrait
User Study 1: Post-study Questionnaire

The purpose of this questionnaire is to gather your opinion about learning and using the system. It should take about 10 minutes to complete Thank you in advance for your time and effort.

These questions are about the booklet you used.

1.) How fun/interesting was the booklet to use (Please circle one)?

| Very engaging and fun to use | Engaging | Don't care | Boring | Very boring |

2.) What do you think about the amount of information the booklet contained (Please circle one)?

| Too little Information | Some Information | Enough Information | A little too much information | Too much information |

3.) How well do you feel you know Alex (Please circle one)?

| Not very well | A little | Neither well nor a little | Quite well | Very well |

4.) Do you know the following information about Alex (Please complete the information)?

    a. What was Alex's job?

    b. What does Alex like to do in their spare time?

    c. Does Alex have any children?

These questions are about the Portrait system you used.

5.) Rate how difficult it was for you to learn how to use the Portrait system (please circle one).

| Very difficult | Difficult | Not difficult nor easy | Easy | Very easy |

6.) What level of training do you think would be required to learn how to use the Portrait system (please circle one)?

| No training necessary | Less than 30 minutes | About one hour | Half of a day | One day |

7.) Rate how confusing did you find the organisation of information on the Portrait's screens to be (please circle one)?

| Very clear | Clear | Not confusing nor clear | Confusing | Very confusing |

8.) How fun/interesting was the Portrait system to use (Please circle one)?

| Very engaging and fun to use | Engaging | Don't care | Boring | Very boring |

9.) Rate how easy you found the following features to use. Please tick relevant box.

	Very easy	Easy	Not easy nor difficult	Difficult	Very difficult
Knowing what to touch for more information					
What information is available in the system					
Reading information on the screen					
Finding the information you wanted					
Changing between topics					
Using the system					

10.) Rate your level of preference for the following features. Please tick relevant box.

	Like Very Much	Like	Don't Care	Dislike	Dislike Very Much
Location of the menu buttons					
Size of the buttons					
Size of the text					
Text font/style					
Colour of the text					
Colour of screen					
Match of the background colour to the button colour					

11.) What do you think about the amount of information the Portrait system contained (Please circle one)?

| Too little Information | Some Information | Enough Information | A little too much information | Too much information |

12.) How well do you feel you know Margaret (Please circle one)?

| Not very well | A little | Neither well nor a little | Quite well | Very well |

13.) Do you know the following information about Margaret (Please complete the information)?

    a.   What was Margaret job?

    b.   What does Margaret like to do in their spare time?

    c.   Does Margaret have any children?

14.) Who do you feel you know better (please tick one)?

☐ - Alex   ☐ - Margaret

What did you like least about using the Portrait system or the booklet:

    1.

    2.

    3.

What did you like most about using the Portrait system or the booklet:

    1.

    2.

    3.

Any Recommendations:

Appendix H – *Portrait* Creation Pack

School of Computing

UNIVERSITY OF DUNDEE

Completing the Portrait Information Sheets

Attached are the required sheets to be completed in order to create an Individual Portrait for your relative or friend. There are six different topics:

- Timeline
- Family Tree
- Things To Know
- Hobbies & Interests
- Family Stories
- Photo Album

I understand that it is not easy filling out all of this information but the more you manage to complete the fuller the portrait will be.

For the Timeline and Family Stories topics if you could please include a photo for each of the events or stories as this helps give the care staff a better idea of the person. Also the Photo Album topic allows you to have up to twelve pictures to help show them throughout their lives.

For the pictures you can give me an electronic version of the photo or the original and I will make an electronic copy of the picture. I will take great care of any information and photos you give me.

If you have any questions about completing any of the topics or anything else to do with the project please do not hesitate to contact me. My contact details are at the bottom of this page.

Thank you very much for being involved in this project.

School of Computing
UNIVERSITY OF DUNDEE

Gemma Webster, *PhD Student*
School of Computing, University Of Dundee, Dundee, DD1 4HN
t +44 (0)1382 386528   *f* +44 (0)1382 385509
e gwebster@computing.dundee.ac.uk www.computing.dundee.ac.uk

Timeline

Timeline can contain up to eight significant events in the person's life. You do not need to complete all eight events. Only add those you feel are appropriate.

Timeline Example:

Title:
> 40th Birthday Holiday

Description:
> Margaret went on her first holiday abroad for her 40th birthday. The holiday was to Magaluf on the Spanish island of Majorca. Margaret went with her friends and Hilary who was 17 at the time.
>
> When they got there it was during the Easter festival so almost everything was closed.
>
> When Margaret got home she told Andy she wanted to go abroad again. Andy refused so Margaret told him she was going next year whether he went or not. Andy did go the following year and loved it and they had many foreign holidays after it.

Please try to keep the description to fewer than 150.

Timeline - Event 1

Title:

Description:

Timeline - Event 2

Title:

Description:

Timeline - Event 3

Title:

Description:

Timeline - Event 4

Title:

Description:

Timeline - Event 5

Title:

Description:

Timeline - Event 6

Title:

Description:

Timeline - Event 7

Title:

Description:

Timeline - Event 8

Title:

Description:

Family Tree

Family Tree is an outline of the person's immediate family. There is limited space so it may not be possible to include every single family member in the tree. Please select the most significant people in their life. I know you may not want to offend anyone by not including them in this tree but it is not a comprehensive family tree. It is included to help staff recognise who the person talks about or visits/phones them.

Family Tree Example:
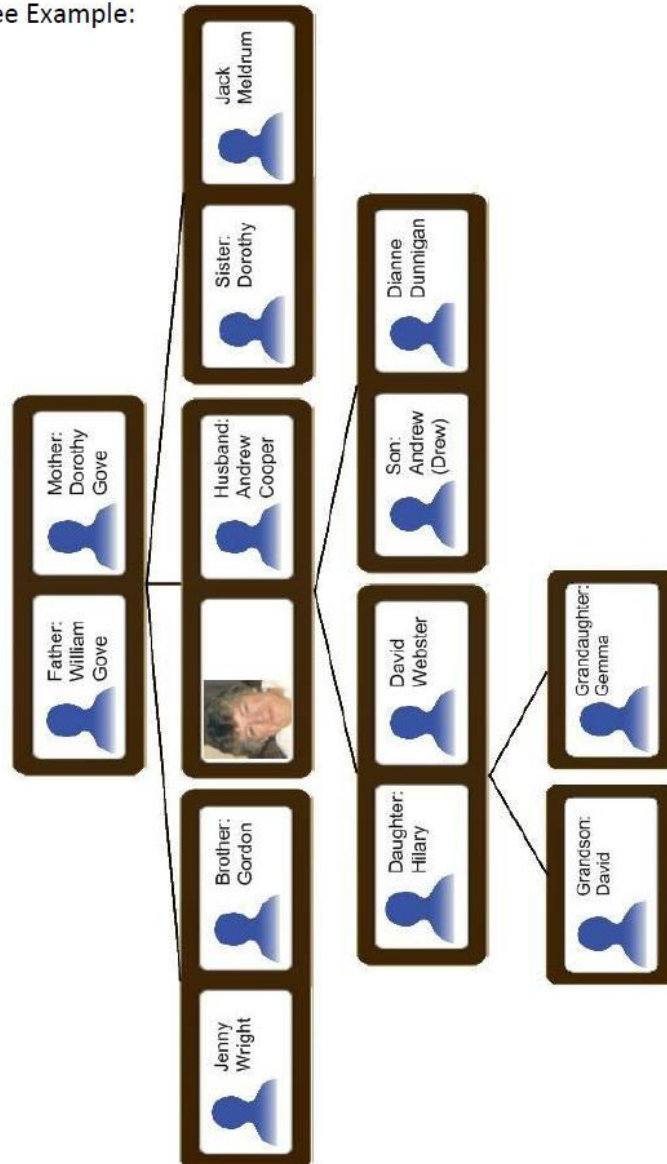
Please indicate relationship to your loved one and gender of all members of your family. You do not need to draw your tree like the example a simple list is acceptable just as long as relationships are clear.

Family Tree:

Top of Tree

Bottom of Tree

Things To Know

Things To Know can contain up to six significant facts about the person that you feel it is important for the care staff to know. You do not need to complete all six facts. Simply put the facts you feel are important to them. In the example Portrait you were shown these facts were sorted into likes and dislikes. You do not only need to have likes and dislikes if you feel different headings would be better e.g. Preferences, allergies. You can have more than two different headings that you feel would be the best descriptions for your loved ones facts.

Things To Know Example:

Heading:

Dislikes

Description:

Dislikes too much organisation. She likes flexibility and her sleep routine changes often.

Please try to keep the description to 1 - 3.

Things To Know - Fact 1

Heading:

Description:

Things To Know - Fact 2

Heading:

Description:

Things To Know - Fact 3

Heading:

Description:

Things To Know - Fact 4

Heading:

Description:

Things To Know - Fact 5

Heading:

Description:

Things To Know - Fact 6

Heading:

Description:

Hobbies & Interests

Hobbies & Interests can contain up to four of the person's hobbies or interests. You do not need to complete all four if you feel the person does not need all four.

Hobbies & Interests Example:

Heading:

> Baking

Description: Margaret loves to bake and cook. Margaret does all the baking even though her husband Andy was a baker.

Please try to keep the description to 1 - 3.

Hobbies & Interests - 1

Heading:

Description:

Hobbies & Interests - 2

Heading:

Description:

Hobbies & Interests - 3

Heading:

Description:

Hobbies & Interests - 4

Heading:

Description:

Family Stories

Family Stories can contain up to three different stories about the person's life. You do not need to complete 3 stories this is simply the maximum allowed. The stories can be anything you feel would be interesting or funny to know or show the person as you would like care staff to see them.

Family Stories Example:

Title:

Evacuation Mischief!

Description:

Margaret, her brother Gordon and her sister Dorothy were evacuated to Brechin during the World War 2. They were sent with their Gran who lived with them but were only away for 2 weeks! Their Gran could not cope with the trouble Margaret and Gordon caused.

While they were away Margaret and Gordon were in a rowing boat with their Gran. Their Gran was telling them off so they jumped out of the boat with the paddles and left her in the middle of the pond!

Please try to keep the description to fewer than 150.

Family Stories - Story 1

Title:

Description:

Family Stories - Story 2

Title:

Description:

Family Stories - Story 3

Title:

Description:

Photo Album

Photo Album can contain up to twelve different pictures from the person's life.

Photo Album Example:

Caption:

> Margaret often went cycling around Scotland as a young woman with her husband Andy, Brother Gordon and sister in law Jenny.

Please try to keep the caption to 1 - 3 sentences.

Photo Album- Caption 1

Caption:

Photo Album- Caption 2

Caption:

Photo Album- Caption 3

Caption:

Photo Album- Caption 4

Caption:

Photo Album- Caption 5

Caption:

Photo Album- Caption 6

Caption:

Photo Album- Caption 7

Caption:

Photo Album- Caption 8

Caption:

Photo Album- Caption 9

Caption:

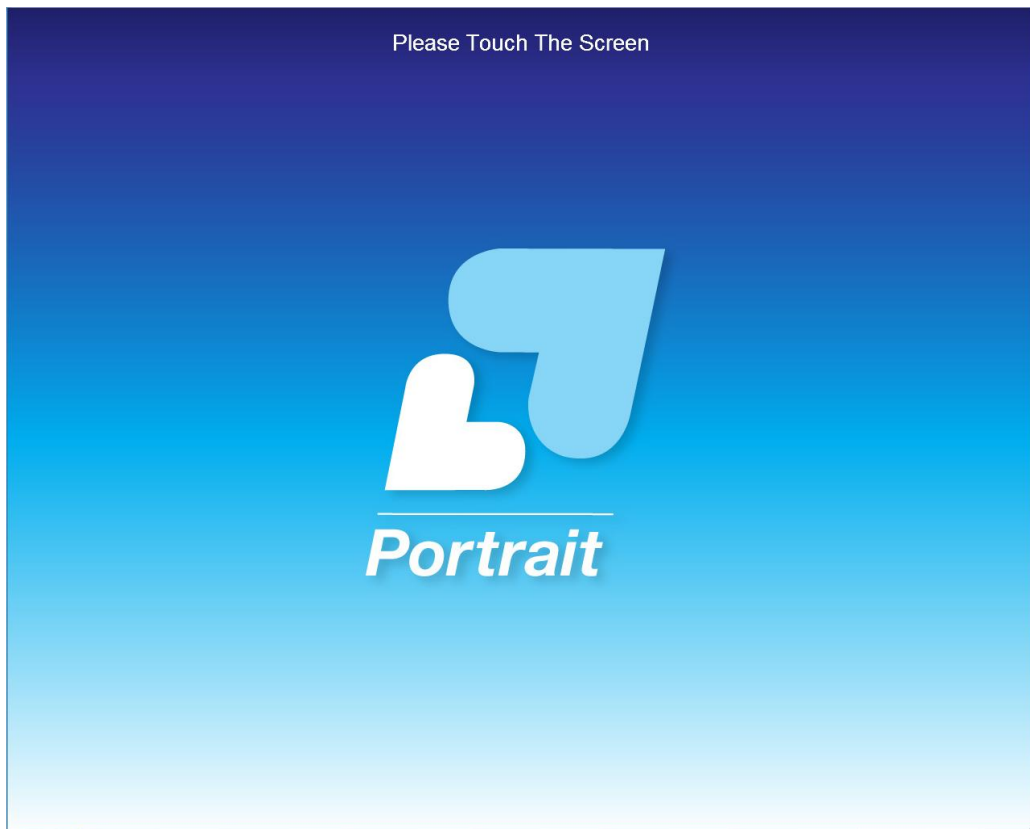**Photo Album- Caption 10**

Caption:

Photo Album- Caption 11

Caption:

Photo Album- Caption 12

Caption:

Appendix I – Example *Portrait*
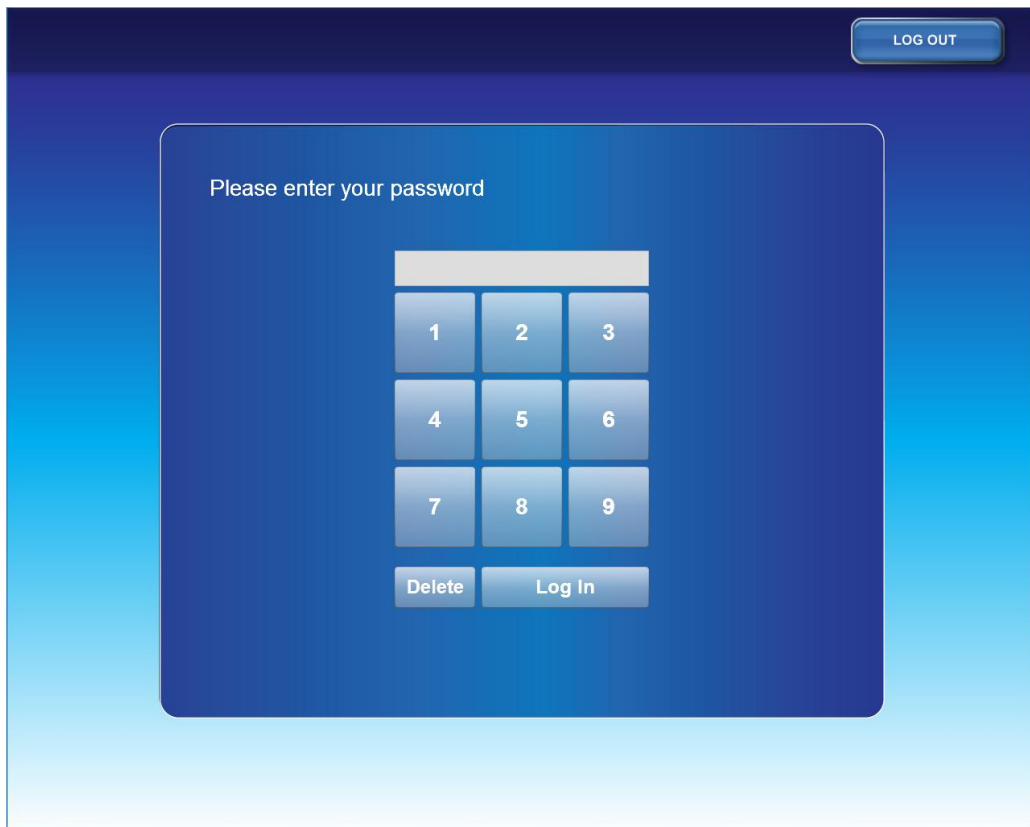
Margaret Cooper

SEE ME NOW

MAIN MENU

WEDDING

FIRST JOB

CHILDREN

Please touch an event to find out more information

TIMEX

CHILDHOOD

RETIREMENT

HOLIDAY

EUROPE

MY LIFE EVENTS

MY FAMILY

PLEASE NOTE

HOBBIES & INTERESTS

FAMILY STORIES

PHOTO ALBUM

Margaret Cooper

SEE ME NOW

MAIN MENU

Childhood

Margaret grew up in Rosebank Street in Dundee.

Her Gran lived with them and Margaret often got up to mischief with her brother to annoy her Gran. Margaret attended Rosebank Primary School and Rockwell Secondary School.

Margaret's Dad was a Stonemason. During the war her Dad did not have to go to war as he had the job of checking the stability of bombed buildings and looking for survivors.

Go Back

MY LIFE EVENTS

MY FAMILY

PLEASE NOTE

HOBBIES & INTERESTS

FAMILY STORIES

PHOTO ALBUM

Margaret Cooper

First Job - Nursery Nurse

Margaret's first job was at Baxter's Jute Mill as a Nursery Nurse.

Margaret did not want to be a Nursery Nurse she had applied for a job on the mill floor but got rejected as her school grades were too good. Margaret was 15 years old when she started working.

Go Back

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper

Wedding

Margaret married Andrew Cooper in 1957 aged 21. Andrew was Margaret's older brother Gordon's best friend and had known her from childhood.

Andy had asked Margaret to marry him before they finally got engaged but she said "no" as Andy had asked as a Christmas present and she wanted leather gloves. Margaret always says never to accept an engagement ring as a birthday or a Christmas present.

Go Back

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper

Children

Margaret had her first child, Hilary, in 1958 a year after she was married. Hilary was named after Sir Edmund Hillary as Margaret thought he was lovely.

Margaret had her second child Andrew (Drew) in 1960. Margaret always called Drew, "Drewy", as a little boy until when asked what he would like for a birthday he asked not to be called "Drewy" anymore.

Go Back

| MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM |

Margaret Cooper

SEE ME NOW

MAIN MENU

Timex

Margaret worked in the Timex factory before having her family and again after.

Margaret was a training instructor in Timex and worked at both the factories in Dundee. Margaret left Timex in 1985.

Margret then went to work with the 'Keep Dundee Tidy' campaign going around Nursery's and Schools teaching children about being clean and tidy.

Go Back

| MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM |

Margaret Cooper

SEE ME NOW

MAIN MENU

40th Birthday Holiday

Margaret went on her first holiday abroad for her 40th birthday. The holiday was to Magaluf on the Spanish island of Majorca. Margaret went with her friends and Hilary who was 17 at the time.

When they got there it was during the Easter festival so almost everything was closed.

When Margaret got home she told Andy she wanted to go abroad again. Andy refused so Margaret told him she was going next year whether he went or not. Andy did go the following year and loved it and they had many foreign holidays after it.

Go Back

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper

SEE ME NOW

MAIN MENU

Europe

Margaret travelled around Europe for a holiday in 1981 and again in 1982 with Andy, Hilary and her son-in-law Dave.

They drove around visiting: France, Germany, Austria, Italy, Switzerland, Luxemburg, Monaco and Liechtenstein. Margaret loved visiting Venice.

Margaret repeated a similar trip in 2003 with Hilary, Dave and her granddaughter Gemma.

Go Back

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper — SEE ME NOW — MAIN MENU

Retirement

When Margaret retired she looked after her grandchildren.

Margret and her husband Andy also did a lot of travelling around Scotland and England in their Caravan.

Go Back

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper — SEE ME NOW — MAIN MENU

Parents
William Gove   Dorothy Gove

Husband
Andrew Cooper

Siblings
Gordon   Dorothy   Nancy   William (Billy)

Children
Hilary   Andrew (Drew)

Grandchildren
David   Gemma

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper

SEE ME NOW   MAIN MENU

Likes

- Enjoys ironing. Margaret likes to iron all her clothes - including her socks!

- Loves to have fresh flowers in the house. Her favourite flowers are carnations

- Enjoys smoking, she smokes around 10 cigarettes a day

- Margaret is more comfortable sitting in the kitchen rather than the living room. She finds this more relaxing.

Dislikes

- Dislikes too much organisation. She likes flexibility and her sleep routine changes often.

- Is allergic to crab but loves any other kind of fish.

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper

SEE ME NOW   MAIN MENU

Cross Stitch and Knitting
Margaret knitted Arran jumpers, toy clowns and baby shawls.

The Computer
Margaret loves to play card games, puzzles and to look for cross stitch patterns on the internet.

Baking
Margaret loves to bake and cook. Margaret does all the baking even though her husband Andy was a baker.

Reading
Margaret loves to read. Her favourite genres are Scottish History, the Royal Family History and Politics.

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper

MAIN MENU

Please touch a picture to get the full story

I fell down a hole!

Evacuation Mischief!

Old Craigie (Dairy Farm)

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper

SEE ME NOW | MAIN MENU

I fell down a hole!

Margaret often recalls the day this photo was taken as just after this picture she fell down a hole and almost drowned.

Margaret is about 4 years old in this picture.

It is taken at Portobello Beach while on holiday. It was a long journey it took two ferries to get there.

Go Back

MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM

Margaret Cooper

Evacuation Mischief!

Margaret, her brother Gordon and her sister Dorothy were evacuated to Brechin during the World War 2. They were sent with their Gran who lived with them but were only away for 2 weeks! Their Gran could not cope with the trouble Margaret and Gordon caused.

While they were away Margaret and Gordon were in a rowing boat with their Gran. Their Gran was telling them off so they jumped out of the boat with the paddles and left her in the middle of the pond!

Go Back

MY LIFE EVENTS   MY FAMILY   PLEASE NOTE   HOBBIES & INTERESTS   FAMILY STORIES   PHOTO ALBUM

Margaret Cooper

Old Craigie (Dairy Farm)

Margaret's Uncle Dave ran the Old Craigie dairy farm. Margaret loved visiting the farm as a child. There was a pony and trap she use to play with.

Her Uncle would pay Margaret and her brother Gordon half a crown to collect geese eggs and the geese would peck and chase them.

Go Back

MY LIFE EVENTS   MY FAMILY   PLEASE NOTE   HOBBIES & INTERESTS   FAMILY STORIES   PHOTO ALBUM

Margaret, her mum and brother Gordon.
Margaret is about 18 months old.

258

Margaret and her sister-in-law Jenny
out for the night at a dance.

Go Back

| MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM |

Margaret Cooper

SEE ME NOW — MAIN MENU

Margaret was the 2nd of 5 children. This is a photo of her with
her younger siblings Dorothy, Billy and Nancy.

Go Back

| MY LIFE EVENTS | MY FAMILY | PLEASE NOTE | HOBBIES & INTERESTS | FAMILY STORIES | PHOTO ALBUM |

Margaret Cooper

SEE ME NOW   MAIN MENU

Margaret and Andy's first Caravan.
They got the caravan in 1965.

Go Back

MY LIFE EVENTS   MY FAMILY   PLEASE NOTE   HOBBIES & INTERESTS   FAMILY STORIES   PHOTO ALBUM

Margaret Cooper

SEE ME NOW   MAIN MENU

This is me now!   ×

Please touch the buttons below to start

MY LIFE EVENTS   MY FAMILY   PLEASE NOTE   HOBBIES & INTERESTS   FAMILY STORIES   PHOTO ALBUM

Appendix J – Study 4 - Family Case Studies

UNIVERSITY OF DUNDEE

School of Computing

Portrait - Information Sheet

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Once you have read the information below you can decide if you would like to take part in the study. If you do wish to take part you should sign the consent form.

Portrait - 'Multimedia Profiles as External Personalities to Support People with Dementia and their Carers' is a research project being carried at the University of Dundee. It started in September 2008 and will continue until September 2011.

Background

It can be very difficult for staff working in care/nursing homes to get to know and learn about the individuals with dementia living in that care home because people with dementia can have limited or no ability to communicate. Yet, without exception all of these individuals have had lives full of events and relationships, jobs, hobbies, awards, and interesting experiences. Establishing some form of communication between carers and people with dementia can have vital implications for everyone's health and well-being. Learning about a person's past history may assist a care giver by providing interesting and important information from which to stimulate discussion and communication. However, this information is rarely available and can be difficult to obtain through patient records or discussions with family especially when the health or medical situation often takes priority.

Overall Project and Purpose of this Study

The project aims to develop software that can act as an external communications bridge between carers and people with dementia through the creation of 'Portraits'. These will take the form of an interactive multimedia presentation containing brief biographical and personal information relevant to a particular person with dementia. It is intended to be used by care staff working with that individual to learn about some interesting aspects of his or her past in a relatively short time. The purpose of this study is to create a Portrait of your relative or friend and gather your feedback on the process of creating a Portrait.

Why have I been invited?

You have been identified as a friend or relative of a person with dementia that lives in a care home. I am inviting you to help me create a Portrait about your friend or relatives life.

Do I have to take part?

Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your friend or relatives care or your relationship with the care home looking after your friend or relative.

What is involved?

You can help this project by helping me to create a Portrait about your relative or friend. Creating a Portrait will involve you gathering photographs and information about different events in your relative or friend's life. This will take place at the care home or your own home and will not involve your relative or friend. In order for me to develop a thorough understanding of what is involved I may ask you to complete a questionnaire or I may simply want to talk to you. I will be in contact with you for about a month to help you while you gather the information for in your friend or relatives Portrait.

You will be asked to sign a form saying that they are willing to participate in the research. The consent form will explain what will be asked and what will happen to any information which is collected. You will be given a copy of this form to keep.

If you would like to know more about this research please contact the researcher, Gemma Webster, on (01382) 385509 or you have questions that cannot be answered by the researcher, please feel free to contact the Project Supervisor, Prof. Vicki Hanson, School of Computing, University of Dundee, Dundee DD1 4HN. She can be contacted by phone at (01382) 385509 or by email at vlh@computing.dundee.ac.uk.

School of Computing

Portrait - Family & Friend Consent Form

As part of my PhD, I am researching and developing software that can act as an external communications bridge between carers and people with dementia through the creation of 'external personalities'.

This page describes what you will be asked to do for the study. Please read through it and then sign at the bottom to say that you understand and accept the conditions of this study. If you have questions, please feel free to ask the researcher.

The Researcher will begin by asking some general information about yourself, your relative or friend and the care home. You will be asked your opinion and thoughts to gain a better understanding of what it is like to have a relative or friend with dementia in a care home. These thoughts and opinions will be obtained through interviews and questionnaires. You may be asked to talk about what you think of your relative or friends dementia, the care home environment and also your feelings and experiences.

The feedback sessions will be recorded using a voice recorder, video recorder or screen capture (recording the computer screen), as this will allow the researcher to incorporate your feedback into the design of the system. Some recordings that show an important point may be used in presentations at future research conferences and meetings.

Your participation in this study is voluntary and you can omit any questions in any questionnaires or you can leave the study at any time without penalty or giving reasons. No undue risks arise from the participation in this study.

All the information which you give and the recordings (that is all data) will be stored in a locked cabinet and kept separate from information about your identity. Access to your data is minimised to the people involved in this research. If information about you is used for publications or presentation, no reference to your identity will be made.

Please note that you are helping the researchers to develop an understanding of what it is like to care for a person with dementia. You are not being tested and your relative or friend is not being evaluated. There are therefore no right or wrong answers to the questions you will be asked. The researcher is very grateful for your help. If you are willing to take part, please sign the consent form below.

I have read the project information (above), & I consent to taking part in this exercise.

Signed: _____

Printed Name: _____

Date: _____

Witness by the Researcher: _____

Printed Name: _____

Date: _____

Gemma Webster, *PhD Student*
School of Computing, University Of Dundee, Dundee, DD1 4HN
t +44 (0)1382 386528   *f* +44 (0)1382 385509
e gwebster@computing.dundee.ac.uk www.computing.dundee.ac.uk

School of Computing

DUNDEE

Portrait
Family & Friends: Pre-study Questionnaire

This survey will gather background information about you and your experience with dementia. The survey will take about 5 minutes to complete. Thank you in advance for your time and effort.

Background Information

1.) Gender (please tick one)

☐ Male   ☐ Female

2.) Age (please tick one)

☐ 18-29   ☐ 30-39   ☐ 40-49   ☐ 50-59   ☐ 60+

3.) What is your relationship with the person who's Portrait you are creating?

☐ Spouse /   ☐ Sibling   ☐ Child /   ☐ Friend   ☐ Other
   Partner   Grandchild

4.) In total, how long has your relative or friend needed care (include all care settings not just current situation)?

☐ less than 6   ☐ 6 months - 1   ☐ 1 - 5 years   ☐ 5+ years
   months   year

5.) How long has your relative or friend been diagnosed with dementia?

☐ less than 6   ☐ 6 months – 1   ☐ 1 – 5 years   ☐ 5+ years   ☐ I don't know
   months   year

6.) How much time do you anticipate it will take to complete the Portrait information pack? Please tick one.

- ❑ Less than a day.
- ❑ 1 day – 1 week.
- ❑ 1 - 2 weeks.
- ❑ 2 – 3 weeks.
- ❑ 3 – 4 weeks
- ❑ 4 weeks +
- ❑ Other, please specify _____-

7.) How do you intend to complete the Portrait information pack? Please tick one.

- ❑ I intend to complete all sections in one sitting.
- ❑ I intend to complete one section at a time.
- ❑ I intend to complete all the information in two or three sittings.
- ❑ I intend to complete the information in small chunks when I have free time.
- ❑ Other, please specify _____-

8.) Will someone else help you make the Portrait? Please tick all that apply.

- ❑ No, I intend to make it alone.
- ❑ With the help of my children.
- ❑ With the help of my grandchildren.
- ❑ With the help of friends.
- ❑ With the help of the person's siblings.
- ❑ With the help of my parent(s)
- ❑ With the help of the person with dementia.
- ❑ Other, please specify _____-

9.) Where do you think you will get the information to complete the pack? Please tick all that apply.

- ❑ From my own memory.
- ❑ From talking to friends.
- ❑ From talking to relatives.
- ❑ From photo albums I have.
- ❑ From photo albums other people have.
- ❑ From video recordings.
- ❑ The person already has a life story book and I will use that.
- ❑ Other, please specify _____ -

10.) How difficult do you think it will be to obtain this information (please circle one)?

Very easy   Easy   Not easy nor   Difficult   Very difficult   I cannot
                                  difficult   predict

11.) What process do you think you will use to gather the information for completing the pack? Please tick all that apply.

- ❑ I will fill out a section and then look for photographs to match.
- ❑ I will talk to family and friends first then fill out each section.
- ❑ I will look through photo albums to help get ideas for each section.
- ❑ I will pick photographs for each section then complete the information.
- ❑ Other, please specify _____ -

12.) Who do you think will benefit from having the information you prepare. Please tick all that apply.

- ❑ Person with dementia
- ❑ Family members
- ❑ Friends
- ❑ Care workers
- ❑ Medical staff
- ❑ Other staff at institution (e.g., nutrition staff)
- ❑ Visiting professionals
- ❑ Other, please specify _____ -

13.) What level of benefit do you think people will have from the information you prepare (please circle one)?

Much benefit	Some benefit	I don't care	A bit of benefit	No benefit	I cannot predict

Appendix K – Study 5 – Care Home Study

School of Computing

DUNDEE

Portrait
User Study 5: Care Home Study Questionnaire

1.) Did you use the Portrait system(please tick one)

☐ Yes   ☐ No

If Yes:
   a. How often did you use the Portrait system (Please circle one)?

   A lot   Several times   Occasionally   Infrequently   Once

If No:
   b. Why did you not use the Portrait system (Please circle one)?

| I already know the resident well | I don't work with the resident's in the system | I forgot to look at it | It took too much time | Did not find it useful |

2.) Any Comments: