
Research to inform development of a guide to online activities for people with dementia

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Institute for Employment Studies

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Executive Summary

Background

Feedback received during the evaluation of the Get Connected grant programme indicated that while care organisations working with people with dementia had hoped to use information and communication technologies purchased with these grants to improve the quality of life of their clients, these aims had been frustrated by the lack of guidance available. As a result of receiving this feedback the Social Care Institute for Excellence (SCIE) decided to commission the production of a guide aimed at the needs of this group of social care providers.

In February 2012 SCIE commissioned the Institute for Employment Studies to undertake research to inform development of the guide, and Sara Dunn Associates to write the guide. This report describes the research and piloting process undertaken.

The research process

Prior to drafting of the guide the research consisted of two phases: the identification of activities currently being used with people with dementia and any resources and/or guidance already available; and review/assessment of activities and guidance available by an Advisory Group convened to support the development process. Following drafting of the guide, the draft guidelines were circulated to the Advisory Group to seek feedback; following revision in line with that feedback the guide was field-tested with staff in care organisations

Identification of activities in use and existing guidance

Existing activities and suggestions for using online technologies were obtained through three routes: a literature review using online databases to identify relevant articles and books; a request for information emailed to Get Connected

grant recipients; and interviews with practitioners, academics and volunteers working with people with dementia. Some of the individuals who responded to the email requesting information were also subsequently interviewed.

Reviewing the information generated

The information gained from this initial trawl for examples of activities, recommendations on usage and identification of existing guidance was compiled for presentation to an Advisory Group. The Group met at SCIE to discuss and evaluate the suggestions compiled and to make further recommendations. The information was revised in line with the comments received and forwarded to Sara Dunn Associates.

Reviewing and field-testing the guidance

Following receipt of the draft guidance it was circulated to members of the Advisory Group and to some of the individuals who had been interviewed in the earlier stage of the research. Feedback was incorporated by Sara Dunn Associates and the revised draft guide was then sent to nine care organisations who worked with people with dementia and who had agreed to trial the guidance.

At each of the care organisations up to four members of staff were interviewed to gain reactions to, and suggestions for any further changes to the guidance. All felt the guidance was clear and would be a useful support for those seeking to use ICTs to improve the services they provided for people with dementia. They recommended that, in addition to print copies, it would be useful if the report could be provided as an electronic copy on the SCIE website, with hotlinks to training videos and other sources of information and support. They were also keen to see the guide promoted through a wide range of routes, and suggested organisations and publications that might be used to promote the guide. One pointed to the fact that the guidance could potentially be applied to all care homes, not only those working with people with dementia.

Final revision and production

Following the field-test stage of the work the feedback received was compiled and sent to Sara Dunn Associates, where the guide received final revisions before being sent to SCIE for production.

1 Introduction

During 2010-2012 the Social Care Institute for Excellence (SCIE) distributed funds from the Department of Health (DH) as part of its Get Connected programme. The aims of the funding were to improve quality of life for care service users either directly, by making online technologies available to them for their own use, or indirectly, through improved access to online information and training for staff. Some 1,245 social care organisations providing services for adults in England received grants to pay for the purchase and/or upgrading of their online information and communication technologies.

The Social Care Institute for Excellence (SCIE) awarded the money in four rounds, and commissioned an evaluation of the impact of the first round of funding distributed (see Aldridge et al. 2012; Miller 2011; Miller et al. 2012). Feedback from surveys conducted as part of that evaluation revealed that in some cases managers and staff had struggled to help service users with dementia make full use of the technology.

A particular frustration for staff was the lack of guidance available to help them. As a result they felt they had been unable to accommodate the improvements they had hoped to be able to provide to their service users. This is evidenced by an extract taken from an email received from a Get Connected grant recipient during the first round of the evaluation:

'We have found it very difficult to get any advice locally on how we can continue to develop the use of technology with our aging (and increasingly failing in mental health) Resident group. We have spoken to our local Mental Health Unit, a couple of local trainers in dementia and the Alzheimer's Society but with no real success.'

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We are currently using children's games to stimulate/entertain the Residents, which hardly needs the computer and seems to defeat, somewhat, the purpose of the exercise in the first place.'

Email from Get Connected grant recipient¹

As the email indicates, some felt that they were only using the equipment to play games and this did not extend the types of activities they could provide. Others found it a particular challenge to find appropriate software that would help carers to engage with service users with dementia. While some sites were using a range of activities, and having some success with those, others felt that what they could currently offer was very limited:

'Our residents have dementia, but enjoy looking at photos of themselves and family members on large screen TV.'

Get Connected survey response

'Most of our residents have now been diagnosed with dementia...We are finding it increasingly difficult to maintain any interest in the various reminiscence tools (quizzes, newspapers etc) and there is no interest/understanding of other tools such as Skype/internet/dolphin etc. '

Get Connected survey response

In response to reports on the lack of guidance, SCIE decided to commission a guide for social care providers who work with people with dementia. The requirement was for a guide that would identify activities using IT that are suitable for use by or with people with dementia from early diagnosis to more advanced conditions.

The main initial task was to identify the range of activities currently in use which social care and other professionals have found to work with these groups. However, given that the rationale in developing the guide arose from the reports of the quite restricted use of technology with these groups, in part because of the lack of guidance and also because at this stage there had been only a few attempts to research this issue, this meant that any existing resources and guidance were likely to be widely-distributed across different organisations, websites and online databases.

¹ Source: Miller, L (2011) *First Survey of Get Connected Grant Recipients*. Report to SCIE.

Before guidance could be developed there needed to be an initial phase in which details of what resources were available and in use (and with what populations) were sought out and compiled. Information on how social care staff and volunteers were helping clients to interact with the technology, including ways in which to first engage the interest of this client group (many of whom may have no prior experience with technology at all), was also sought, as this appeared from the Get Connected evaluation to be a key stumbling block for some staff.

This report describes the research that was undertaken to inform development of the preliminary guide, and the subsequent piloting and refinement of the final guidance documentation. The research was conducted in early 2012 with the guide being drafted in May/June 2012 and trialled in July and August 2012. The guide itself was written by Sara Dunn of Sara Dunn Associates² and was intended to form a companion piece to '*Get connected to e-learning for social care providers*' (also written by Sara Dunn). The guide to the use of online technologies with people with dementia is available as a free download from SCIE at: **INSERT ADDRESS**

² www.saradunn-associates.net

2 Summary of the methodological approach taken

This chapter provides a summary of the methodology that was used to construct and test the guidance documentation. A more comprehensive overview of the methodological approach can be seen in Appendix 1.

Six broad stages to the work were planned:

- a. identifying activities currently being used with people with dementia and any resources and/or guidance already available;
- b. reviewing/assessing activities and guidance available;
- c. drafting the text for the guide
- d. seeking feedback on early draft guide and revision
- e. field-testing the guide with care organisations
- f. reviewing and revising the guide in light of the feedback from the pilot.

Activities a, b and e were undertaken by IES; activities c, d and f were undertaken by Sara Dunn. Summary details of the research and development processes are reported in the following sections.

2.1 Identifying existing activities, resources and guidance

2.1.1 Literature review

Relevant evidence was sought from the academic literature and websites. The EBSCOhost database was used to search for relevant material during March 2012

in addition to searches of journals associated specifically with dementia and ageing.

A total of 136 papers were generated via the search; four were found to be relevant to the research and subsequently downloaded and reviewed. A list of the articles reviewed is shown at Appendix 2. A visit to Stirling University Dementia library also produced an additional five books and three papers which were included in the review.

2.1.2 Website search

It was noted that a limited number of websites both in the UK and abroad - primarily in the USA and Australia - had started to produce support and guidance materials for staff and carers of people with dementia.

A total of 39 websites were examined (see Appendix 3) and the information ascertained from the search was used to inform the literature review of the field.

2.1.3 E-mail request to Get Connected beneficiaries

It was noted that some Get Connected service providers had found innovative ways to use the technology and so all first tranche Get Connected beneficiaries were emailed to request examples of the ways in which they had used the technology with people with dementia. Where appropriate, these were followed up with telephone discussions. A total of 25 responded to the initial email and telephone interviews were undertaken with four of them to discuss their use of ICT in more detail.

2.1.4 Telephone discussions with relevant professionals

In parallel with these activities a series of telephone discussions were conducted with individuals at dementia charities, universities with specialist knowledge in the field of dementia research and other relevant organisations and professional bodies. The purpose of these interviews was threefold: to ask about any relevant experience they had in using technology with people with dementia; to enquire whether they were currently conducting any projects looking at supporting the use of ICT with individuals with dementia; and lastly, to ask for any suggestions they might have regarding literature on this topic, activities or other resources that could be relevant for the work.

A total of 17 interviews were conducted with professionals during March 2012. The interviews with professionals also yielded an additional seven papers and one book which were included in the review. The professionals also pointed the researchers to various dementia specialist websites.

A discussion guide for the interviews was drawn up by researchers at IES and this can be seen in Appendix 4.

2.1.5 Analysis of activities and other information

Once the information was collected it was analysed to identify the various activities, the ways in which the technology was being used and the approaches that care staff were adopting (or were encouraged to adopt) to engage their clients with the technology and activities. This content was set out in a PowerPoint presentation to present at a workshop with the Advisory Group.

2.1.6 Reviewing the information gathered

A workshop was convened at the SCIE offices in April 2012 at which the information generated was reviewed by members of an Advisory Group. A list of the Advisory Group members can be seen in Appendix 5.

The purpose of the workshop was to review the information that had been gathered, assess the extent to which members of the Advisory Group thought the various components should be recommended in the guide and to filter out any activities that could constitute bad practice. The discussions were recorded by the researchers and these were used as the basis for revision of the outline guidance which was sent to Sara Dunn Associates (SDA) for development into a draft guidance document. A copy of the outline guidance can be seen at Appendix 6

2.2 Field testing the draft guidance

Following receipt of the draft guidance from SDA IES arranged visits to nine care organisations to test the guidance with care staff.

The sites were visited by a researcher during September 2012 and between one and four members of staff were interviewed at each site. A total of 18 care workers including carers, activity co-ordinators and care home managers were interviewed. The interviews focussed on the utility of the draft guidance and sought information about any changes required to make the guide more accessible and/or useful. A discussion guide was designed to guide the interviews; this is shown at Appendix 7.

3 Literature review

This chapter presents the outcomes of a literature review based on materials generated through a search of the academic literature, a website search and from recommendations gained from interviewees. The papers obtained during the literature search plus those recommended by the academics were reviewed. Where these generated other references of interest these papers were obtained and included in the review.

Details of all documents obtained during the literature trawl, website search and discussions with experts were uploaded onto an End Note file which was provided as a separate document to SCIE.

3.1 Background

There are currently around 670,000 people with dementia in England (Department of Health 2012) and around 820,000 people within the UK. It is estimated that dementia costs the UK around £23 billion a year in care costs and lost productivity (Alzheimer' Society 2012). With an ageing population it is predicted that the number of people with dementia will continue to rise to reach 1.7 million by 2050. There is therefore a moral imperative and a strong financial argument to improve and develop new services for dementia care.

3.2 Caring for those with dementia

Dementia is a progressive condition which affects the ability to think rationally and come to conclusions, making it difficult for the individual with dementia to initiate and perform tasks. As a result they may feel restless and frustrated. In addition to this, dementia can also lead to deterioration in communication skills and the development of aggressive and monotonous behaviours such as screaming, fighting and restless walking around (Edberg 2002 cited in Tobiasson 2010). Working with people with dementia and providing the necessary support

can be very demanding on the physical and mental well-being of carers. Both formal (paid care staff) and informal (family, relatives) carers report difficulties in coping with the burden placed upon them and can be left with feelings of failure towards the individual and society, which can result in mental health conditions such as depression and burnout, particularly in female caregivers (Mahoney et al 2005).

Pharmacological treatments have been used in the past to control some of the negative effects of dementia, such as aggressive behaviour and screaming, and these may help to alleviate some of the stress that carers face. However there are moves to reduce the prescription of some drugs used in controlling dementia and there is an increased need therefore to look for other ways of reducing such distressing behaviours.

Recent research has shown that interventions using Information and Communication Technology (ICT) can have benefits for both the person with dementia and their carer. Although some of these interventions are not new and the activities supported may previously have been carried out using other methods (reminiscence work using paper scrap books, photo albums), evidence has shown that ICT has the ability to improve such interventions, making them less arduous for the carer and potentially more beneficial for the person with dementia. This in turn can improve the quality of life of both the person with dementia and their carer. It is therefore of value to consider both the ways in which ICTs can be used to support people with dementia, and the types of guidance required by those who care for people with dementia. This is the purpose of the research described here.

3.3 Communication and Information Technology

Newall et al. (2002) has suggested that well designed ICT systems have great potential to enhance the quality of life for people with dementia by:

- Allowing them to retain a high level of independence and control over their lives
- Providing appropriate levels of monitoring the supervision of 'at risk' people, without violating privacy
- Keeping people intellectually and physically active
- Providing communication methods to reduce social isolation

In turn this can help improve the well-being of carers as such changes can help reduce the responsibility and burden placed upon them in their caring role as well as providing them with the opportunity to use the technology to conduct more

insightful conversations with their caree, resulting in a more fulfilling interaction for both parties.

Much of the literature around ICT and dementia focuses on the benefits of Assistive Technology and the way in which technological devices have the potential to act as a 'cognitive scaffolding' to support individuals in undertaking tasks and decisions, supporting or taking over functions which have been affected by dementia and ageing (Newall et al. 2002). Although this literature continues to grow (Department of Health 2011), Assistive Technologies fall outside the scope of the current review and the reader is referred to Lauriks et al. (2007) for further information on this. Instead, the current review will focus on the types of activities which are currently used by carers and carees using ICT, the ways in which they can improve the quality of life for the person with dementia and their carer through improved opportunities for communication and the provision of entertainment and stimulation. There is growing evidence that leisure activities such as singing, listening to music, dancing and gardening (Gotell et al. 2002) can be beneficial in ameliorating some of the effects of dementia (Karp et al. 2006; Fratiglioni et al 2004) and many of these activities are more easily carried out or supported using the technologies now available. There is also a growing range of specialist software and technology aimed at this segment of the market.

The focus of this review therefore is primarily on lessons that can be learned from current practice both in using specialist technologies and the more widespread readily-available equipment and software to help guide carers who wish to start using such technologies to improve the lives of people with dementia. The review will conclude by exploring the potential benefits that touch screen tablets may have in the future as well as assessing the role that prototypes and specialist technologies that are currently being developed may play.

3.4 Engaging people with technology

Before engaging in ICT, a number of potential issues need to be addressed to ensure that the care intervention is a success for both the person with dementia and their carer.

First and foremost is the importance of including the person with dementia in their own care intervention. The notion of human rights and citizenship in dementia care nursing is currently a hot topic of discussion (for a review of the current debate see Kelly and Innes, 2012 and Perry et al. 2009). It is important to ensure that people with dementia are enabled to exercise their rights rather than simply assuming from the outset that it is too risky to allow them to make their own choices and decisions (Clarke et al. 2010), particularly when it comes to improving care interventions.

However, due to the debilitating symptoms associated with dementia, it can be difficult for people to communicate and therefore provide consent. There are techniques that can be used to help ensure that the voice of the person with dementia is heard and that they have an input into their own care. Researchers developing specialist dementia software tools have highlighted the benefits of including people with dementia and their carers in the whole design process of a care intervention for its final success (Alm et al. 2004, Meiland et al. 2007).

Although research has shown that people with dementia have the ability to engage with ICT and electronic equipment (Lauriks et al. 2007), it may be the case that, for a range of reasons, they do not want to. Nyman (2011) has shown that even where a care intervention is well designed and executed it is unlikely to work if it does not have the full participation of the person with dementia. Nyman (ibid.) has attempted to outline the psychosocial issues in engaging older people with interventions based on the Theory of Planned Behaviour and has suggested that older people are more likely to participate in an intervention if it fits with a positive self-identity, if the positive benefits are emphasised and if they have a high level of perceived behavioural control and reside in a socially supportive environment. It is therefore important that carers understand the factors that help encourage people to participate and take care to ensure that people are willing to engage with technology and have given their consent.

That said, of course, it is entirely likely that people will refuse to give consent where they have fears about the technology or simply do not understand its potential benefits or why it is being offered to them. It is therefore important to try to ameliorate the fears that people with dementia initially may have over using ICT. This is often best done by carers not focussing on the device itself but rather on the activities the technology is being used to help facilitate. This puts less emphasis on the technology which can lead to people with dementia feeling less threatened by it.

Work by Dinah Murray and Ann Aspinall (2006) has provided examples of ways in which people with learning difficulties and dementia were helped to engage with computer technology. Their approach was to initially focus on items of interest to the person and then use the technology to find photographs of the thing or topic of interest. For example, one young man was wearing a teeshirt showing a map of Australia and it emerged that he had an interest in the country, and so was helped to find pictures of Australia using the internet. Only when the person became comfortable with the technology did they attempt to use it to carry out more complicated care interventions.

Of equal importance is the willingness of carers to participate in the ICT intervention. Their role is vital in supporting and motivating the person with

dementia to use the technology and therefore it is essential that they themselves feel comfortable using technological devices (Szymkowiak et al. 2004 cited in Lauriks et al 2007). Engstrom et al. (2009) found that when introducing an ICT support package within a care home setting, carers themselves could initially be sceptical of the technology and fearful of using it. However, with the right time and support, this feeling can change to one of having control over the technology and security when using it. When implementing an ICT support package, there needs to be plenty of time and support given to ensuring that employees and volunteers are fully confident in using the technology. Therefore employers need to consider the support needs of their employees before they are asked to help people with dementia to try out the various technologies.

Further to this, recent work by Nugent (Nugent, personal communication) has shown that the extent and nature of the support provided to the person with dementia within the first two weeks when implementing ICT predicts the extent to which technology is successfully taken up both initially and in the longer term. Low levels of support leads to higher drop out rates. Nugent (ibid.) has attempted to develop a profiling tool which can predict whether a carer will succeed or drop out with the technology. Two weeks appears to be the key point; if they persist with it for two weeks then they will most likely continue and this will have a positive impact on the uptake of the technology for the person with dementia. Managers might bear this in mind when planning support and development activities for staff likely to be involved in the implementation of ICT interventions.

3.5 Reminiscence work

3.5.1 Importance of reminiscence

Although pharmacological treatments have received a great deal of attention, there is increasing evidence that psychological interventions may be equally effective in improving the quality of life for people with dementia (Subramaniam and Woods 2010; Banerjee 2009). These involve reminiscence work, which is '*the act or process of recalling the past*' (Butler 1963 cited in Subramaniam and Woods 2010). In remembering the past, this helps a person to recall and reflect on former activities and accomplishments which brings awareness to the present and a sense of control over the past, present and future (Housden 2007). For those with dementia, memories can become confused and disconnected and people can have difficulties experiencing wholeness and meaning (Khilgren et al. 1994); therefore reminiscence work can help people with dementia to maintain a sense of self and retain memories of their life story (Surr 2006). There are two broad approaches based on reminiscence, which are:

- **Reminiscence therapy**, which typically involves the discussion of past activities, personally significant people, events and experiences, usually with the aid of tangible prompts such as photographs, music and sound recordings (Wood et al. 2005). This therapy has positive effects for cognition and mood of people with dementia in both institutional (Wang 2007) and community settings (Tadaka and Kanagawa 2004, 2007 cited in Subramaniam and Woods 2010) and also helps to facilitate social involvement for people (Gibson 1994 cited in Kikhia et al. 2010).
- **Life review**, which is described by Wood (2005) as an activity which *'typically involves individual sessions, in which the person is guided chronologically through life experiences, encouraged to evaluate them and produce a life story book'*. An assessment of the outcomes of 'life review' work have shown an improvement in the mood of people with dementia fewer behavioural problems, improved self esteem and social interaction (Haight et al. 2003, Tabourne 1995 cited in Subramaniam and Woods 2010) and some improvement in some aspects of cognitive function (Morgan and Woods 2010 cited in Subramaniam and Woods 2010). Carers who participated in the process have also reported significantly reduced burden when carrying out their caring responsibilities (Haight et al. 2003).

One output from this type of work is the 'This Is Your Life' style of scrapbook which can provide people with dementia with a tangible reminder of their lives and personal history. Haight et al. (2003) have suggested that story books should be created by the individual themselves, using their own choice of pictures, props and words which can serve as a reminder to them of their life and as a legacy for their family. Although Haight et al. pointed to the value of individuals having control of this activity, in reality it will often be the case that people with dementia may require the assistance of a carer in order to do so. The important point to remember is for the carer's actions to be led wherever possible by the person with dementia.

3.5.2 Use of ICT to conduct reminiscence work

ICT has been used to support this process, producing outputs similar to the 'This Is Your Life' scrap book but in a digital format. This has the advantage that it can be amended and updated as required. Traditional reminiscence work includes the use of videos, sound, music and written material which can be very time consuming to search for, particularly if it necessitates visiting a library to find a specific book etc. ICT improves on traditional resources/means of access as it allows for virtually all media to be accessed almost instantaneously (photographs, music, video clips), on a more user friendly interface than traditional bulky

photograph albums (Yasuda et al. 2009) and with better quality of vision and sound.

Capstick (2011) describes using computer applications such as Google and YouTube to find images and clips of things that interested people outside the day centre they attended. These included local landmarks, historical buildings and favourite holiday destinations. She reported that on one occasion a brightly coloured image of a café in Leeds City Market triggered a chain of reminiscence about shopping between two people with dementia who rarely interacted. Interestingly, work by Newall et al. (2002) looked to identify how each individual medium added to the reminiscence process and what effects were produced by the various media. It was found that with videos, clients were only able to strongly identify with them when they triggered off specific personal memories, whereas songs and photographs were more generally (that is, more widely) appreciated. In contrast, though most of the videos and photographs and all of the songs were able to spur conversations. Attention was held the longest by songs, which were particularly enjoyed when played repeatedly with everyone singing along. They generally found that multimedia presentation produced a great deal of interest and motivation amongst the people with dementia, highlighting the benefits that ICT has in being able to access and present a range of media simultaneously.

Guiding the behaviour of people with dementia (for example, reminding them to eat their meals) through music and sung messages broadcast from an IC recorder (basically a voice digital audio recorder that can be connected to a computer and the recordings uploaded and played back) has been found to be highly effective. This work also highlighted the importance of a multimedia approach and found that music may have a strong effect on the mental stability of people with dementia (Yasuda et al. 2006).

Work by Dinah Murray and Ann Aspinall (2006) has shown how Power Point presentations can be used to help people with dementia create an interactive multimedia life story. Important things to take into account in setting up a computer for this type of activity include: taking into account the colour of the screen, the font and size of the lettering and the positioning of the monitor so that the conditions are optimal for the person with dementia. The carer can then encourage the person to talk about all aspects of their life (past, present and future aspirations) using graphics and photographs which can be uploaded onto the computer and added to the Life Book. In the example described by Murray and Aspinall the person with dementia was encouraged to select the colours for the book and to provide a voice over on each of the pages along with various bits of animation. It was suggested that the fact that they chose bold colours and were willing to use their own voice in the commentary gave an insight into their

personality; they were more outgoing than they otherwise appeared (something which may not have been elicited through conversation only). Each page of the Life Book was tagged with a hyperlink so that the person could easily access the relevant pages at a later date from the contents page. The Life Book was an on-going document which the person with dementia could easily update and amend as their aspirations changed or alternatively they could remove certain pages if they wished to keep one document for their own private reminiscence with another version to present as a public document for their relatives and friends.

Gene Cohen (2000) has also shown how life stories of people with dementia can be created using Therapeutic/Restorative Biographies (TR-Bios). Carers (informal volunteers) team up with the person with dementia and their family to obtain stories that reflect happy or interesting events that have occurred over the course of the person with dementia's life. This can include videotaping interviews with significant others, videotaping family snapshots and enlarging them on a TV screen, using old videos or films of the person with dementia. The final video can be presented with commentary and music in order to maximise interest and pleasure for the person with dementia. When watching the final output, people with dementia showed increased attention when compared to a control, a reduction in agitation and an improvement in mood during the intervention and afterwards. Family and staff satisfaction was also shown to improve.

Subramaniam and Woods (2010) highlighted important issues which need to be kept in mind when conducting reminiscence work using ICT.

- Although the internet can provide access to generic materials which can be useful for the reminiscence process, more personalised material is also needed for the life story document. This requires a major resource commitment and will almost certainly need additional input from the family. If possible it's important to obtain this information from the person with dementia before their condition progresses.
- The person with dementia should have editorial control of their life story and the carer should act only as the facilitator of this process. As this may be more challenging with people with more severe impairments it is useful to encourage people with dementia to develop their multimedia biographies early in their condition. The fact that the document can be saved on a computer and is easily accessible may have additional advantages if the person with dementia moves to a new environment or if their carer changes.
- When reminiscence work is conducted to encourage communication (particularly within group settings) then the materials do not need to be personalised but they have to reflect the participants' preferences and interests. If this work is carried out in a group setting then projection systems and/or

large screens will be required and group leaders will need to be trained to facilitate discussion and allow space for participants to share stories and enjoy the narratives.

- The memory triggers will determine the flow of the participant's conversation and the carer should facilitate this rather than being driven by a set of programmes of images or music (the technology should not be the focus of the activity). When using ICT to access the relevant materials it is important that the person with dementia does not become a passive viewer but that they are engaged with the system.

3.6 Enhancing communication

3.6.1 Importance of communication

Deterioration in communication is a prevalent symptom in many dementia-related conditions (Allan, 2001; Clare, 2001) and therefore carers can face significant challenges when attempting to communicate with people with dementia. It is important, however, that carers are encouraged to maintain communication with the person with dementia so that they can: understand how the person is feeling and respond accordingly; enable the person to maintain a sense of empowerment and so reduce the likelihood of secondary conditions such as depression; and allow the person to consent to and have an input into their own care interventions in accordance with a person centred approach (NICE/SCIE 2006) so that the most effective care management strategies can be developed. Clare and Shakespeare (2004) have shown there to be a strong association between enhanced communication and improvements in the challenging behavioural and psychological symptoms of dementia.

Conventional methods of communication can often be tricky to use with people with dementia, due to the symptoms associated with their condition, and so Allan (2001) established a list of alternative techniques that could be adopted by carers:

- Use carefully chosen pictures
- Make use of verbal and non-verbal communication
- Give people opportunities to talk in indirect ways
- Give people time to express themselves
- Provide resources to help staff communicate

If these communication techniques are to be used within a care setting, where there are often substantial restraints on time, money and staff resources (Care

Commission 2005), it is important that managers ensure staff are provided with the appropriate training and development and feel fully confident when using any new techniques or technologies. The next section describes some ways in which ICTs have been used to enhance communication processes.

3.6.2 Use of ICT to enhance communication

Talking Mats

We start this section by considering a technique developed by Joan Murphy and her colleagues based on the use of a black mat and a 'smiley face' scale (happy, sad and unsure). In conversation with the carer, the person with dementia was given a number of pictures of various activities, foods etc and then asked to place them on the appropriate point on the scale depending on whether they were happy about them, sad or unsure. At the end of the interaction the mat could be digitally photographed and uploaded to a computer in order to review the conversation at a later date. This development was called a 'Talking Mat' and Murphy and her colleagues evaluated its effectiveness as a communication resource to enable people with dementia to express their views about their well-being.

Murphy et al. (2007) compared three different interview techniques (unstructured conversation, structured conversation and Talking Mats) to establish whether Talking Mats helped people with dementia to communicate better and whether it benefitted both those in the early stages of the condition and those in the later stages equally. The Talking Mats interview was conducted in a similar fashion to the structured conversation interview, except that topics and options were represented in picture form. Each option was shown to the participant, who was invited to indicate what they felt about a certain subject by placing it on the mat under the appropriate point on a visual scale (happy, not happy or unsure). A digital photo was then taken of each completed Talking Mat to analyse for meaning. The results showed:

- Talking Mats were more effective than structured and unstructured conversation in allowing people with dementia to communicate their views on their well-being
- Talking Mats improved participant engagement with the conversation, particularly evident in people with moderate and late stage dementia
- People at all stages of dementia were able to make use of the three point scale

The results highlight the value that the use of pictures can have in improving communication with people at all stages of dementia. By adopting this technique,

people with dementia gain the ability to readily communicate what they wish to do on a daily basis, communicate to a carer how they feel or how bad their pain is, make key decisions on their care intervention, remember what they have said and hold a structured conversation between themselves and their friends and relatives.

Although the Talking Mats technically did not use ICT, the work does highlight the value of using pictures in communicating with people with dementia (these benefits have been widely noted, for example see Allan, 2001). With the advent of computer technologies and access to the internet carers now have instant access to an almost limitless number of photographs which can be shown to the person with dementia to facilitate conversation and assist with daily living activities, understanding their well-being etc. The Talking Mats approach would be readily transferable to touch-screen technology, making the system even easier.

As a further example of the way in which pictures can be used to aid communication researchers at Worcester University have shown how the favourite foods of people with dementia can be identified through the use of pictures. Once the individual's preferences have been identified the carer (or in the original instance, the researcher) can then work together with the person to make the food using the recipe which accompanies the picture (Upton 2011). Although this method of communication may be time consuming, it enables both better communication and better quality of life for the person with dementia.

Flipcams

Recent work by Andrea Capstick (2011) has shown that people with dementia can participate (at least to some extent) in film-making to enable them to communicate and reconstruct their sense of identity and enhance their social engagement. The work is grounded in the ideology that research should look at the 'whole life' of the person with dementia rather than just their experience as patients from the point of diagnosis and in order to do this better ways of communication need to be found (Bartlett and O'Connor 2010 cited in Capstick 2011). A participatory approach was adopted and during the nine month video-making project, participants were actively involved in the film-making process, including deciding on a subject, capturing images and editing and they were able to use images that were personal to them rather than generic. This allowed the participants to be active commentators on services rather than a passive recipient of them (Capstick 2011).

The camera equipment was adapted so that elderly people with dementia would be able to use it easily. The camera was lightweight and portable and a 'flipcam' (an ultra portable camcorder) was used in preference to more complicated equipment due to its size and the fact that it has just one button for record/stop and another for play. The people with dementia who were involved in the

research were more enthused by the idea of being in the films than the technicalities of film-making and while some of them could not leave the day centre to conduct any of the external filming they did play an active role in narrating events.

The results of the research show that more animated and humorous conversation can be elicited when asking people with dementia to take on the role of 'critical consumers' within a recognised terrain that they associated with previous life roles. It also highlighted how the participants began to communicate between one other and even used each others' names during the narration of the films (Capstick 2011). The research was an important demonstration of how inclusive and participatory approaches to working with people with dementia can be designed and highlighted the way in which new media can be used to compensate for a physical loss of mobility and social agency.

Skype and email

A number of ICT applications are useful for enabling people with dementia to stay in touch with their family and friends. One of these is Skype which has the ability to reduce the impact of geographical separation and increase the frequency with which the person with dementia can keep in touch with their family and friends. This is particularly useful when family members reside abroad. This was noted as a particularly beneficial application on the iPad (Upton 2011).

In similar research, studies by Mickus and Luz (2002) and Savenstedt et al. (2003) showed that the use of a videophone as a communication tool promoted social contact and enabled people with dementia to regularly communicate with their family. This also had an impact on the families, as this additional contact led them to feel less guilt at not being able to visit so often and also provided reassurance by letting them see the physical and emotional state of the patient on a daily basis. The studies noted that on some occasions the conversations were more focussed and of better quality than during face-to-face visits, although there was more need for family members to direct and lead conversations, which they found demanding. The relationship between staff and family members also improved as a side effect of helping the person with dementia to use the videophone.

Email has also been used by people with dementia in order to keep in touch with their family and friends and to participate more within society. Typically they do require support to do so, although there are now some email systems which have been designed to be simple to use by older people with reduced cognitive functioning (Newall et al., 2002). Interestingly it was found that this system was preferred by some executives to the standard email system which they were used to. This highlights a more general point, that when people with impairments are

taken into account when designing systems then often the result is to produce a more usable system for everyone. Additionally, this points to the fact that for designers to produce specialist technology or software for certain user groups they may require further, specialist training.

It is also worth noting that email forums now exist hosted by organisations such as the Alzheimer Association in the Netherlands which enable people with dementia and their carers to post messages and chat with others in a similar situation. There is also an internet-based application called Alzheimer's Carer Internet Support System (ACISS), a useful resource which provides carers with clinical, decision-making and emotional support.

Modified mobile phones

Lekeu et al. (2002) showed that people with mild dementia are able to learn how to use a simplified mobile phone within an 'errorless learning' method (Clare et al. 2000). The principle of this method is to prevent eventual errors by repeatedly providing people with dementia with the correct response rather than asking them to explicitly retrieve or guess it. In the Lekeu et al. (2002) study the intervention consisted of pasting on the back of the phone a card describing each stage of utilisation and illustrating keys that had to be pressed and in which order.

Other research exploring the use of mobile phones showed that people with dementia were able to use the 'Mobile Telecoach' (a one button mobile phone which allows direct answering) and this had a significant positive impact on their social experiences and self esteem, although users were dissatisfied with its weight, size and battery life (Kort 2005). Other projects such as the Mobile Rescue Phone (MORE) at the University of Dundee have looked at redesigning existing mobile phones and simplifying the user interface to meet the needs of elderly and disabled people and make mobile phone services accessible to them.

3.7 Entertainment

3.7.1 The importance of entertainment

The use of ICT for entertainment purposes is relatively new but it is likely that in the future, with the further development of low cost systems such as the Nintendo Wii and Xbox Kinect, more research will be conducted that explores the benefits of these systems for people with dementia. Indeed, already in some healthcare settings the Xbox Kinect has been introduced to aid the rehabilitation of people with strokes and cancer and improve the general mobility of elderly people (Microsoft 2012).

Research on general ageing has identified four key areas that are needed in order to age well (Thille and Wrammer 2000 cited in Tobiasson 2010):

- physical activity, to improve oxygen uptake, muscle strength, walking ability and balance,
- good eating habits, to postpone or prevent disease requires access to healthy food;
- support for social interaction, having a good social support network has a positive effect on mental and physical health; and
- participation in meaningful contexts to allow a feeling of being needed and to support positive self-esteem and mental well-being.

As people develop conditions such as dementia it becomes more difficult for individuals to continue with the various activities and interactions that they could when they were younger or more independent, yet the above research has shown that bodily movement helps support cognitive processes (see also Brown and Cairns 2004). Therefore the potential benefit of introducing support for activities such as these can be seen on several levels. Playing games can be a way to mediate social and affective communication and balance and regulate emotions (Lazzaro 2004 cited in Tobiasson 2010). Research conducted by Burke (2008) and Nystrom (2005), a dance therapist, has shown the benefits of working with people with dementia to help them communicate through their movements when spoken language is in decline, as well as having a positive impact on physical well-being. Technologies such as games consoles similarly have the potential to encourage people with dementia to take part in activities such as dance and sport which keep the body on the move and can help challenge the brain and therefore both contribute to a better quality of life and potentially reduce the risk of people with dementia deteriorating so rapidly.

3.7.2 Using ICT for entertainment purposes

Nintendo Wii

Research exploring the use of games consoles with people with dementia is currently limited; however one study by Tobiasson (2010) examined the impact of a care intervention on people with dementia living in a care home using the Nintendo Wii. A range of techniques was used to ensure people with dementia could participate in all stages of the design and execution of all tasks. The players all had different stages of dementia. The Wii Sports Game was used in the study and the console was set up in a large room in front of a projector screen displayed on a wall to enable other residents to watch. This opened up possibilities for social

interaction, as well as ensuring that there was enough room for the required physical movements among individuals.

The study found that the Wii gave players an opportunity to move, compete, improve, focus, learn and interact in ways that are not otherwise easy to provide within the care home setting. Players might be seen as the winner of the Wii-bowling competition (as an example) and relatives commented that they were happy to see their grandma playing the game and winning. The Wii helped people take part in a wider range of physical activities and regain more of a sense of belonging, two of the four cornerstones to healthy ageing identified by Thille and Wrammer (2000) cited in Tobiasson (2010).

The intervention also increased interactions amongst users and other residents within the care homes as they began to comment on each others' performances, with both high scores and low scores being equally noticed. Residents also began to try out new vocabulary expressions and when game time was over many stayed behind to cheer-up the players or congratulate the winners (Tobiasson 2010).

The Wii requires participants to undertake activities requiring balance, adjustment, force and tempo. As a result of this caregivers commented that their relatives had become more alert and more active. Many of the users could remember that they had won something although sometimes were not sure quite what. Tobiasson (2010) suggested that this may support the ideas put forward by Fratiglioni and von Strauss (2007) that being involved in activities that are mentally stimulating reduces the risk of dementia, and by Karp et al. (2006) that engaging in activities that cover more than one of the mental, physical or social components is more beneficial than to be engaged in only one type of activity.

Although this area of research is relatively new, the benefits seen through this intervention mean that there is likely to be further progress in this area in the future. Indeed a study is currently underway at Bournemouth University Dementia Institute to explore the impact of computer game technology on the well-being of men with dementia in rural areas of Dorset.

Living in the Moment games (LIM)

LIM games are currently under development by the same team that was responsible for the CIRCA system. These are interactive games that are delivered through touch screen technology within an engaging 3D environment and they have been created by working extensively with people with dementia and their carers. The games were developed to allow people with dementia to enjoy entertaining and stimulating activities, working on the principle that the user does

not need working memory (short-term memory) to operate and enjoy them, as frequent prompts guide the user to interact with each game.

Astell (2008) reported that the games were developed on the principle of 'flow experience' which refers to immersion in an activity for its own sake with the result that one feels a sense of satisfaction and loses track of time (Csikszentmihalyi, 1996 cited in Astell, 2008). In order to maintain a level of flow, the activity needs to reach a balance between the challenges of the activity and the ability of the participants. If the game is too hard then the activity becomes overwhelming and generates anxiety and if the challenge is lower than the ability than it produces boredom. LIM games have therefore been designed to reach the appropriate level of 'flow' for people with dementia.

The research showed that two types of games worked particularly well and these gave the user the chance to exercise skill and be creative. As all the action happens in a short time they can be enjoyed by those with short-term memory problems. In addition the instructions were designed to be clear and intuitive to support people using the system on their own (Astell, 2008).

The games which are now complete and tested are: Beat the Goalie, Coconut Shy, Shooting Gallery, Painting a Pot, Playing Chimes and Blowing Bubbles. The games allow people with dementia to play them on their own, with a carer or within a group.

As the games have only recently been developed there is little empirical research to demonstrate any impacts for people with dementia or their carers.

Observational research has suggested that people do improve at the games the more they play them, which suggests that some learning is taking place. The games tap into procedural memory and throughout a twenty minute session people have improved at the games and then returned to a similar level of competence the next time they engage with them (Astell, 2008). As the games can be played within a group or with a carer then it can enhance social interaction which will have positive effects for people with dementia and their carers as shown with the Nintendo Wii (Tobiasson, 2010).

Gaming Apps

Alongside the development of tablets, a number of free applications and games have been created which are suitable for people with dementia. These are currently being trialled by Worcester University in their evaluation of iPad

technology in care homes (Upton, 2011). They have created a website 'Memory Apps for Dementia' and within this have produced a list of recommended apps for people with dementia³. These apps vary in the skills needed to undertake them and are suitable for people with varying degrees of dementia. Some apps merely require individuals to touch the screen in order to create different shapes and colours (easy to use and stimulating for people with severe dementia) while others are more complicated, such as a Maths App which can be used by people to stimulate reminiscence by remembering the times tables.

Again, as these apps are under development very little empirical evidence has been obtained on their benefits; although as work progresses it is inevitable that research evaluating their impact will be conducted. Nonetheless they point to the types of development currently underway and carers would be advised to check the internet for news updates on these products.

3.8 Tablets

Touch screen tablet computers such as the Apple iPad, Samsung Galaxy Tab, Motorola Xoom and the Asus Eee Pad have grown in popularity in recent years. These devices have reduced many of the issues which may have prevented older people engaging with more traditional computers. Their touch screen interface has overcome the need to use a keyboard or mouse which older people with dexterity issues may struggle with and their relative size and 'look' (in comparison to ominous looking monitors and PC units), in combination with the interactive and intuitive nature of the screen display can reduce the 'fear factor' that older people unaccustomed with computers may experience when first attempting to engage with them. Many of the tablets also have an online application store where users can download purpose-built applications to run on the device such as those found on the 'Memory Apps for Dementia' website and this reduces the need to physically go out and buy new software and games which can be difficult for older people.

Research has highlighted some of the limitations of the technology such as the difficulty in viewing in sunlight due to their reflective screen and their relative weight which makes it difficult for older adults to hold with one hand whilst navigating with the other (Upton et al., 2011). However both of these issues have been fairly easily overcome in practice: using a cover for the screen helps limit reflection off the surface while use of a cushion to rest the device on helps

³ <http://memoryappsfordementia.org.uk/>

overcome the weight issue. With such difficulties resolved these devices have an advantage over traditional computers in that they are portable and do not require typing skills or mouse control. In addition, as they have touch screens the user does not have to look down to a keypad and then back up to the screen but can see what they have touched and how this has a direct impact on the activity on screen. However, it should be noted that other, more basic limitations, such as a lack of staff training and confidence in using the technology, as well as access to Wifi in the care setting, are also barriers. These may take more time to resolve.

Preliminary evaluative research conducted by Upton et al (2011) on the use of iPads to improve the well-being of people with dementia in residential and care home settings across the West Midlands and South West, has provided some early indications on the benefits of the technology for people with dementia. During one-to-one work with the iPad a range of benefits have been identified, including supporting reminiscence work (and so increasing rapport between carer and the person with dementia), assisting in activities of daily living and increasing interpersonal interactions between the person with dementia and their carer or with younger family members through talking about, and exploration of the technology. Using the iPad during group sessions encouraged residents to engage with others around them. The most beneficial app for this activity was YouTube, which allowed facilitators to search for and play music or films that people with dementia recognised from earlier times.

Upton et al (2011) suggests that there is a potential rehabilitative role for the iPad and touch screen technology more generally for people with dementia. Their research supports the findings of Smith et al (2011) which suggested that people with dementia were better able to learn information that required an accompanying action. The action of dragging pictures across and then naming the places could provide a method for enhancing everyday memory skills. Upton et al (ibid.) report that two participants showed progression in cognitive skills over six months (Upton et al 2011).

The use of interactive applications on easy to use touch screen technology is enabling new ways of incorporating 'restorative memory' and creative therapy interventions with people with dementia (Upton et al. 2011). Although it is early days and research is still very explorative, touch screen devices and tablets may ultimately provide a resource to facilitate interventions to improve the welfare of older residents and people with dementia.

3.9 Prototypes developed for working with people with dementia

A range of specialist technology is currently being developed to support the care of people with dementia. The technology is typically designed by a multi-disciplinary team of researchers, designers and occupational therapists, working alongside people with dementia and their carers/family members throughout the whole process to ensure that the technology developed takes account of the 'needs, abilities and desires' of the intended users (Goodman-Deane et al. 2009). Although anecdotal and preliminary qualitative evidence has shown that some of the prototypes and specialist equipment are successful in improving the quality of life of people with dementia and their carers, the high costs required to purchase the equipment can be prohibitive for many care settings, particularly in the current economic climate. This causes many care homes to seek cheaper alternatives. The following section outlines some of the prototypes and specialist equipment that are available to buy or currently under development.

ENABLE

The overall objective of ENABLE (enabling technologies for people with dementia) was to investigate whether it was possible to facilitate independent living of people with dementia and promote their well-being through access to enabling technological systems and products. The study was cross-national and explored work in England, Finland, Ireland, Lithuania and Norway. Many of the devices tested were assistive technologies and therefore beyond the remit of this review. However some of the devices were used to provide pleasure or comfort for people with dementia and, in turn, of their carer. These were the picture gramophone (a multi-media programme) and the My History device (PC with touch screen showing pictures of people and places with familiar voice narrative).

Picture gramophones have buttons with the names and/or symbols of songs which the person with dementia used to enjoy singing. The trials among people with mild to moderate dementia indicated that these technologies were useful at enhancing well-being by giving positive experiences and reducing anxiety in people with dementia and their informal carers (Gilliard and Hagen 2004). The usefulness of the picture gramophone was also not associated with the severity of dementia or with diagnosis of a dementing illness (Topo et al. 2004).

COGKNOW

The COGKNOW technology was developed based on the needs of people with dementia. Working with a multi-disciplinary team of researchers and designers and consultation with people with dementia and their carers, the research team

identified four main areas which required further support for people with dementia. These were mainly in the form of Assistive Technologies for memory (electronic calendars, medication management technology) or to enhance the feeling of safety (smoke monitors or warnings to close the door). However, other needs included supporting social contacts and enabling communication with family and friends (mobile phone device with picture dialling function on a touch screen) and supporting pleasurable activities such as listening to music (picture gramophone).

Devices to address these requirements, by increasing communication and providing entertainment were developed, including a picture dialling phone service and a touch button activated radio which would play pre-selected favourite tracks at random. Issues which the COGKNOW team also tackled included adjusting the screen size to facilitate easier viewing and to accommodate a larger font size if required. This also reduces the need to scroll down so much to read all of the text, which can be difficult for those people with dexterity issues.

Research is currently underway to evaluate the COGKNOW technology and to assess the benefits of the system.

CIRCA

CIRCA is a multimedia computer system, developed by a multi-disciplinary team in consultation with people with dementia and carers, to support and promote communication between people with dementia and their caregivers (Alm et al. 2004). CIRCA is based on reminiscence and provides a broad range of stimuli which can be easily accessed to prompt reminiscence among people with dementia. However, it requires care staff to generate themes and find and organise materials to prompt reminiscing. CIRCA can be used to support discussion in group sessions or on a one-to-one basis⁴.

Currently results show that CIRCA (when tested alongside a 'control' group) provides a more enjoyable activity for people with dementia and their caregivers to carry out together (Astell et al., 2010). It has also been shown to support relationships between carers and people with dementia by providing an engaging conversation maintenance activity that is not replicated in traditional reminiscence sessions. CIRCA provides people with dementia the opportunity to talk about new topics by offering them a greater choice and range of items than are typically available in traditional reminiscence activities (Astell et al. 2010). This can lead to

⁴ <http://www.computing.dundee.ac.uk/projects/circa/>

increased enjoyment, with carers spending more time with people with dementia as there were fewer burdens in maintaining conversation.

My Life

My Life Software⁵ is a similar piece of technology to CIRCA and has been developed for carers to use when working with people with dementia. My Life is a touch screen tool which can be used to facilitate conversation between carer and the person with dementia.

The software is designed for use on either a one-to-one basis or within a group setting using entertainment packages and applications such as digital Bingo or Karaoke and quiz games.

The system is easy to use and, similarly to the CIRCA system the software promotes conversation using a range of different mediums such as photographs, videos, songs etc. The software allows people to upload their own photographs on it or use more general photos to help with reminiscence work. Other aspects of the device such as Skype, email, video messaging and text messaging help the person with dementia to keep in touch with their relatives.

Little research has been conducted to date on the device, although analysis is currently being conducted using a visual analogue scale (Telephone interview with MyLife representative 2012). This will assess the mood of the resident and the relative and will explore how engaged the resident is during the use of the technology and examine this in comparison to the time they have spent on the software.

Memory Lane and Sense Cam

Memory Lane⁶ is an ICT external memory aid which supports a person with mild dementia in coping with memory problems by recording their past, current and future activities to help with later recall (Kikhia 2012). The device is based on the principles of 'Lifeloggging' which is the use of technology to build a comprehensive archive of some or all aspects of a person's life in a digital format. The idea is that Lifeloggging can provide a digital memory of the individual's life, such as people they have met, places that they visited and activities they have undertaken (Blighe 2009 cited in Kikhia 2012).

⁵ <http://mylifesoftware.com/>

⁶ <http://www.memorylane.nu/project>

Currently there are two prototype recording devices called Microsoft SenseCam⁷ and its upcoming commercial version Vicon Revue⁸ which can be used for automatic recording of images and some environmental data. These are portable devices which the person with dementia wears around their neck and which automatically captures pictures of their day and logs the places they have visited and the time this occurred.

The images are then transferred to a much larger stationary system for review at the end of the day called the 'Review Client.' This operates through touch screen technology to allow the person with dementia and their carer to review the day's recordings.

The technology is currently in its preliminary development phase but it is believed that it will improve quality of life for people with dementia by supporting reminiscence processes. As their social involvement increases in both volume and quality better and more memories are recorded for later retrieval. Initial qualitative analysis showed that one person with dementia said they felt more alive and alert when using the device and her carer felt the reviewing process at the end of each day helped them both to talk about the memories of the day.

⁷ <http://research.microsoft.com/en-us/um/cambridge/projects/sensecam/>

⁸ <http://viconrevue.com/>

4 Interviews with academics, practitioners, care staff and volunteers

This chapter highlights the key themes that emerged from the interviews with academics, practitioners, care staff and volunteers. In general, the academics who were interviewed were working on specific projects or technologies to improve the lives of people with dementia and for that reason this tended to be the focus of those conversations, whereas practitioners and care staff spoke more broadly regarding any technology they used within their care setting and the practicalities of using it with people with dementia to ensure the best outcomes.

4.1 Range of technology being used

What was most noticeable from the interviews was the sheer range in the types of technology that were being used in care settings to improve the lives of people with dementia. This included basic devices and software such as a computers/laptops and Microsoft Word or Powerpoint, through to flip cameras, iPads, Skype and more specialist software such as CIRCA, MyLife or COGKNOW. Interviewees noted that each piece of technology had its pros and cons - for example, iPads and other tablet computers were viewed generally as good, as their touch screens appear to be more intuitive for people with dementia to use but the lack of keyboard makes them harder to type on by those who lack the appropriate skills or co-ordination. However the main message was that all software, regardless of how advanced or expensive it was, had the potential if used effectively to engage people with dementia and bring about noticeable improvements in their well-being:

'The different types of technology make a difference too and it's not always how you might expect. It depends on the individual's experience. For instance there are some tiny roller ball mice which we thought would be useless and found it difficult to use ourselves, but it was very good for one particular lady [with dementia]. Big keyboards are not necessarily good for people who can type. The good practice is in

having the flexibility enough to think about the person, trying out the different things/equipment to find out what is best for them. Empower and stretch them but not to the extent that you distress them.'

Care assistant

As well as the different types of technology being adopted, there was also a variety of purposes the technology was being used for. These included:

- **Facilitating better communication**, either between carers and the person with dementia or between the person with dementia and their relatives. Additionally, in some places technology was being used to facilitate better social interaction and communication between the residents. Skype was being used in some care homes to enable people with dementia to communicate with relatives who lived abroad. One care home explained how the iPad had been used to breakdown the intergenerational gap between a person with dementia and their grandchild. Both parties had communicated and laughed together whilst using the technology to look for pictures and songs that they both enjoyed. Another project was encouraging people with dementia to film their interests and hobbies using a flipcam. These films were projected on to a screen in the care home, along with voiceover commentary, for people to watch, enjoy and comment on.
- **Facilitating more effective reminiscence**. Whilst using laptops, computers or tablets, people were able to access information quickly and in a variety of formats such as pictures, films or music which enabled a smoother reminiscence process when working with people with dementia. The important thing to note was that whilst in many cases the technology did not change the information obtained - for instance, carers might previously have obtained pictures and information from the local library - the use of IT made the process much easier and quicker, '*more instant*'. There is little or no interruption to the conversation or the reminiscence process. The technology also means that additional formats, such as films or music, can be added to the range of options available too. Care homes were also using the technology to enable people with dementia to make digital 'life story' books which could be revisited and updated throughout their stay at the home.
- **Facilitating participation within society**. One project was encouraging people with dementia to use webpages. Each week a new topic would be discussed and the people with dementia were encouraged to write their views on a webpage and then invite comment from other readers in the care home and the wider society.

- **Enabling engagement with hobbies or interests.** There are a multitude of websites dedicated to various hobbies, crafts and other interests, meaning that people with dementia can more readily access information about topics of interest to them. For example one lady was very fond of dogs, so the carer had found the web site of a Labrador breeder in Devizes: *'It's just part of interacting with that person rather than being 'about the technology' – that is too clunky. It should be a seamless part of the day'*. One care home had used the iPad to show pictures of vintage cars to a resident with dementia who was renowned for having aggressive tendencies. However, when shown photos of the cars – one of his main interests – he remained calm and engaged for an hour while looking at the photos. Another care home had electronic games and jigsaws for their residents to use. This format was easier for people with dexterity issues to cope with as they only needed to touch the puzzle piece and drag it into the correct place rather than having to physically pick it up. Again, the message here is about using new technology to do existing activities more easily.

4.2 Severity of dementia is not necessarily an obstacle to using technology

All interviewees were keen to emphasise the fact that all people with dementia could engage with technology if it was used by the carer in the most appropriate way. It's important not to just assume that a person with severe dementia cannot take part in activities using technology; it's often possible to find ways to help include and involve them.

'How you do this (engage a person with dementia with technology) has to vary for different people and depending upon their abilities. That will define the extent of their interaction. But almost everyone can interact at some level; if you are making a birthday card, you can ask [the person with dementia] 'Do you want me to change the colour?' and they can nod to say yes. This can range right up to a woman who can touch type. Everyone with dementia can be engaged because computers are interesting, you can do interesting things with them, it's about the skill and what level you engage people with it. The skill is in the carer or volunteer, they need to be able to engage but not take over.'

Practitioner

One academic had been running a project encouraging people with dementia to make films. They had initially thought people with severe dementia would not recognise themselves on camera but this proved not to be the case. The people participating were encouraged to make films of their environment and the activities they enjoyed. This interviewee felt that the stage of dementia was not an issue as all activities and tasks undertaken were individual to each person. They

had found that it was therefore always possible to engage the person with dementia in some aspect of the activity, whether that was to encourage them to record and edit the film or just hold the camera (usually for those with severe dementia and learning difficulties), and therefore to gain some benefit from the activity.

4.3 Introducing the technology

Both academics and practitioners highlighted the need for the carer to show sensitivity when introducing new technology to people with dementia. Technology continues to advance at a fast pace and many older people with dementia will be unaccustomed to much of the software that is now available. It is important that when introducing technology, carers do so in a way that will not intimidate the person with dementia or make them fearful of engaging with it. One practitioner said that in fact they tended to avoid using the word ‘computer’ at all as this made people very wary of the technology. Instead they would open up an activity using words such as ‘shall we take a look at this?’ or ‘have you seen this?’ and then show them a picture or film of something that would interest them or play a song or movie. This takes the focus away from the technology and allows the carer to use it more as a device to facilitate conversation with the person with dementia.

Several of the academics had undertaken research to attempt to reduce what is often referred to as the ‘fear factor’ regarding the use of technology. As an example, one academic team had produced a prototype of a piece of assistive technology that was also designed to facilitate conversation. However, they had found that people with dementia had been reluctant to engage with the device due to its ominous appearance. In contrast, one practitioner said that a particularly good aspect of the iPad was that it was so small and unlike a computer in its appearance. This made people who might otherwise be scared of computers more willing to engage with it. When introducing the iPad to residents they usually began with simple games to help the person first become accustomed with the technology before moving onto anything more complex:

‘We begin by using simple games to engage people with the iPad. This can involve iFishpond which is a touch screen game and when the person touches the screen it makes a splash. This activity and the noise it makes are very entertaining for the person. It also helps them become accustomed with the touch screen technology. Once this has been done you can then move onto other applications which can be focussed around their interests and hobbies.’

Volunteer

Another of the academics had also found that people with dementia were initially reluctant to operate flip cameras and they had therefore used a number of methods to help people overcome this fear. They had found that one particularly useful approach was to use technology that was in a bright and attractive colour:

'We had a black camera and one which was pink and white. We found that people with dementia engaged more readily with the pink and white camera rather than the black one which was too daunting for them.'

Academic

Other approaches that had been tried included having old fashioned cameras on show alongside the new style cameras. This helped people associate the technology with the older style of camera they had grown up with and used in the past, and so allowed them to gradually become accustomed to the newer cameras. The academics also recorded themselves on camera and then played the recordings back to the group of people with dementia to illustrate what could be accomplished with the technology. Groups shown these types of examples of what could be done were more likely to engage with the technology.

4.4 Do not set people up to fail

Both the academics and the practitioners were aware that people with dementia should not be asked to undertake tasks which they will find too hard given their impairments and then inevitably fail. This can lead to greater frustration for the person with dementia and is likely to do more harm than good. It is important that when people are given tasks to complete or games to play then the skill level is set appropriately. In addition to this, if two people with dementia are asked to compete against one another on a certain game, it is important that the skill levels can be adjusted according to the competence of both people. This way one person does not continually beat the other which can have a negative impact on their self esteem. The activities that are given to people with dementia should always focus on the abilities which they still have intact rather than asking them to use skills which they have lost. In doing this it will set them up to succeed rather than fail.

'Good practice when working with people with dementia is undertaking activities that people can take part in. The activity needs to focus on the abilities that the person still has and work with them rather than those that they may have lost. This will give people with dementia the opportunity to take part in their own care and support. The approach needs to be person centred and not a one size fits all. It is important that people with dementia are not grouped into one single category.'

Academic

In addition to this it was also noted that not everyone with dementia will be willing to embrace the technology and it is important that carers do not push it on them because they are being told to from an external source. Practitioners also noted that the mood of the person on a particular day played a significant role in whether they chose to undertake the ICT activities or not. As this mood will fluctuate from day to day or hour to hour, it is important that the carer understands the person with dementia that they are working with and chooses the most opportune moment to introduce the activities.

4.5 Technology is not a replacement for human interaction

It was noteworthy that practitioners, care staff and volunteers (and some academics too) emphasised that fact that technology should not be used to replace human interaction. Just as people with dementia should not just be placed in front of a TV or radio and left to listen to it, they should not be given technology and expected either to cope with it on its own or to use the technology as a substitute for interaction with a human carer. Care staff were unanimous in saying it was important first to gain the trust of the person with dementia and then to work with them in operating any piece of technology. If this human interaction is not present then it is very unlikely that people with dementia will engage with technology. One interviewee from a charity that specialises in using the iPad with people with dementia said that they encouraged their care staff to learn the names of every person in the care home they are visiting before beginning any activities. This personal touch goes a long way towards helping gain the trust of the person with dementia.

'It is important to establish a connection with the person with dementia. There is no point in just rolling up to the care home and ploughing on with the activities. The relationship will be more fragile and the results will not be as good. It is important to establish that human connection and to firstly engage with them on a human level. Find things to talk about that you have in common and find interesting. It is also important to have an open body language and to learn their name before progressing as well as having patience and understanding towards the difficulties they have with their memory.'

Director of charity working with people with dementia

A number of interviewees commented that once a person with dementia has engaged with the technology it is important that they are then allowed to lead the activity. Activities should be participatory with the person with dementia being involved in every step along the way – to a greater or lesser extent, depending on

their willingness and ability. If the person with dementia is merely a passive viewer of the activity then they are unlikely to gain many benefits from it.

4.6 Staff confidence in using the technology

The important role that care staff play in the uptake of technology by people with dementia was noted by both academics and practitioners. If the carer is not comfortable using the technology and unwilling to embrace it, then it is unlikely that the person with dementia will be, either. Using evidence from his own research one academic suggested there is a 'critical period' of two weeks within which carers need to engage the person with dementia with the technology. If this engagement does not take place during this time period then it was unlikely that it ever will (within this carer and caree relationship- although another more confident carer may be able to engage them with the technology at a later date). It is therefore important that the carer is comfortable working with the technology and uses their time effectively

4.7 Designers

A number of the academics highlighted the fact that technology tended to be designed without taking into account the needs of people with dementia or other physical and mental conditions. Many recommended that, ideally, whenever new technology is being developed a multi-disciplinary team of designers, psychologists and other specialists should be consulted to ensure the product is as user-friendly as possible:

'It is important for designers to take into account the needs of people with dementia. They could be given a brief to ensure that a product was user friendly for people with cognitive problems.'

Academic

In contrast, much of the specialist dementia software has been designed by multi-disciplinary teams of psychologists, IT specialists and dementia specialists who have worked extensively with people with dementia, assessing their needs and wishes prior to developing any technology. This ensured that the final product was fit for purpose:

'We developed this technology through extensive work with people with dementia and carers within the care home setting. One problem we noticed was that people with dementia could not communicate with family members when they came to visit and this could be frustrating for both parties. We therefore decided to build a system that would enhance communication between family members and people with dementia. We did this by steering the exercises towards long term memory and

using generic vignettes, photos, videos and songs to prompt long term memory. Having generic material such as well known Laurel and Hardy sketches helped to trigger personal memories within people with dementia by enabling them to remember what they were doing when they first saw the sketch or other related memories.'

Academic, CIRCA system

As is often the case when accessibility issues are considered as an integral part of the design process, making the software accessible for people with dementia meant that it was more readily-accessible for all parties. In particular, carers found they were able to use the software without requiring a great deal of training:.

'As the machine has been designed for the person with dementia to easily interact with, it also means that carers should have little problem in operating it.'

Academic, CIRCA system

Clearly, designing a piece of software from the outset to be user friendly for people with dementia or other physical and mental health conditions is the optimal approach. However, where standard equipment has been bought there is a range of hardware which can be attached to computers, laptops or tablets and software that can be loaded to make standard equipment more accessible to people with dementia or other additional needs. Practitioners and care staff gave examples of such products; including bigger keyboards, voice recognition systems etc.

4.8 Outcomes of using the technology

Initiatives to encourage the use of ICT by people with dementia are still in their infancy and therefore many of the positive outcomes associated with using technology with this client group tend to be anecdotal. Nonetheless these accounts of the positive outcomes of improved self-esteem, social interaction, mobility and well-being, reported by both academics and care staff, point to the potential benefits that can be gained.

'We have not had any systematic outcomes of our study just yet as we have been measuring and monitoring the activities using participatory video. Anecdotally though we have seen improvements in self-esteem and social inclusion for the people involved and it has given them a product to be proud of. The people with dementia have shown their film to other people around the care home and this has helped to improve their self-esteem.'

Academic

The academics noted though that if this area of activity was to continue to grow and develop then it would be important that more rigorous tests are undertaken to provide more conclusive evidence of the beneficial impacts that technology can have on the lives and well-being of people with dementia. For this reason a number of the more specialist dementia equipment manufacturers were seeking to measure and record these outcomes as part of the development and marketing of the software.

Some academics noted that this may place more of a burden on carers, as they may be required to record this information. Therefore some researchers were looking to incorporate more user-friendly measurement systems into the developments. One idea is a visual analogue scale built into the software to allow relatives to record the mood of the person with dementia and report on how engaged the individual had been with the technology. This should be relatively simple to use and ensure that carers do not spend too much time in recording the results:

'We are now developing a future version of the system which will enable people to monitor the progress of the people with dementia that they are working with and enable them to record any benefits that they have noticed. However this might mean that the system becomes more complicated to operate as you will need to type in passwords each time you work with a new person and also type in any data about that person. Currently the system is very simple to use and this is one of its benefits.'

Academic

4.9 Conclusions

The interviews with practitioners, carers, academics and volunteers identified both a range of issues to take into account when introducing technologies into the care setting but also a range of benefits that can be gained when they are introduced with sensitivity. Together with the findings emerging from the literature review the key themes and issues from the interviews were used to develop an outline document for the Advisory Group to consider. This part of the development process is described in the next chapter.

5 The Advisory Group

It was agreed that an Advisory Group would be convened to assess the information gathered and ensure that the recommendations that went forward as potential content for the guide were sound. A further expectation was that the group might contribute further information for the guide.

5.1 Inviting participants

The first stage of this part of the process was to agree with SCIE a list of potential candidates to invite to form the Advisory Group. During the telephone conversations, all of the experts were asked if they would like to be involved in an Advisory Group and all of them accepted in principle. From this list, IES selected a panel of six experts based on their areas of expertise and their working background (occupational therapists, academics, dementia charities) and a discussion was held between SCIE and the IES researchers. Once the panel of experts had been approved by SCIE, invitations to join the Advisory Group meeting were emailed to the participants and all except one agreed to attend the meeting (one person was unable to join the meeting due to prior commitments but agreed to be a member of the Group).

5.2 Advisory Group meeting

The Advisory Group meeting was held on the 16th April 2012 and consisted of the five invited experts plus two members of the IES research team and two members of the SCIE team. It was held at the SCIE offices in London and ran from 12 noon until 4pm. A recording was made of the session (following consent by the panel) and sent to Sara Dunn Associates following the meeting, along with a copy of the notes from the discussion.

The meeting was chaired by the IES project manager and was conducted in a way that encouraged an open forum for discussion. An initial presentation on the Get Connected project was given by SCIE to provide the group with background knowledge to the current project. Following this, the IES project manager presented slides which outlined the current thinking around the area of ICT and dementia gained from the literature review, web search and telephone interviews. The presentation covered the following themes:

- Overview of the aims of the project
- Issues around introducing technology to residents in care homes
- Uses of technology for reminiscence work, entertainment purposes, communication purposes
- Issues around older people and those with dementia using the different types of technology
- Role of tablet computers versus conventional PCs and the various issues to consider with both formats
- Information on specialist technologies
- Issues around what constitutes best practice
- Differences between group work and one-to-one work when using technology
- Why and how residents well-being outcomes should be measured

Throughout the presentation members of the Advisory Group were encouraged to comment on and discuss the information presented and to provide their views on whether the information was correct or not, whether it should be presented within the guidance documentation and if so, how this should be achieved. The Advisory Group were asked if the information about the different technologies could be grouped more effectively and if certain pieces of technology had been missed and therefore should be included in the guidance. They were also asked to comment on whether the activities could be used for residents with varying degrees of dementia and whether they were most effective in a group or one-to-one setting.

The meeting was tape recorded and notes were taken throughout by both IES researchers. These were written up after the meeting and additional information and examples were extracted from the literature review and interviews to illustrate the points made. This document, along with a tape recording of the meeting, was provided to Sara Dunn to enable drafting of the guidance documentation.

5.3 Outcomes and handover

The final document provided to Sara Dunn Associates contained information gleaned from the literature review and interviews, and the suggestions made at the Advisory Group meeting. The report included practical examples of the technologies being used in care settings. The final document sent to Sara Dunn can be seen in Appendix 6.

6 Testing and evaluation of the guidance

Following drafting of the guide by Sara Dunn Associates the documentation was piloted in nine small scale providers of adult social care for people with dementia. These were drawn from the list of organisations which received funding through Get Connected and from sites at which the Alive! Charity provided support. In particular, participation was sought from Get Connected grant recipients who had previously highlighted difficulties in finding guidance to help them in using the technology with their clients.

6.1 Piloting methodology

At each of the nine organisations up to four interviews were conducted with staff who had responsibility for working with people with dementia, and their managers (and/or their Activities Co-ordinator, where this role existed in the organisation).

Interviews were conducted face-to-face to enable a rapport between interviewee and interviewer and help the researcher gain more of an idea of any immediate problems they may have with comprehending the material. This method allowed a more in-depth understanding to be gained of where any ambiguities or other issues resided within the guidance which interviewees may not have been able to convey adequately if a more remote means of gathering feedback was used, such as an online reporting system.

Selected grant recipient sites and those care homes recommended by Alive! were contacted by email and phone during July to alert them to the forthcoming trial of the draft guidance (to be conducted during September) and to request their participation. The sites were selected to ensure a spread of organisations across variables such as region, type of service provider and number of service users but

the priority was on gaining participation from those working with adults with dementia which had expressed a difficulty in understanding how to use and develop the new technology.

While the discussion guide was used as the basis for the interviews the interviews were very much led by the participants' reactions to the guidance and any queries they raised. Depending on responses of the participants, either during or following testing the guidance the researchers explored:

- whether participants believed the language was sufficiently clear
- whether participants were able to follow the ideas suggested in the guidance
- whether the suggestions were helpful – were they able to think of ways in which they could apply the suggestions in their own setting?
- what barriers exist in the care setting to prevent the uptake of ICT?
- who the guidance should be targeted and what methods were most appropriate to reach these people?

A full list of the issues explored during interviews can be viewed in the discussion guide in Appendix 7.

6.2 Feedback from the fieldtest

6.2.1 Background to the care homes interviewed

All of the care staff interviewed supported people with dementia within their care home setting, and many of the care homes also housed residents with other physical or mental health conditions. The level of dementia of the residents varied greatly between the care homes interviewed. Some carers worked with people they considered to be at the mild stage of dementia, with some memory difficulties, whereas others worked with those in the more advanced stages of dementia, who had severe memory problems and additional symptoms such as poor language skills and repetitive behaviours. Seven of the care homes used ICT but the extent to which they used it varied greatly. Three care homes were very proficient and had a wide range of software whereas others were very limited in the technology available. All the care homes tended to use music, although the extent to which it was employed varied greatly. Some actively incorporated it into activities with the residents to stimulate and entertain them, whereas others just played it in the background of the care home to provide more of an appealing atmosphere. Some of the care homes also brought in specialist charities to run activity sessions for their residents using ICT.

6.2.2 Barriers to introducing ICT

Staff training

As highlighted in the literature and during interviews with academics and practitioners, care homes also felt that staff training would be a problem to introducing ICT. Many care staff are not computer literate (particularly the older care workers) and therefore it is important that they are given the appropriate training before being required to carry out the activities.

'Our main barrier would be staff training. A lot of the carers we have here are not computer literate and so it is important that they are given the right training before they are expected to use ICT.'

Care home manager

Resident apathy

A few care homes alluded to the fact that their residents were very much *'stuck in their ways'* and it would be difficult to interest them and engage them in the technology. As the residents have not grown up with technology they may find it difficult to come to terms with it or see any reason for using it. In these cases it was felt that it would take a lot of skill from the carer to introduce it to residents in a way that they would feel comfortable with.

Costs

ICT can be expensive to invest in and a number of the interviewees cited this as a barrier in introducing it to the care home. In the current climate, funding is minimal and if care managers do not see the potential in ICT then they are unlikely to invest the little money they have into technology⁹.

'The biggest issue in our care home is cost. We don't have a great deal of money to spend on technology.'

Care manager

⁹ It should be noted that this comment was not from one of the sites that had received Get Connected funding

6.2.3 Initial impression of the guidance

All the care homes interviewed felt that the guidance was easy to read and comprehend. The language adopted was very simple and contained nothing that would be considered too 'techie.' This would enable carers to follow it without too much difficulty. One carer stated that the '*language should not get any simpler as then it could be construed as being condescending.*' A number of interviewees spoke about the '*flow*' of the document being very good and the fact that it took a logical approach when working through the issues around establishing and using ICT within the care setting.

'It was very useful that the guidance touched on both static forms of technology such as a computer and monitor and also more mobile forms such as the iPad. This made us think about the technology that would be useful in our care home given the residents we have and the activities we would like to carry out.'

Care manager

The care staff noted that they had very little spare time and so the fact that the guidance was relatively short pleased them as it meant that they could read through it fairly quickly (although despite this a number had not managed to do so prior to the visit). As the guidance is split up into sections, the interviewees were able to easily navigate the document and either read a section at a time or return to certain sections at a later date when it was more applicable to their situation, or they had more spare time.

'The length of the document is about right and would be easy for any carer to read. As it's split up into sections this would make it easier to re-visit a certain section at any point without having to read the whole document again. We all (care staff) viewed the document as very useful and relevant.'

Carer

All those interviewed agreed that everything they read was very useful and could be practically implemented within the care home, although certain barriers (discussed previously) might prevent this. Despite these barriers though, the guidance inspired most of the care staff, particularly those who had made very limited use of ICT until then, to think about the range of technologies described and to evaluate whether they would be useful for their residents and the activities they wished to carry out in the care home. Some commented that although presently they did not use ICT within the care home, many of the activities that they do undertake with the residents could easily be transferred across to this format and would most likely be easier to run as a consequence.

6.2.4 Improvements to the guidance

Revisions to some of the tasks suggested

Some interviewees who were currently undertaking some of the ICT activities suggested in the guidance had experienced difficulties when using them with people with dementia. They were therefore keen that these problems should be highlighted in the guidance.

- **Emails:** not everyone with dementia wants to use emails even if it may be a more effective way of communicating. Some people with dementia prefer postcards as they like receiving the physical object and enjoy looking at the handwriting. Another interviewee highlighted the fact that some people with dementia find it very difficult to comprehend words and therefore find using pictures a lot more beneficial. They encourage relatives and family members to send emails but to only include pictures rather than text, and in return the person with dementia will respond using photographs and pictures. This is easier for the person with dementia to understand and therefore a more engaging and enjoyable activity.

'Whilst email is a good method of communication, in my experience many people with dementia do not understand words and the idea that you can describe emotion through words. I have had more success with emails and pictures. Whilst people cannot translate words they can understand pictures of family members, new babies. People with dementia are better able to make links more readily with pictures that are sent to them.'

Care home manager

- **Skype:** Although people with dementia enjoy seeing the picture of their relative or their friend many of them do not realise that you can actually engage with that person via Skype and that this person can actually see them as well. One carer found that people with significant dementia tended to just sit in front of the computer screen and not speak at all. It required a lot of effort from the carer to engage the person with dementia in a conversation and this was very distressing for their relative. The carer found that the level of dementia was an important factor in whether the individual engaged with the Skype software. Those with mild memory issues tended to be able to conceptualise and understand what was happening but it was too complicated for those with more advanced cases of dementia.

'We found that only one resident was able to use Skype more than once. They were able to conceptualise the technology and used it fairly often to speak to their daughter in France. Most people with dementia did not appreciate the technology as

they are used to the television (which they associate Skype with) and so don't understand you can talk to the person at the other end.'

Activity co-ordinator

'Skype is a very good tool to use and can be beneficial to the resident. It's important that you introduce it early on though so that people can become accustomed to it. If people are in the advanced stages of dementia they are likely not to use it.'

Care manager

- Nintendo Wii: One care home had invested in a Nintendo Wii and found that it had been beneficial to the residents as it encouraged them to undertake more exercise and it helped to promote social interaction within the care home. However they found that only certain games worked well with people with dementia. Games such as tennis, where people are required to hit a moving ball, were unsuccessful due to resident's dexterity issues. However games such as golf where the player is required to hit a stationary ball proved to be much more successful. It is also possible to adjust the skill setting on some of the games and this meant that people with dementia were not being set up to fail.

Addition of other activities/resources

One care home whose staff were proficient at ICT suggested a number of activities which they undertook with their residents that might be useful additional information for the guidance. One was the use of Pro Show software to create a slide show of the resident's life. The Activity Co-ordinator said that the program was very good at putting together informative slides of the resident's life and linking these with music and film clips. The slide show can then be downloaded onto a DVD and played through a projector to other residents and family members.

Another additional source of reminiscence materials was museum websites which archive old films. These films tend to be focussed on the war and are accompanied with music. They are around 2-3 minutes long, so short enough to maintain the attention of people with dementia. However the resolution is low and therefore a good projector is needed to ensure that people can fully appreciate the clip.

Better references to training

Many of the care staff interviewed, particularly those who worked in a care home which did not embrace ICT, felt that they would not be confident enough to undertake some of the activities suggested in the guidance and would therefore require further training. These interviewees asked for more references and links

on ICT training courses to be included within the reference section of the guidance.

A couple of interviewees also suggested that if the guidance was to be made electronic, then there could be links throughout the document (but particularly accompanying the case study examples) to YouTube videos of people undertaking the activities suggested or experts providing training on how to go about a specific task. This could be something for SCIE to consider if the guidance is made into an online interactive document.

Using volunteers or allowing staff to bring in their own technology

Money was seen as a major barrier, firstly in purchasing ICT but also in preventing staff from obtaining the required training to undertake activities using ICT. Carers also highlighted the fact that they had little time to attend training courses even if they wanted to. Two interviewees suggested that the guide could recommend recruiting volunteers who are ICT literate to carry out these activities in the care home and so relieve some of the burden and expectation placed upon the carers.

Another interviewee suggested that it might be good if the guidance highlighted the fact that carers could bring in their own technology and use this with the residents. This would mean that the care home did not have to invest in the technology themselves but would of course rely on having willing carers who may be worried that the software will be broken.

'Currently one of our care staff brings in their iPad to use with the residents. However this can cause further issues if the iPad is broken or lost. It may be good to have a section in the guidance that encourages relatives to bring in their own equipment when they visit their family members. Although we would need to highlight and demonstrate the benefits this might have.'

Carer

Take account of the different levels of dementia

Some interviewees felt that while the activities suggested were very good it would be impossible for some people in the more advanced stages of dementia to undertake them. It was felt that the guidance, rather than adopting the blanket term 'dementia,' needed to take into account the various stages of the condition and how this is likely to impact on any activities that carers wish to undertake with people.

'The guidance would benefit from taking more account of the levels of dementia and showing an understanding that some people with dementia will be able to carry out

some activities but others won't depending on how advanced their condition is. This would be the case in both one-to-one and group activities. People in the early stages of dementia will be able to pick up the activities fairly quickly but those in the later stages will find it more difficult.'

Activity Co-ordinator

Reference to other equipment

A few interviewees said that for those with physical disabilities such as poor sight or hearing, references could be made to other software which could be attached to the technology in order to improve its user friendliness. This included software such as the RNIB Dolphin which is used to help people with poor vision, as well as the voice activated software and the simplified email and web browser systems.

'It is important to touch more on the physical side of the residents. Perhaps the guidance should explore the pros and cons of using certain types of equipment particularly for those that are visually impaired as nearly all the residents at our care home are. Many of the residents will struggle using a keyboard due to their dexterity issues and their limited vision but it would be good if the guidance could suggest other equipment they can use instead or anything that can be done to the keyboard to make it more accessible. The physical impairments and limitations of the residents needs to be taken into account more within the activities suggested.'

Carer

More emphasis on forward planning

Those interviewees, who were proficient at using ICT with people with dementia, highlighted the importance of forward planning before undertaking any activities. One care home ran group sessions on topics such as the Paralympics, the Harvest, Christmas etc. Some of the sessions could last up to an hour and would use a range of different media, such as film clips, music and pictures. In order to run these sessions effectively it was important to plan them well in advance and download any required material beforehand. This particular care home would plan possible threads that the conversation may take and then download additional resources or videos in case the conversation moved onto that topic. They were keen to highlight the fact that carers should not just rush into an activity using ICT but plan in advance for the possible scenarios that may occur. If the carer is forced to stop a session for a couple of minutes then it is likely that the people with dementia will lose interest in the conversation and it will be hard to re-engage them again. They also said that it is best to keep the sessions to no more than 20 minutes unless there is a wide variety of media being presented otherwise people will lose concentration and interest.

'The amount of time that you need to prepare for an activity depends on how complicated the tasks is and how long the activity or discussion will last. For the discussion on the Paralympics which lasted around an hour, we began preparing for that about a year in advance as this activity had lots of different media formats and potential routes for conversation. These all needed to link together to ensure that the conversation kept the residents stimulated. However once you have prepared a discussion once you can always keep re-using it.'

Activity co-ordinator

Obtaining funding

One of the major barriers to investing in ICT is having the appropriate funds to do so. One care home manager felt it would be useful if the guidance highlighted areas where additional funding could be obtained that would provide the care home with more money to invest in ICT.

'One of the major obstacles for us is funding and so it would be good if the guidance could highlight places where funding for ICT could be obtained.'

Care home manager

Case studies

All interviewees agreed that the case study examples provided throughout the guide were excellent. They offered succinct and varied examples of how technology could be used in a variety of settings to engage people with dementia. One interviewee suggested that it might be useful to have some case studies of residents who had more complex needs as well as dementia. This would provide more varied accounts of how ICT can be used to support people with dementia that may also have physical disabilities or additional learning needs.

'The case studies are varied and very useful. They contain enough information to give carers an idea of the activity without going into too much depth and over complicating it. This allows the carer to think for themselves as well.'

Carer

One care manager also stated that a number of the carers at the care home had dyslexia and therefore struggled when reading the case studies. It would help a great deal if the title of the case study example outlined exactly what was trying to be achieved in the activity rather than a more generic title eg, 'Searching Google to find pictures of interest to the resident' rather than 'ICT in action: Using Google.'

'One thing we did pick up on is the fact that the activities or case studies are not clearly headed. We have some staff with dyslexia and they were unsure what the activities were trying to achieve. It may be better to state this within the title.'

Activity Co-ordinator

6.2.5 Promoting the guidance

The general consensus from the interviewees was that the guidance was applicable to all care staff including the care home manager, the activity co-ordinator (if applicable) and the carer. It was suggested that it may be more beneficial though when promoting the guidance to target it at care home managers and activity co-ordinators as they will have the final say on whether ICT will be introduced into the care home. If the manager feels they do not have the budget, then it is unlikely they will invest in ICT regardless of how the carer may feel. It is therefore essential that the long term benefits of using ICT to improve the well-being of people with dementia are highlighted at the start of the guidance to help managers realise it is a worthwhile investment. Once they have overcome this barrier, managers can then disseminate the appropriate information to the carer on how to use the technology and the types of activities that can be undertaken. This will help to reduce the time burden placed on the carer as they will not need to read the entire guidance.

'I feel that the guidance is very good but it will take time to filter through. There are many issues currently with money and budgeting and this will mean there will be a lot of resistance to introducing ICT particularly from care home managers who have limited funds. It is important to change their mindsets to show them that this is a long term investment that has the potential to be very beneficial for the residents.'

Carer

Avenues suggested through which the guidance could be promoted included:

- Care Home Associations
- SCIE seminars and training workshops
- CQC
- HSE
- Care Learning Conference
- National Association for Providers of Activities for Older People
- Journal of Dementia Care

- Dementia Care Conference
- Alzheimer's Society
- Social media such as Twitter and Facebook would be good to advertise it to the carers
- Internal BUPA events

One manager felt it would be good to promote the guidance through as many avenues as possible and not just dementia related conferences/events. The guidance can be applied to all care homes and it would be a *'travesty'* if it was only used in the context of people with dementia.

6.2.6 Taking the guidance forward

Three interviewees mentioned that they would be keen to see the guidance moved onto an online format as well as in hard copy. Care staff would be able to interact with the online guidance and click on links which would take them straight through to the equipment/applications suggested or the training required. Care staff would always know where to access the guidance and could click straight through from the contents page to the specific section which they required.

'It would be good if the guidance was a little more interactive and had links which you could click on to get straight through to access the information. This could be done in the games section and the music sections to save on time.'

Carer

Another interviewee suggested that if the guidance was made into an online format then it could include a forum for care managers and staff to discuss with each another the types of technology that they had introduced into their care homes and whether it had been a success or not. Care homes could recommend the most appropriate activities to use for certain residents and the most effective methods for carrying out these activities. They could highlight the barriers that they faced when undertaking activities and the most appropriate ways to combat them. It was suggested that the website could also be set up in a similar fashion to the 'Amazon' website, where care staff can review certain products and then suggest others that would work well given the environment that the person is working within. The interviewee, who had previous experience within the IT sector, was willing to help set up this website and with his consent his details were passed to SCIE.

'What would be very useful is having a place where carers and care homes can communicate with one another on pieces of technology that they wish to use and the best activities to carry out on certain bits of technology. A forum or knowledge

repository would allow care homes to give first hand experience and advice to one another. This would enable carers to find things easily and to learn from one another on what works well with certain types of residents.'

Care home manager

6.3 Conclusion of the fieldtest

Following completion of the fieldtest, notes from the interviews with feedback from the interviewers were forwarded to Sara Dunn Associates to enable appropriate amendments to be made to the guidance.

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Appendix 1: Full methodology

Six broad stages to the work were planned:

- a. identifying activities currently being used with people with dementia and any resources and/or guidance already available;
- b. reviewing/assessing activities and guidance available;
- c. drafting the text for the guide
- d. seeking feedback on early draft guide and revision
- e. field-testing the guide with care organisations
- f. reviewing and revising the guide in light of the feedback from the pilot.

Activities a, b and e were undertaken by IES; activities c, d and f were undertaken by Sara Dunn. Details of the research and development processes are reported in the following sections.

Identifying existing activities, resources and guidance

Literature review

Relevant evidence was sought from the academic literature and websites. The EBSCOhost database was used to search for relevant material during March 2012 in addition to other journals associated specifically with dementia and ageing. It was envisaged that this phase would be very brief as it was recognised that the area was still emerging and so it was anticipated that little information would be found via this route.

The EBSCOhost database was used to search for relevant material during March 2012. This database searches through a range of other academic databases associated with health, social care, communication and business. These include:

- Academic Search Complete
- AMED
- Business Source Complete
- CINAHL
- Communication and Mass Media Complete
- eBook Collection
- ERIC
- Medline
- PsycArticles
- PsycBooks
- PsycInfo

In addition to this other journals associated specifically with dementia and ageing were explored. These included:

- Alzheimers and dementia
- American Journal of Alzheimers disease and other dementias
- Dementia
- Dementia and Geriatric Cognitive Disorders
- Aging and Mental Health

The initial search terms 'Technology and Dementia' were used but these yielded 829 hits and therefore more specific terms were employed to narrow down the search for relevant material. These were 'ICT and dementia', 'Information Technology and Dementia', 'Communication Technology and Dementia', 'ICT and cognitive impairment', 'Information Technology and cognitive impairment', 'Communication Technology and Cognitive Impairment'. A total of 136 papers were generated once all of the duplications had been removed. On inspection very few dealt with the practical issues around the use of online technologies with people with dementia. Just four were subsequently downloaded and reviewed. A list of the articles that were reviewed is shown at Appendix 2.

A visit to Stirling University Dementia library also produced an additional five books and three papers which were reviewed.

Website search

It was noted that a limited number of websites had started to produce support and guidance materials for staff and carers of people with dementia. The strategy employed was firstly to undertake a search for organisations supporting people with dementia and their carers and then search those websites for relevant information on using technology to improve quality of life of those living with dementia. This included the websites of overseas organisations – primarily in the USA and Australia – to see if resources were available there.

A total of 39 websites were examined (see Appendix 2) and the limited information ascertained from the search was used to inform the literature review of the field.

E-mail request to Get Connected beneficiaries

Although it was reported that some Get Connected service providers had encountered real difficulties in finding ways to use the technology with people with dementia, others had found innovative ways to use the technology. Therefore all first tranche Get Connected beneficiaries were emailed to request examples of the ways in which they have used the technology with people with dementia and, where appropriate, these were followed up with telephone discussions.

A total of 1,182 service providers were contacted of which 25 responded. Additional details were sought from 12 of these and telephone interviews were undertaken with four of them, to discuss their use of ICT in more detail.

Telephone discussions with relevant professionals

In parallel with these activities a series of telephone discussions were conducted with individuals at dementia charities and other relevant organisations and professional bodies. The purpose of these interviews was threefold: to ask about any relevant experience they had in using technology with people with dementia; to enquire whether they were currently conducting any projects looking at supporting the use of ICT with individuals with dementia; and lastly, to ask for any suggestions they might have regarding literature on this topic, activities or other resources that could be relevant for the work.

In addition, universities who have specialist knowledge in dementia studies were contacted and asked about any research they were currently conducting in the area.

A total of 17 interviews were conducted with professionals during March 2012. The interviews with professionals also yielded an additional seven papers and one

book which were included in the review. The professionals also pointed the researchers to various dementia specialist websites.

A discussion guide for the interviews was initially drawn up by researchers at IES and following this, Sara Dunn Associates and SCIE were given the opportunity to comment on it. When agreement had been reached regarding the final format for the discussion guide the telephone discussions were arranged and undertaken. The final discussion guide can be seen in Appendix 3.

Analysis of activities and other information

Once the information was collected it was analysed to identify the various activities, the ways in which the technology was being used and the approaches that care staff were adopting (or were encouraged to adopt) to engage their clients with the technology and activities. This content was set out in a PowerPoint presentation to present at a workshop with the Advisory Group.

Reviewing the information gathered

A workshop was convened at the SCIE offices in April 2012 at which the information generated was reviewed by members of an Advisory Group.

A list of potential members of an Advisory Group was drawn up in discussion with SCIE and invitations were sent to all invitees (see Appendix 4 for the Membership of the Advisory Group). No-one declined to join the Advisory Group, although two of the Group were unable to attend the session. A full list of the Advisory Group can be seen in Appendix 4.

The purpose of the workshop was to review the information that had been gathered and to assess the extent to which members of the Advisory Group thought the various components should be recommended in the guide. A key objective for this part of the work was to consider the examples of practice that had emerged from the trawl and an early intention of the researchers had been to agree the extent to which examples appeared to exemplify good or best practice. However, it was subsequently agreed with SCIE that, given there was so little activity at that point (hence the need for the guide) it would be difficult to identify 'best' practice and this would lead to a very limited set of examples for the guide. The over-riding need was to help and encourage people to use the technology in any way that served to support wider use. Therefore the aim of the workshop was to check that any use did not constitute bad practice and to add to the guidance and examples generated by the preliminary work.

An overview of the collated findings from the initial research phase was developed into a presentation outlining the potential types of activity or topics

that the guidance would need to cover, in particular noting any activities and recommendations that had emerged from the literature and interviews. This presentation was then used to stimulate discussion with, and feedback from, the Advisory Group members. The discussions were recorded by the researchers so that the points made during the discussions could be used as the basis for production of a revised version of the outline guidance.

Handover

Following the workshop the outline guide contents were revised in line with the comments received from the Advisory Group. A copy of that document is shown at Appendix 5. The information was then handed over to Sara Dunn Associates to inform development of the draft guide.

Field testing the draft guidance

Once the draft guidance had been produced by Sara Dunn Associates, IES arranged visits to nine care organisations to test the guidance with care staff. Organisations were identified through the following means:

- A selection of sites were contacted by Alive! charity and agreement in principle reached for a visit
- One of the Get Connected sites that had been instrumental in raising awareness of the need for the guide for re-contacted and invited to participate
- The research team's personal contacts who were working within the care home environment

The sites were visited by a researcher during September 2012. Between one and four members of staff were interviewed at each site. A total of 18 care workers including carers, activity co-ordinators and care home managers were interviewed. The interviews focussed on the utility of the draft guidance and sought information about any changes required to make the guide more accessible and/or useful. A discussion guide was designed to guide the interviews; this is shown at Appendix 6.

The guidance was emailed to each site ahead of the visit in the hope that they would be able to read the document in advance of the visit, but in the event few did, emphasising the lack of time available in many care settings to read even short documents. On the day of the visit the researcher went through the guide with the various members of staff, with the questioning strategy being led by the structure of the discussion guide.

Appendix 2: List of the articles identified in database search or through recommendations

Papers

1. Astell A, Ellis M, Bernardi L, Alm N, Dye R, Gowans G and Campbell J (2010) 'Using a touch screen computer to support relationships between people with dementia and caregivers'. *Interacting with computers*. Vol 22, pp 267-275
2. Capstick A (2011). 'Travels with a flipcam: bringing the community to people with dementia in a day care setting through visual technology'. *Visual Studies*, vol 26
3. Damianakis T, Crete-Nishihata M, Smith K, Baecker R and Marziali E (2009). 'The Psychosocial Impacts of Multimedia Biographies on Persons with Cognitive Impairments'. *The Gerontologist*. Vol 50 No 1 pp 23-35
4. European Commission (2004) *Enabling Technologies for people with dementia*. Cross National Analysis Report
5. Hodges S, Berry E and Wood K (unpublished) *Sensecam: A wearable camera which stimulates and rehabilitates autobiographical memory*
6. Kikhia B (2011) *Supporting Lifestories through Activity Recognition and Digital Reminiscence*. Licentiate Thesis
7. Kikhia B and Hallberg J (2010) 'Building digital life stories for memory support'. *International Journal of Computers in Healthcare*. Vol 1 No 2
8. Meiland FJM, Reinersmann A, Bergvall-Kareborn B, Craig D, Moelaert F (2010) *COGKNOW: Development and evaluation of an ICT-device for people with mild dementia*

9. Murphy J, Gray C and Cox S (2007). 'The use of Talking Mats to improve communication and quality of care for people with dementia'. *Housing, Care and Support*, Vol 10 iss 3, pp 21-28
10. Subramaniam P, Woods B (2010). 'Towards the therapeutic use of information and communication technology in reminiscence work for people with dementia: a systematic review'. *International Journal of Computers in Healthcare*. Vol 1 No2
11. Tobiasson H (2011). *Game over or play it again and again...Participatory design approach within Special Housing*. Industrial Ergonomics
12. Topo P, Saarikalle K, Clarke N, Begley E, Cahill S, Arenlind J, Holthe T, Morbey H, Hayes K, Gilliard J (2004) 'Assessment of a Music-Based Multimedia program for people with dementia'. *Dementia*. Vol 3 pp 331.
13. Upton D, Upton P, Jones T, Jutilla K and Brooker D (2011). *Evaluation of the impact of touch screen technology on people with dementia and their carers within care home settings*. Department of Health West Midlands.
14. Wiersma E (2011) 'Using Photovoice with people with early-stage Alzheimer's disease: A discussion of methodology'. *Dementia*. Vol (2) pp 203-216
15. Woods B, Aguirre E, Spector AE, Orrell (2012) *Cognitive stimulation to improve cognitive functioning in people with dementia (review)*. The Cochrane Collaboration. John Wiley and sons.

Books

1. Innes, A and McCabe, L (2007) *Evaluation in Dementia Care*. Jessica Kingsley Publishers
2. Gregor, P and Newall A (2004) *Technology in Cognitive Rehabilitation*. Taylor and Francis Inc
3. Barlow, J and Breeze, M (2005) *Teleshopping for older and disabled people: an evaluation of two pilot trials*. Joseph Rowntree Foundation
4. Murray, D and Aspinal, A (2006) *Getting IT: Using information technology to empower people with communication difficulties*. Jessica Kingsley Publishers
5. Mulvenna, M and Nugent, C (2010) *Supporting people with dementia using pervasive health technologies*. Springer-Verlag
6. Savitch, N and Stokes, V (2011) *We can do IT too: Using computers as part of activity programs for people with dementia*. Speechmark publishing

Appendix 3: List of websites examined

Websites

1. Alzheimer's Society:
<http://alzheimers.org.uk/site/scripts/documents.php?categoryID=200120>
2. NHS Dementia
<http://www.nhs.uk/Conditions/Dementia/Pages/Introduction.aspx>
3. Dementia UK
<http://www.dementiauk.org>
4. Age UK
<http://www.ageuk.org.uk/>
5. Alzheimer's Research UK
<http://www.alzheimersresearchuk.org/>
6. Alzheimer's Scotland
<http://www.alzscot.org/>
7. Carer's UK
http://www.carersuk.org/media/k2/attachments/Care_and_technology_in_the_21st_century.pdf
8. Mental Health Foundation
<http://www.mentalhealth.org.uk/>
9. Carer's Trust
<http://www.carers.org/>

10. Friends of the elderly

<http://www.fote.org.uk/>

11. NAPA

<http://www.napa-activities.co.uk/>

12. NCPC

<http://www.ncpc.org.uk/>

13. FAST UK

<http://www.fastuk.org/research/projview.php?id=665>

14. At Dementia

http://www.atdementia.org.uk/editorial.asp?page_id=23#anchor1816

15. CPVS

<http://www.compeng.ulster.ac.uk/showResearchProject.php?projid=947>

16. Dementia Voice

<http://www.dementia-voice.org.uk/>

17. Housing 21

<http://www.housing21.co.uk/>

18. CIRCA

<http://www.computing.dundee.ac.uk/projects/circa/>

19. COGKNOW

<http://www.cogknow.eu/overview>

20. Joseph Rowntree Foundation

<http://www.jrf.org.uk/bookshop/details.asp?pubID=931>

21. IATSL

<http://www.ot.utoronto.ca/iatsl/>

22. Networked Carers

http://www2.warwick.ac.uk/fac/med/research/hsri/research/ehealth/dementia_carers/

23. Safe2Walk

<http://www.safe2walk.com.au/>

24. Sense Cam

<http://research.microsoft.com/apps/dp/search.aspx?q=sensecam&x=13&y=10#p=1&ps=36&so=1&sb=&fr=&to=&fd=&td=&rt=&f=&a=&pn=sensecam&pa=&pd=>

25. UTOPIA Project

<http://www.computing.dundee.ac.uk/projects/utopia/>

26. Dementia Care Matters

<http://www.dementiacarematters.com/>

27. Music for live

<http://www.wigmore-hall.org.uk/learning/in-the-community/music-for-life>

28. Dementia Services Development Centre

<http://dementia.stir.ac.uk/>

29. SCIE Dementia Gateway

<http://www.scie.org.uk/publications/dementia/index.asp>

30. NICE

<http://www.nice.org.uk/CG42>

31. BRACE

<http://www.alzheimers-brace.org/>

32. Alive!

<http://www.aliveactivities.org/>

33. Young Dementia

<http://www.youngdementia.org/>

34. Young Dementia UK

<http://www.youngdementiauk.org/>

35. Alzheimer's Disease International

<http://www.alz.co.uk/>

36. Alzheimer Europe

<http://www.alzheimer-europe.org/>

37. Bradford Dementia Group

<http://www.brad.ac.uk/health/index.php>

38. Dementia Action Alliance

<http://www.dementiaaction.org.uk/downloads/4/resources>

39. Sonas

<http://www.sonasapc.ie/>

Appendix 4: Discussion guide for telephone interviews

SCIE IT and dementia- Discussion guide for experts

Introduction

- Introduce self and the organisation.

We have been commissioned by the Social Care Institute for Excellence (SCIE) to seek examples of how IT and communications technologies have been used to enhance the lives of people with dementia. This will contribute towards the development of a guide for those working with people with dementia to support them in the use IT/ICT. As part of the work we are talking to people with expert knowledge in this area and who may be in a position either to highlight examples of how ICT is being used to enhance the lives of people with dementia or to give suggestions for further people to contact, and that's why I've got in touch with you. Do you have a little time to speak to me now? I'd expect this discussion to last around 20 minutes. Is it convenient for you to speak to me now?

[If not convenient, arrange time to call back.]

I should also mention that as part of this work we'll also be reviewing literature in this area and so if you are able to direct us to further literature or authors within the field then that would be really helpful too.

The idea is to pull together information from all these various sources and develop an accessible guide for care workers to use when using IT/ICT to support people with dementia.

- Are you happy for me to record the interview? This will only be used to help me produce an accurate set of notes from our discussion.
- Check everything is clear and then begin

Interviewee's background

1. Can you tell me about your background and your current role?
 - Probe for number of years working in the field
 - Frontline experience or academic/research experience (or both)
2. Can you tell me about your organisation/ department?
 - Probe for number of people working in dementia
 - Type of work that the organisation carries out
 - Have they (organisation or personally) been given any type of award or recognition for any of the work they do in the field of dementia?

Examples of using ICT

3. Can you give me any good examples of how ICT is being used to support and enhance the lives of people with dementia? (Use these probes for all examples given)
 - (If not clear) Is this something that you/your organisation are directly involved in (or another organisation?)
 - What equipment/software do you (they) use?
 - In what way is the equipment/software being used? (as way of supporting or enabling activities or entertainment/as aide to memory/as way of communicating with families, staff or outside world/as way of obtaining services etc.) – probe for full details:
 - do all staff do this or just a few who are specially trained
 - are any adaptations needed?
 - Do you have any evidence to show that it works? Qualitative/quantitative data?
 - Have you encountered any problems when [eg conducting this activity / edit in line with way in which technology is being used]?
 - Have you managed to overcome these issues? How have you done that?
 - Can this activity be used for all people with dementia or does their stage of dementia matter?

- Do you think that this activity would be easy/appropriate for care workers to carry out? Is there particular advice you would give or training that you would recommend?
4. Is it easy to get people with dementia to engage with ICT, in your experience?
 - Is there a best way to facilitate their engagement? Have you found (of heard of) anything that works particularly well?
 - Is the person's stage of dementia important to consider when using ICT? Have you mainly worked with people with early or late stage/advanced dementia?
 5. Are there any other issues which may affect the extent to which ICT can be used to support people with dementia?

Definition of 'good practice'

1. SCIE are keen to only use examples of 'good practice' within the guidance documentation. As you can imagine, as this is a fairly recent area of development we are keen to gain people's views of what might constitute 'good practice'. Could you tell me what would you personally consider 'good practice' to look like when using ICT to work with people with dementia? What are the important issues to consider?
2. Is there any work being carried out using ICT to enhance the lives of people that is not specifically for those with dementia but could be transferable?
 - Do you think this activity could be used with those with dementia?
 - How easily could this be done? Would any adaptations be needed?

Literature and organisations to be considered

1. As previously mentioned we'll be undertaking a literature review as part of this work. Is there any literature/existing guidance you would like to highlight on ICT and dementia that we should be aware of? *If their publications, can they email or post a copy*
 - Is there any literature outside of the UK that we should examine? Are there any issues around transferring that to a UK setting?
2. Is there any literature which considers the use of ICT to enhance people's lives but not specifically for those with dementia that you feel we should also look at?
3. Can you suggest any other organisations that are using ICT to enhance the lives of people with dementia, or who are doing research in this area, that you think we should contact?

- Can you give me an idea of the sort of work they're doing?
- 4. Are there any organisations/charities/academic departments carrying out work using ICT but not specifically in relation to dementia that you think it would be useful for us to speak to?
- Can you give me an idea of the sort of work they're doing?

Closing the interview

1. Is there anything else you would like to add that we have not touched upon?

Thank you for talking with me today, the information you have provided is very valuable. Later on in the work SCIE will be bringing together an expert panel to consider the various examples of practice and information gathered from the work and assess them as good practice or not. Might you be willing to be part of the expert panel? Unfortunately you cannot be paid for this, but your expenses will be covered. *(If agree then say you will pass on their contact details to SCIE who will contact them in due course to arrange the panel meeting).*

Many thanks again for your assistance with this important work to improve the lives of those with dementia. I will keep you informed on the progress of the project and when the guidance is available.

Appendix 5: Members of the Advisory Group

1. Norman Alm (University of Dundee)
2. Andrea Capstick (University of Bradford)
3. Anthea Innes (Bournemouth University Dementia Institute)
4. Tim Lloyd-Yeates (Alive!)
5. Deborah Miranda (Alzheimer's Society)
6. Chris Nugent (University of Ulster)
7. Nada Savitch (Innovations in Dementia)
8. Verity Stokes (South Warwickshire Foundation Trust)

Appendix 6: Document sent to Sara Dunn Associates following the Advisory Group meeting

The aims for the Advisory group meeting were:

- Review the findings emerging from the literature search and interviews
- Attempt to group the findings into mini chapters/sections for the guidance
- Establish 'good practice' in how people are engaged with technology
 - Personalisation is central to 'good practice' and to the guidance documentation

The group considered the emerging findings and helped shape the structure of the guidance to be produced.

Draft structure for guidance on using IT with people with dementia

The general structure that was needed was thought to be a chapter on general issues to do with introducing technology followed by chapters dealing with broad groupings of activities, followed by summary of broad technology issues (eg when tablets are best used etc.)

Issues to consider in introducing (new) technology

- Rationale for introducing technology – it may be necessary to justify investment to the Board
 - Possible future link to CQC inspection criteria

- Increasing Personalisation agenda (point to SCIE Rough Guide to Personalisation; <http://www.scie.org.uk/publications/reports/report20.asp>)
- People will soon expect it
- It can increase inward funding as it can make organisations look better (through range of ways: facilities available, but also web page showing the home and its facilities and emphasising the availability of technology)
- It can be part of staff development to help them progress and become more au fait with IT skills
- Inclusion agenda: why should people with dementia not be able to 'do the same as everybody else' eg:
 - 'Press red button' after tv programmes
 - Having increased choice
 - Be in control (within limits of their ability/extent of cognitive impairment)
 - Have a sense of achievement

One care home was teaching their residents to use iPlayer functions on the television. This allowed them the freedom to carry out other activities and return to watch their programs at a time that better suited them.

Before purchasing any technology it is important to assess the needs of the care setting and have an idea of the tasks you wish to carry out and the appropriate technology that will enable you to do this. One care home had used a pot of funding to invest in laptops but soon realised that these were unsuitable for their residents or the tasks they wished to perform.

- Technology is not a replacement for human interaction
 - Need for relationship before commencing any work

Alive! Charity work within a number of care homes for a set period of hours each day. As many of the staff are unknown to the residents it is essential that they quickly develop a relationship with them before attempting to introduce any technology. Their outreach workers make determined efforts to learn residents' names and to ensure that their body language is seen as non-threatening and encourages open communication with the residents.

- Staff need some skill but enthusiasm and confidence or willingness to 'give it a go' are just as important
 - Research indicates that support provided in the first two weeks predicts extent to which technology adoption is successful initially and down the line.

Where support is low drop out is high. This can be important in getting staff to use the technology.

- Researchers have explored what predicts whether a person will succeed or drop out with technology and this work suggests that two weeks is the key point – if they keep going for two weeks they will most likely continue. Again, could be useful for predicting the best staff to involve in these sorts of activities
- some staff can feel they are ‘not doing proper work’ if they work one-to-one with clients on activities such as looking at the internet – there may be implications for organisational culture, giving permission to staff/legitimising use of technology in this way. In some care home settings it may be necessary to ensure management commitment and buy in to any technological initiatives that are introduced.
- There are tutorials available on YouTube to help people to get familiar with the various software applications and technology
- Similar issues apply with residents/users. One interviewee said: Residents are initially very wary of the technology and it can be difficult to introduce it to them. However if you do not make a great deal out of it then residents will get used to it. We had one resident who would not use the technology and was slightly scared, however once they had slowly introduced it to her, within a week she was using Skype on her own. It is then important to keep encouraging them to use the technology as if not then residents may relapse despite having made the initial breakthrough.

Engaging with users

One of our interviewees said “How you do this has to vary for different people and depending upon their abilities. That will define the extent of their interaction. But almost everyone can interact at some level: if you're helping someone make a birthday card, you can ask them 'Do you want me to change that colour' and they can nod to say yes. So they range from that level up to the woman who can touch type [*this refers to someone who was a touch typist before developing dementia*]. They should all be 'engaged' as they wish to be. Everyone with dementia can be engaged because computers are interesting, you can do interesting things with them, it's about the skill, what level you engage with people at. The skill is in the carer or volunteer, they need to be able to engage but not take over.”

Another said: “The level of dementia is important but people should not be underestimated, just because they have got dementia they are still able to operate machines and to carry out certain tasks. With people [with more advanced

dementia] it is much harder to do complicated tasks with them, however they can still enjoy the pictures and the music which the technology allows them to do.”

- Start from what you know and have – more people have smart phones and iPads – in some cases it may be better to start from these than to go straight to use of a computer.
- Care needs to be taken in the words used to describe the technology
 - Some people are fearful of the word ‘computer’ (or it has associations with past work life, rather than use for pleasure) and so are reluctant to use it – and in fact, few people nowadays refer to tablets or laptops as ‘computers’
 - It is important that staff do not become frustrated with residents when assisting with the technology as this could deter them from using it in the future.
- One interviewee said ‘You can just say “have you seen this?” and then introduce the technology. The piece of technology should be used to facilitate the conversation rather than be at the centre of the task. People will then engage with it much better.’ Another said that just picking up a tablet or laptop and saying ‘let’s have a look at this’ is more neutral and may be the best approach.
 - One care home gave the example of a female resident who was initially fearful of the computer. However carers did not push the technology until the resident was used to it. Over time they slowly introduced the technology to her and within a week she was using Skype on her own. Following this they continued to encourage her to use the technology as they found that a number of other residents who had made similar breakthroughs tended to relapse if they were not provided with the correct reinforcement.
- Technology should not be the central issue; a better approach is on considering these items to be ‘everyday devices’ which can
 - facilitate conversation/communication
 - provide people with stimulation
 - provide entertainment/access to entertainment
 - support creative activities
 - help increase choices available to the individual
- Some examples from our interviewees:
 - One said “It’s ‘just another way’. There’s a lot of chatting in support groups and you can use the internet to find stuff that people are interested in talking

about. It's just another thing to use - you might be having a conversation about the Olympics and just look up something to do with it. And you can look up/obtain things that would be difficult to find otherwise". Another said: "I tend to use the iPad almost as you would a magazine - you pick it up, use it, put it down again. There is no concentration on technology as being an activity, and this is quite an important distinction. People get very wrapped up like 'We must now go and use the iPad' but it really doesn't work like that. It's just lying around and it's all to do with use. it's an incredible tool for reminiscence."

- One Forum for people with Alzheimer's would identify an 'Issue of the month' that was important to the participants, such as driving; they would then talk about it, write it up onto their webpage and then invite comment. They had a laptop and would take it round to the people and say 'let's play a game', they would "just do general stuff".
- "You have to start from the point of view of 'This is your day, what do you want to do?' You need to listen to them and then look at the web. For example one of my ladies is very fond of dogs, so I listened to her and then went to the web site of a Labrador breeder in Devizes. It's just part of interacting with that person rather than being 'about the technology' - that is too clunky. It should be a seamless part of the day. The focus has to be on 'what you're here for'. Forget about the IT, it's about 'appropriate technology', just another tool. What these things do is just become part of the day, part of what you are trying to do. Is it appropriate to use in my time with this person?
- Focus on individual's interests is usually a good way of getting started with most types of software.
 - For example, one of our interviewees said: We have one lady whose husband was in the Air Force and she was in the WRAF, she is quite difficult to get through to and quite confused, and we used Google images to find pictures of the various WRAF uniforms and went through them until we found the one that she had had, and after that we looked at airbases, we just followed the string through. Or you can use Streetview to find their road, or usually you can find a pub that looks the same more or less as it used to. We managed to find a picture of the lady's husband and his aircrew and showed it to him when he came in, he didn't even know the photo existed. You just follow the thread and it's like holding a picture frame. You can ask someone where they got married, and show them a picture of that, it is instant reminiscence. Before this you could have done this, but you would have had to write it down, go to the library, look it up, and go back to them a week

later you've got it straight there. It is much more immediate...Some of the [day care centre users] have got the idea that you put your finger on the street in Streetview and push it you go down the street, which is really cool plus extremely amusing in the process...You Tube is also very good. We have ex-musicians, cyclists, ex-boxers. For instance one of our men is interested in the Belgian cyclist Eddie Mercks, we found a video of him on YouTube and he just sat watching it for about four minutes. You use it as you would an interesting article in a magazine, it only requires a short attention span.

- Dinah Murray and Ann Aspinall (2006) showed the importance of finding something which interests people and then using the technology as a communication tool to build on that interest. They described the situation of a carer working with a boy with learning difficulties. The carer noticed the boy was interested in T-shirts and so used this to discuss the colours and the picture on the T-shirt (picture of Australia). The carer then introduced the technology as a way to show the boy other T-shirts that could be found on the internet and also provide him with further information on Australia. Although this example is related to a boy with learning difficulties many of the principles can be applied when introducing new technology to people with dementia.
- Note that, while you may be able to do a general introduction to an activity/use of software package with a group, more detailed work may require working one-to-one, which has staffing implications; use of volunteers could be helpful
- it's important not to make assumptions about people's ability to use technology; this will depend on their background as well as the extent of impairment. Even in the late stages of dementia applications can be used for sensory functions such as producing patterns or music. *[give link to free sensory apps/software in resource appendix]*
- the support given should enable the individual to remain in control of the technology – supported not led (eg 'Do you want to press the mouse to change the colour?')
- don't underestimate the importance of being able to give people a print off of what they've done/produced
- it is helpful to have laminated copies of printed instructions on:
 - how to log on
 - the top ten things that can go wrong (and how to fix them)
 - contact telephone numbers for help when things go wrong

- Make sure you use consistent language – either ‘enter’ or ‘return’ but not a mix
- Other resources you may find useful include different sizes of ‘mouse’, equipment with large buttons, large print stickers to put on keys – eg for ‘space’, because the space bar is usually not labelled
- If you want to use portable equipment then you will need to check whether you Wi-Fi access is available throughout the building and/or whether a dongle will work in all locations
- It doesn’t have to be rocket science. Think about all the various activities that people get involved in in care settings. Technology can be used simply to make those same activities easier or more immediate – eg look for photos on the web instead of going to the library to look for a book to bring back to the care organisation.
- There is a need to establish the appropriate safeguards before people with dementia begin to use technology. Care settings need to ensure that people with dementia have a safe space where they can use the technology.

NB When supporting people with dementia to use technology it is important to bear in mind general issues that can affect the individual’s performance such as time of day, amount of time available, how lucid they are, their particular mood on that day; but these are general issues; while they should not be noted in the guide, we should give reference to general guidance on working with/supporting people with dementia.

Remembering the past

Note: Avoid use of word ‘reminiscence’ as this is associated with therapy, for which care assistants would not be trained.

- Literature suggests type of work is better facilitated using ICT
- Consider the range of potential formats/media that are available
 - Photos (digital or scanned), videos, music, text, speech
 - Search and download general material
 - Scan, record and upload personal material
- Technology – the different types of media being used may mean that different types of technology are better for some types of activity/media:
 - Tablets good for accessing information but poor for typing and there can be some problems with linking to printers. Typing problems can be overcome by use of ‘add on’ keyboards

- Keyboards better for text entry - but have their own issues, especially regarding physical dexterity/manual control
- Important to consider issues of contrast, font size, height of the monitor, size of the mouse pointer so that movements can be easily tracked etc., for clarity of presentation
- People will vary in the amount of support required for the different types of activity/media
- Remembering as an activity is good for use with individuals or with groups
 - With individuals, remembering the past can be linked to development of a personal history (see next section)
 - With groups, remembering can be facilitated by interchange of remembrance within the group and lead to searches for old photos and old music, etc. and to singing – YouTube is a good source of music
- If you want to do group activities you may wish to consider investing in a large screen, good speakers and good printers.

Life Story work and scrapbooks

Creating a life story is one of the activities frequently undertaken in conjunction with, or as an outcome of, remembering the past. Scrapbooks and albums are similar products that can be developed using the same approach. The aim is to help people with dementia remember certain events and enable them to provide a tangible legacy for their family and friends.

- Life stories can be for personal viewing only or for sharing with friends and family – or a private and public version can be created. ICT allows for quick amendments to the life stories so that different versions of the final output can be created.
- Life stories can also be used to help an individual express their likes and dislikes
- Many of the points to bear in mind are therefore similar to those that apply in using technology for remembering:
 - Consider the range of potential formats/media that are available
 - Photos (digital or scanned), videos, music, text, speech
 - Vicon sensory camera (straps to the individual and takes photos at preset intervals)

- Search and download general material
- Scan, record and upload personal material
- Note that while commercially-available photos, videos or recordings may be available for personal use, there can be **copyright issues** if the history is made publicly available and you should check this out with the source of the material in question.

Murray and Aspinal (2006) describe how the use of simple PowerPoint presentation equipment can be used to create life stories. They worked with a person with dementia to create a story of her life; her past, her present and her future aspirations. They used graphics and photos and then added colour, animation, voice overs and sound to the presentation. All of these aided her memory when developing and re-visiting the book and provided a better understanding of her personality. Her choice in colours (very bold) gave a greater insight into her character and suggested she was slightly different from the timid persona she outwardly presented. Her choice of voice overs and the fact that she was willing to be recorded also revealed more of her character and the carer was able to use this information to develop a better relationship with her. On the front page she was able to highlight the important aspects of her life and each one was given a hyperlink so that they could be accessed quickly. As her aspirations continued to change, the fact that the life story was based on the computer meant that they could easily amend it at any point.

A number of care homes are also producing talking photobooks for their residents. This is a photo album which tells you the name of the person in the photo, what they are doing in the photo and their relationship to the person with dementia. The voice narrating the photobook tends to either be the person with dementia or a familiar person to them. One interviewee said "This tends to be a good method to help people with dementia with their failing memory. The best way to produce a photobook is by the carer and the person with dementia working together in the early stages of their condition to ascertain all of the relevant information and to record it in the photobook. When the person with dementia then moves into the more advanced stages of the condition then it enables them to remember certain people better. This may take time to set up and do but may be quite beneficial in the long term."

An important point with life history work is to plan ahead so that any activities which are designed to enable the person with dementia to remember certain people and incidents and to leave their legacy are carried out before the condition progresses to a point where this is not possible.

- Technology – the different types of media being used may mean that different types of technology are better for some types of activity/media:
 - Tablets good for accessing information but poor for typing and there can be some problems with linking to printers. Typing problems can be overcome by use of ‘add on’ keyboards
 - Keyboards better for text entry - but have their own issues, especially regarding physical dexterity/manual control
 - Important to consider issues of contrast, font size, etc., for clarity of presentation
 - People will vary in the amount of support required for the different types of activity/media

It can be useful to tie in introductions to the various technologies/opportunities into the production of a lifestory.

Creative activities and hobbies

- A range of creative activities and hobbies can be supported using technology. These include
 - Making music
 - Writing stories
 - Writing poetry
 - Drawing/painting
 - Making things such as cards, menus and calendars
 - Photography and related software such as *Photoshop* [*is there a generic term for this type of software or a non-commercial version?*]
 - *Need to provide link to some software for music and drawing?*
- People’s interests can be readily catered to using the web – you can use the technology to explore and find information and pictures relating to their past work and/or hobbies. This could include
 - Looking for photos of work uniforms, work equipment, trains, buses, airplanes, armed forces, old factory photographs, accounts of work in their areas, find out what’s going on in the industry now

- Looking for photos to do with hobbies: animals (horses, dogs, cats, rabbits etc.) football teams, knitting, sewing and other craft sites, sites for hobbyists/collectors.
- One interviewee said they had found that the touch screen has been good for the motor skills of the residents and they have used it for story painting.
- One care home described how they had used a tablet to show one of their male residents pictures of cars. He had dementia and was known to have aggressive behavioural tendencies; however when he was sat down with a tablet and was allowed to search for pictures of cars his mood became more mellowed and his wife felt more comfortable sitting next to him and looking through the pictures.
- Searching YouTube for music videos to use in singalongs
- In one care home setting they had given the residents a Kindle to read from. The Kindle has many functions which help people with dementia to read more easily than when using traditional books. These include the ability to alter the font size, a light function to brighten the screen and the ability to reopen on the same page you left it when you turn it on again.
- Work has been carried out in Day Centres to enable people with dementia to create a film show using digital cameras. These courses lasted around 8 weeks and were sold to the attendees as a way to learn more about 'digital technology.' This removed some of the negative perceptions that people had around attending a Day Centre as it was seen as more of a way to learn about new technology. Innovations in Dementia have developed a guide to making films with people with dementia and this is available on their website.

Entertainment

- Examples of use of technology for entertainment include:
 - MP3 players
 - Videos and film streaming
 - Games and other apps (eg Raindrops, brain exercises)
 - Sensory games consoles
 - YouTube
 - Social media especially Facebook
- Examples from our interviewees:

- “We use 'loads of CDs' because music and poetry are important with people with dementia.” This interviewee had asked carers to bring in ten favourite tracks for their person with dementia. For each day, he has uploaded those eight people's ten favourite tracks onto an iPod and then he sets it to 'shuffle' so that those people's favourite tracks are played throughout the day. They only hear those tracks (ie whatever is playing is always going to be somebody's favourite). A lot of music - even the obscure stuff - is available on the web nowadays so it's fairly easy to compile. It's a little thing but the important thing is it's a comfort factor, the familiarity of hearing music you remember.
- The same interviewee is very interested in photography, and so he asked 'How can we use that? There is an immediacy to it, and it is very cheap.' They have a small display screen with members' photos on it, they change every few seconds or so and the members are fascinated by the photos they have taken. Also the Centre gets a professional photographer in when they have events etc. in the garden and the members are particularly fascinated when they see photos of themselves involved in various activities they will say 'Oh look there's me'. And because it is so cheap they can afford to do prints which they give to the carers who may be having a difficult time and they can see their loved ones are being taken good care of.
- Currently games are being developed which are suitable for people with dementia. Part of the work that Worcester University is undertaking is to rate the appropriateness of the games for people with dementia. Some games can be found on the website www.memoryappsfordementia.org.uk
- Games must be appropriate for people with dementia ie. they are not too complicated, do not have a long delay between action and event/outcome, the main point of reference for the game is clearly positioned on the screen etc. People with dementia should not be given games which set them up to fail as this will frustrate them further and undermine their self confidence.
- Games can also be used to improve IT skills [more likely to be of use to staff?]
- There are 'Serious Games for healthcare' [eg see for example <http://www.slideshare.net/wths/jos-luis-bayo-montn-serious-games-for-dementia-illness-detection-and-motivation-the-emotiva-experience> but I am not sure if this is a commercial product – Jennifer is trying to find out more]
- Games have also shown to be able to tap into procedural memory. This memory still functions in people with dementia and trials have shown that they can improve their performance in 20 minute sessions on games and still retain that level when they return to the game a week later. This enables people with dementia to continue to learn and provides them with a sense of fulfilment.

- Games can be played by both the carer and the person with dementia which allows both parties to enjoy them together. This can help to improve the relationship between them.
- Games are also available through social media.
- Note that use of social media may not be suitable for all people with dementia, as there is an element of delay between posting information and receiving a response. Staff may need to remind users to return to the site.
- One of our interviewees had started to put apps on the iPad, “These are mainly games. Some people have no interest in them, others lots. So far I have put on Koi pond, Find the coin (it’s mainly men that like this, some of them have fairly marked mental problems but can follow this), Hangman, Celtic harp - it is like the real instrument and we have one client who was a good piano player and we are going to try it with him. Raindrops – this has piano notes programmed in so they get a nice tune too, the BUPA Brainzap - there are different colour shapes to memorise and then select from three you are then shown, chequers/draughts, word search (although we have found that this is too difficult, the letters are too small), tic tac toe [or what we call noughts and crosses] and Hole in the Wall.
- Another said “We begin by using simple games to engage people with the iPad. This can involve IFishpond which is a touch screen game and when you touch the screen it makes a splashing sound. People like doing this and it helps them to become accustomed to the touch screen method. Once this has been done then you can move onto other applications. These apps can then be geared towards people’s interests and hobbies.”

Increasing choice and participation

Technology can be used to increase the choices available for people with dementia. The list of potential activities includes:

- Democratic participation
 - Write to councillors/MPs
 - Research and arrange services
 - Write letters to local newspapers
- Plan shopping trips – get street views of where the shops are, what the shops look like, plan where to go using Google maps to help you find your way

- Plan your holidays – eg one care home involved all residents in planning their holiday, looking at places to visit, stay etc.
- In some care settings people with dementia were encouraged to talk about a topical issue or issues that were important to them, to write up their opinion onto a web page and then encourage other people to comment on it. This was a way of improving communication between the residents and allowing people with dementia to participate more within society from their care home setting.

Shopping

- On line sites can be used to allow individuals more choice over the purchases they make.
- However, there are issues to do with security (giving credit/debit card details) and potentially with repeat purchases for those with deteriorating memories.
- Where access to shopping sites is to be organised it is best to involve the family in this decision
- MORE NEEDED ON SECURITY ISSUES HERE?

Communication

- Technology appears to be most widely used for communication purposes
- Where individuals have family or friends with access to technology then this can be a good way of introducing people to the use of technology
- Research from Worcester University on the introduction of iPads into care settings found that this helped to enhance communication between generations. Young people who were more accustomed with the technology would willingly work with their older relatives to show them the various functions that the iPad could achieve. This improved intergenerational communication and bonding.
- Examples include
 - Skyping
 - Videophone
 - Email
 - Digital cameras
- Skype can be used by people who are profoundly deaf to communicate using sign language

- Research from Worcester University showed that the communication devices could be used to improve daily living activities. They commented that one person with dementia could not remember the name of her favourite food. However they were able to find a picture of it on the internet using the iPad and then make it by following the cooking instructions together.
- WiFi facilities can be used by families when they visit and can provide a new discussion point/shared activity for grandparents and grandchildren
- As with use of technology for other purposes there are some issues to consider:
 - Remembering the numbers of their contacts
 - The number of stages between first thinking of calling and acting may cause problems for people with severe memory problems
 - It is important to consider the relationship between the person with dementia and their relatives. If this is poor then technology to help improve their communication will be pointless and may be detrimental to their well-being and self esteem

Choosing and using technology

- Need correct IT infrastructure within the care setting to allow Wifi access
- Touchscreen technology is easier to use for some activities – but not typing. But add-on keyboards can be obtained. Touchscreens good for drawing, intuitive and tactile. May need extra cables to enable connection to printer.
- Keyboards better for typing/text-based activities and for those with previous typing/computer experience; main issues in use are regarding physical dexterity/manual control
- Portable equipment can be used either in group or one-to-one sessions – providing wifi connection allows this.
- Potential rehabilitative role for touchscreen technology
 - Worcester University research highlighted that the actions of dragging documents (with your finger) from the screen and placing them into a named folder facilitated the process of remembering (*but may be beyond role of care assistant*)
- Individual activity or careworker facilitates use for group work
- If using portable items, consider the weight. They can be made more comfortable for the user by resting them on a cushion on their lap.

- Minimise the amount of clutter on a screen – for instance, avoid having lots of icons on the desktop
- Consider the lighting and avoid glare/reflection off the screen
- Consider individual differences in hand-eye co-ordination and motor skills for using mouse and keyboard
- Support may be needed to help individual associate their actions on keyboard/mouse with those on screen
- Important to consider issues of contrast, font size, etc., for clarity of presentation
- Battery life
 - Who is responsible for putting machine on to charge overnight?
 - Where can it be left to charge securely?
- Ensure clear instructions are available on the keyboard (use labels)
- Use consistent language
- Vicon sensory camera (straps to the individual and takes photos at preset intervals) increasingly being used.
- Need to factor in costs of apps, software, maintenance.
- All technology must be stored securely to avoid it being stolen

Good practice

What is really needed is enthusiasm amongst care workers and time for them to get used to the equipment.

‘Seize the moment’ – everybody can do something. In general,

- Activities should be led by the person with dementia but supported by the carer. It can often be a fine line for carers to tread as they tend not to want to see people with dementia struggle and so leap in to do the activity rather than assist.
- The carer should be accustomed to and confident with the technology
- Focus on the abilities that the user still has and work with them rather than those they have lost
 - Do not set them up to lose – and the same principle applies to the care worker too

- Take into account the user and their functional limits and knowledge
 - What works with one user will not necessarily work with another. An example of this is Big Keyboards. These will be beneficial for people with limited typing skills; however people with dementia who have retained the ability to type will find them very difficult to use. It is important for the carer to match the equipment to the person they are working with. This will help to empower and stretch them without distressing them.
- Take into account the mood of the user
- Always keep the activity fun and engaging. One care home noted that all their activities were visual and involved bright colours to attract and engage people with dementia.
- If people are not interested in new technology then it should not be forced upon them. There is a fine balance between showing people with dementia new technology that may facilitate some of the activities/hobbies they currently enjoy but not forcing it on them if they are reluctant to engage with it.

Group work or one-to-one?

Training should be as personalised/individualised as possible but activities are more feasible in groups.

- Group work has the ability to promote social interaction within the care setting
 - Entertainment methods such as music, film, photographs
 - One care home used a projector screen to show old movies that the residents were interested in. They accompanied this with popcorn during the film and then a discussion post film to promote social interaction. They find it very useful for these activities as it means that they can all sit round in a group and share the experience.
 - Another care home used technology to play Bingo. They found it much simpler to use the computer to run the game rather than the more onerous task of manually setting up all of the equipment
- One-to-one can be tailored towards the individual
 - Better for remembering personal life book/story, but remembering in general can be facilitated/stimulated in groups
 - Good where there are confidentiality issues relating to anything that is discussed

- However, relatively expensive in terms of staff time
- If working in groups, need to have a decent sized screen for viewing
- In organisations where staff feel they are not carrying out 'proper work' when they undertake one-to-one activities then it can be useful to sell the project as something which will produce an outcome such as 'making a calendar or a presentation.' This will mean that carers feel more like they are doing something. It may also be useful to timetable these activities in and give them a time limit.

Monitoring outcomes

- It can be useful to monitor outcomes:
 - To demonstrate quality to CQC (and to potential clients and their families)
 - To prove your investment has been worthwhile (has had some impact)
 - Improve on existing practices/activities that are currently being undertaken using the technology
- How can you do this?
 - You can look at your original aims and find a way to collect information relating to those
 - Or you can think about the general improvements you hoped to bring about when you made the changes.
 - This gives you a choice of types of information you can gather:
 - A simple headcount of people taking part in technology-based activities or sending/receiving emails
 - Interviews with clients and their relatives or friends
 - An activity log to show what activities are being engaged in using the technology
 - A comment board for clients and friends and relatives to post comments about the technology and what they think of it
 - Or an online survey!
 - One care home encourages their carers to write a short summary of the activities they undertook with the person with dementia after each session. They are encouraged to note any positive outcomes of the session

(changes in mood of the person with dementia, the amount of conversation etc) and any improvements that could be made.

Appendix 7: Discussion guide for trialling of draft guidance

1 Introduction

- *Introduce self. Remind them IES is independent and has been contracted by SCIE and that we are working alongside Sara Dunn Associates.*
- *Remind them of the research and its purpose:*

SCIE has asked IES to help them produce guidance to help care homes and carers who wish to use Computers to improve the lives of people with dementia. Before the final guidance is published we want to try it out with people like you to find out whether it's ok, if you think it's useful and likely to be helpful to people and whether any changes need to be made.
- *As you are aware I sent through the guidance (some carers may have been forwarded it from another contact within their organisation) a few days back to give you a chance to have a look at it. So today I'd like to ask you some questions to get your views on the guidance and whether you think any changes need to be made. We are talking to a number of care homes that have experience of either using ICT with their residents or who are potentially looking to use it in the near future.*
- *The discussion is likely to take around 30 minutes, is this ok?*
- *Explain anonymity:*

When we report on this study we will not link any specific findings with individuals or organisations. We will identify any quotations we use according to role of the person (eg line manager). Any names or other identifying details will be removed to protect the anonymity of the interviewee and any individuals discussed.

- *Say we can stop or pause the interview at any time (or skip to another topic) if they feel uncomfortable for any reason*
- *Ask permission to record the interview.*

2 Background

- Can you explain your job title and role within your organisation please?
- *(Only ask to managers)* Can you give me a bit of information about the care home please? How many people do you have in the care home? How many with dementia? Do you have residents with other conditions/learning difficulties?
- Who has responsibility for ICT work *(if work is ongoing)* or who will take on this task *(if looking at using ICT in the future)*?

3 First impressions

- Before we speak about the guidance in detail, we are interested in your reactions to seeing it the first time. Please remember this is a text only version, it will be formatted to look more attractive, boxed quotes and examples in the final publication. What was your initial impression?
- First, what about the amount of information in it, did it immediately strike you as too much, too little, about right?
Probe to establish whether this was just a first impression that changed when they started looking at it in more depth
- Do you think it will be useful to other carers or activities organisers?
- Does it give information on the right sorts of things? Do the activities make sense to you, do they look useful suggestions?
- Was there anything that struck you straight away as not useful/relevant?

General feedback on the guidance

- Does the guidance tell you what you need to know to help you improve or establish the use of ICT within your care home? *If not what needs to change to make it easier?*
- Overall, do you think the guidance is easy to follow? Is it logical in its approach? *If not what needs to change to make it easier to follow?*
- Do you feel that anything is missing from the guidance?

- Are there any other activities you use within the care home that could be included in the guidance? Are these activities specifically for residents with dementia or for those with other conditions?
- Do you feel the pitch or tone of the guidance is appropriate?
- Has the guidance given you any more ideas on how to use ICT within the care home?
- Do you feel more confident in using/setting up ICT within the care home or trying new activities? Are there any barriers which may prevent this?

4 Sections of the guidance

- Do you think all of the sections within the guidance are necessary (is anything not really needed)?
- Are there any other sections you would like to see included within the guidance? What are they? Why do you think that would be useful?
- Do you think the sections work as stand alone sections or would a care home need to receive and read through all of the guidance from start to finish? (If start to finish, ask, 'and do you think that's ok, are they likely to do that, do you think?')

Sections:

Work through each section asking the same questions highlighted below (sections 2 and 3 are given as an example):

Sections 2 and 3

- Looking at sections 2 and 3;
 - Do you think this section is necessary?
 - Does anything need amending?
 - Is there anything in this section that you do not feel would work in practice or needs more explanation or detail?
- For sections 5,6,7 and 8
 - Are these ideas useful to you?
 - Do you think you can do any of these things with your residents/clients?

Case studies

- What do you think of the case studies?
- Are they easy to follow?
- Do the case studies give you enough information? What other information could be given?
- Might you be able to follow a similar approach within your care home?

Value of the guidance and its promotion

- Is there anything that can be done to the guidance to ensure that it has maximum value within your care home?
- Is there anything that can be done to improve the value it has more generally?
- How do we ensure that the guidance has the biggest impact possible? Which channels should we use to promote it?
- At whom should we target the promotion? Managers, carers, Activity Co-ordinators?

Thanks for your valuable in-put. The final version of the guidance will be published at the end of September and I would be happy to send through a link to the documentation once it is available.