
The case for investment in technology to manage the global costs of dementia

Martin Knapp, James Barlow, Adelina Comas-Herrera, Jacqueline Damant, Paul Freddolino, Kate Hamblin, Bo Hu, Klara Lorenz, Margaret Perkins, Amritpal Rehill, Raphael Wittenberg and John Woolham



**PIRU Publication
2016-18**

For further details, please contact:

Martin Knapp

Personal Social Services Research Unit
London School of Economics & Political Science
Houghton Street
London WC2A 2AE
Email: M.Knapp@lse.ac.uk
www.piru.ac.uk

The case for investment in technology to manage the global costs of dementia

Martin Knapp¹, James Barlow², Adelina Comas-Herrera¹,
Jacqueline Damant¹, Paul Freddolino^{1,3}, Kate Hamblin⁴,
Bo Hu¹, Klara Lorenz¹, Margaret Perkins¹, Amritpal Rehill¹,
Raphael Wittenberg¹ and John Woolham⁵

¹ Personal Social Services Research Unit, London School of Economics
and Political Science

² Imperial College Business School, London

³ School of Social Work, Michigan State University

⁴ Oxford Institute of Population Ageing, Oxford University

⁵ Faculty of Health and Life Sciences, Coventry University



Acknowledgment

The research on which this report was based was funded by the Department of Health (DH), in part through its funding of the Policy Innovation Research Unit, with some inputs also coming from the MODEM project funded by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR). All views expressed in this report are those of the authors and are not necessarily those of the DH, ESRC or NIHR. The authors would also like to thank the individuals who kindly agreed to be interviewed as part of this project. We also thank Margaret Dangoor for her help in accessing valuable experiential evidence.



Contents

Executive summary	1
1. Introduction	5
2. Evidence review	9
3. Evidence on matching technology to needs and preferences	18
4. Current state of development of new technologies	34
5. Views of people with dementia and carers	55
6. Lifetime costs of dementia care and potential impact of technology	64
7. Investment and state action	71
8. Conclusions	93
References	98



Executive summary

Worldwide growth in the number of people living with dementia will continue over the coming decades and is already putting pressure on health and care systems, both formal and informal, and on costs, both public and private. One response could be to make greater use of digital and other technologies to try to improve outcomes and contain costs. We were commissioned to examine the economic case for accelerated investment in technology that could, over time, deliver savings on the overall cost of care for people with dementia.

Our short study included a rapid review of international evidence on effectiveness and cost-effectiveness of technology, consideration of the conditions for its successful adoption, and liaison with people from industry, government, academic, third sector and other sectors, and people with dementia and carers. We used modelling analyses to examine the economic case, using the UK as context. We then discussed the roles that state investment or action could play, perhaps to accelerate use of technology so as to deliver both wellbeing and economic benefits.

Evidence review

Our literature review sought studies that evaluated technological interventions in the care and support of people with dementia and their (unpaid) carers. We found 47 papers that met our inclusion criteria (eight of them literature reviews). The quality of the evidence was mixed, but generally not strong.

Few studies found outcomes for people with dementia as a result of using a particular technology, but some reported evidence of increased independence. More studies reported outcomes for carers, often reporting reduced carer distress, burden or mental health morbidity, or better quality of life.

Effectiveness evaluations in this area are complicated by the speed of technological development, the need to tailor technologies to individual circumstances for best outcomes, and because technologies are used alongside other services, making it hard to identify their separate effects.

Matching technology to needs and preferences

We looked for evidence on how well technologies are matched to individual needs, circumstances and preferences. We identified conditions that would be necessary for successful adoption of technology:

- emphasise the need to match technology to need through careful and ongoing assessment;
- conduct user-focused rather than technology-based assessments, integrated within usual assessment processes;
- include carers in those assessments, as they often play key roles in operating devices and can benefit from technology-based support;
- recognise that many people with dementia are dependent on others for many activities of daily living;
- provide up-to-date, independent, understandable information about products and services to inform purchasing and deployment decisions (by all parties);
- be aware of potential ethical issues when technology is used to support people who may have limited capacity to consent;
- introduce people to technology-based possibilities before they reach current eligibility thresholds for local authority support;



-
- provide guidance to help relatives choose telecare technologies that they are purchasing independently.

Current state of development of technologies

We interviewed experts from industry, government, academic and third sectors, and obtained information through various channels from people with dementia and carers. Among other things, we asked them about the current state of development of technologies, and what *potentially* it might achieve.

For someone with MCI or mild dementia, technology is often focussed on supporting people to live independently, helping them address memory problems, be safe and self-manage their health. Technology might also be used to deliver care and can reduce worry for relatives. People with MCI or dementia and carers are increasingly using social media and the internet to understand their needs, share experiences and obtain support.

For someone with moderate/severe dementia living at home, assistive and safety technology could support independence and help maintain skills. There is growing 'therapeutic use' of technology (e.g. tablets or digital music players to support reminiscence).

Technology can deliver interventions to improve the health and wellbeing of carers, and provide 'respite' and reassurance. It can help in coordinating care and support between different unpaid carers, or between those carers and professional staff. More generally it can facilitate social interaction and networking, and might be used to deliver training.

For someone with moderate/severe dementia living in a care home or other congregate care setting, technology could help them retain some degree of independence, or provide therapeutic effects (e.g. through pet robots), or therapeutic 'entertainment and reminiscence' (e.g. through photo albums, music and games). Technology could help them maintain links with their family. Relatives may also get involved in, or at least have a better understanding of, the care provided. Some congregate care settings use mobile technology to facilitate person-centred care, carry out risk assessments and coordinate with other professionals.

New areas of research and development include:

- analytics technologies, including 'stratified medicine' and diagnostic tools designed to identify people at risk or in the early stages of dementia;
- integration of 'digitalised care pathways' of long-term conditions into mainstream care systems to connect information from different agencies;
- gaming technologies, increasingly used to support management of long-term needs and maintain health; also being developed as tools to encourage behaviour change such as medication reminders;
- memory and augmented reality technologies to help carers understand the experiences and needs of people with dementia.

Views of people with dementia and carers

We could not directly interview people with dementia because the study was too short to obtain ethical approval, so we accessed publicly available sources such as blogs written by 'technology-friendly' people with dementia. They mostly used technologies not specific to dementia (e.g. smartphones and computers),



generally with positive experiences. Negative experiences included the challenge of remembering passwords or the purpose of specific alarms.

Carers involved in another of our projects reported mostly using technology not specific to caring or to dementia (e.g. tablets, baby monitors, smartphones, light sensors, 'speaker pillows'). The greatest barrier to technology use was difficulty obtaining advice and support.

Economic modelling

The lifetime costs of dementia care in old age in England average £200,000 per person from point of diagnosis to end of life (which averages 4.5 years); this includes health care, publicly and self-funded social care and unpaid care by family and friends.

Our ability to explore the economic case for technologies was heavily constrained by the availability of evidence. We examined the impact of technology on lifetime costs through three scenarios, each considering the impact on carers.

Scenario 1 modelled a situation where assistive and safety technologies postponed care home admission by 8 months. Health and social care costs over 4.5 years were reduced by £13,000. If the cost of a technological intervention – plus assessment and care services accompanying the technology – is less than £13,000 over the same period, then there would be cost savings from a health and social care perspective. But we estimate there would be higher unpaid care costs of £21,000 if daily hours of unpaid care remain unchanged, so the intervention would not be cost-saving from a societal perspective. If the intervention not only postponed care home admission but also improved wellbeing, then it could still be cost-effective if the outcomes were held to justify any higher cost.

Scenario 2 built on an evaluation of a computerised platform to minimise carer burden and stress by converting findings about carer quality of life improvements into monetary values by reference to NICE thresholds for cost-effectiveness. From a societal perspective, the technology would be cost-effective if its cost (plus assessment and any accompanying care services) was less than £3,000 or £4,500 (depending on threshold value used) over 4.5 years. There would be no reduction in formal service costs and so no cashable savings. To achieve cost-effectiveness from both health and social care and societal perspectives, there would need to be not only quality of life improvements but also delays in care home admission and/or reduction in unpaid care hours.

Scenario 3 examined how much benefit, relative to costs, a technology would need to generate to be cost-effective if its cost (along with the accompanying assessment and services) was £5,000 over 4.5 years. The technology would be cost-effective from a health and social care perspective if it postponed care home admission by at least three months, and cost-effective from a societal perspective if it either reduced unpaid care hours by about 8% or improved carer quality of life by 0.06 to 0.08 QALYs per year.

Barriers to wider use of technology

Digital and other technologies are not yet playing major roles in dementia care and support. We did not find evidence of 'market failure' on the supply side. But there are numerous other barriers to the use of technologies by people with dementia and carers:

- under-developed technologies
- a weak evidence base



-
- price or cost
 - design
 - trust and preferences
 - limited awareness of people with dementia and carer
 - the need for individualisation
 - commissioning
 - societal attitudes
 - staff skills, awareness and attitudes.

State action

Each of these barriers has implications for action by public sector bodies. Such action could take many forms:

- to encourage technology industries to see the 'dementia market' as an attractive prospect;
- to be alert to any barriers to future market entry that would limit choice for purchasers;
- to support generation of reliable evidence on technologies;
- to help make that evidence widely available and in a form understandable to all potential purchasers, including people with dementia and their carers;
- to encourage commissioners to be aware of what technologies can achieve in dementia care;
- to encourage commissioners across different systems to overcome boundary-related disincentives;
- to encourage greater attention to how carers can use technology, with potential benefits both for them and the people they support;
- to support efforts to help the market reach a size where economies of scale can be realised, bringing down prices for public and private purchasers;
- to improve broadband coverage across the country;
- to support efforts to help older people gain technological literacy;
- to encourage involvement of people with dementia and carers in development of new technologies;
- to require that technologies purchased publicly meet certain standards of design;
- to take actions to allay (well-founded) fears held by many older people about identity theft, fraud and other cyber-crime;
- to recognise the high value that many people with dementia and their carers place on face-to-face service contacts, so that technologies that seek to reduce these contacts are unlikely to be accepted or used (or, if they are, could exacerbate problems associated with social isolation and loneliness)
- to note that cashable savings are more likely to be achieved if admission to a care home or other congregate setting can be delayed;
- to ensure that assessments are person-centred and integrated rather than technology-dominated and separate;
- to encourage development of personalised technologies that respond to individual needs, circumstances and preferences;
- to continue to raise awareness of dementia and change social attitudes;
- to improve awareness, attitudes and skills of key health and social care professionals in relation to digital and other technologies through training, qualification requirements and continuing professional education.



1. Introduction **Context**

The expected worldwide growth in the number of people living with dementia over the next few decades has focused attention on three areas: how to prevent or reduce the risk of dementia, how to cure it when it emerges, and how to improve care and support when prevention and cure are not possible. While research continues apace to find preventive solutions and cures, the current emphasis in every health and care system across the world is inevitably on how to use available resources to improve care and support systems so as in turn to improve the lives of people with dementia and their carers.

Against this background, the Department of Health (DH) in England commissioned a scoping study from the Policy Innovation Research Unit (PIRU) 'to undertake a cost-benefit analysis, to consider the hypothesis that accelerated investment in technology could, over a series of different timeframes, deliver savings on the overall cost of care [for people with dementia]. The focus of this work is on interventions along the care pathway – and not on clinical research and development.' It was expected that the work would generate 'a robust estimate of the quantifiable savings across different time periods – short (three years), medium (five years) and longer term (10 years +) and how the cost-benefit case, timescale for returns, and case for capital investment may differ for different types of technology and at different parts of the care pathway.' The DH was 'keen to look at how to better use and exploit the technology which is already available to drive savings, but also look at how to stimulate new innovations in the future.' ... 'At the same time, the study must also consider the impact on the quality of care and overall outcomes for those people living with dementia and their carers. Through any intervention the quality of care must improve, or at least remain constant.'

Study aims

In response to this call, a team coordinated through PIRU and led by Martin Knapp at the London School of Economics and Political Science (LSE), agreed to conduct a four-month study with the following seven aims:

1. To conduct a very rapid review of the evidence on the effectiveness and cost-effectiveness of digital and other technology in health and social care.
2. To conduct a rapid review of digital technology, robotics and other technology (as relevant) in the care and support of people with dementia and/or their unpaid family and other carers. This review will seek to describe developments to date, and any evidence on effectiveness and cost-effectiveness.
3. To review the necessary conditions for successful adoption of digital and other technology, including the quality of the assessment that enables proper matching of technology-based services with needs and preferences. The focus will be on technology that is already available or likely to be available in the near future.
4. To liaise with industry, government, academic, third sector and other experts (in the UK and elsewhere) to understand the current state of development of new technologies for care and support in dementia, and the possible new technologies that could become available very soon.
5. To engage with people with dementia, carers and their representatives, in order to understand their views on the use of digital, robotic and other technologies in dementia care and support.
6. To use the evidence drawn from the review and consultation to examine the economic case in the UK (over different time frames) for the use of digital, robotic and other technologies in the care and support of people with dementia and/or their carers.



7. To get an understanding of the type of investment required to develop technologies in this field, and for what types of technology. This would include examination of the role that state investment could play, and whether it could act as an effective accelerator to development of the technology and delivery of subsequent economic benefits.

Terminology

There are, of course, a great many ‘technologies’ currently or potentially available to support individuals with health or care needs in their own home or in a care home, and/or to support their unpaid carers. We will describe those technologies later in our report. Those technologies have a range of purposes:

- Some are designed to reduce risk of adverse events, such as safety and security monitoring, such as to detect when someone has left the gas on or the door unlocked.
- Some are for the purposes of monitoring the individuals themselves such as their vital signs, or whether they have had a fall.
- Some are physical assistive technologies that aid mobility or control the environment.
- Some use information and communication technology to provide customised information and advice, or support with medication or self-care.
- Some support the ability of people to live independently, through reminders of medication and daily tasks, voice or visual cues.

Those technologies also vary in terms of their complexity (both technical and human – who needs to be involved?), their target populations and conditions (needs), and their costs. When thinking about the resources required, it is important to remember that most technology-based interventions cannot be thought of solely in terms of the physical devices that are deployed; most of them also need organisational and service delivery support underpinned by the interactive and non-interactive transmission of digital data.

There is also great variety in the terminology employed:

The terminology for this set of applications is wide and rather woolly, and includes at least the following terms: telecare, telehealth, telemonitoring, home monitoring, telemedicine, assistive technology, and smart homes. These and other terms have tended to be used interchangeably to describe the remote delivery of health and social care to people outside conventional care settings (Barlow and Knapp 2014).

We do not intend to get bogged down in discussion about terminology. We employ here a set of terms that are now quite widely accepted, and again we draw on the earlier discussion paper by Barlow and Knapp (2014):

It is useful to make a distinction between ‘telemedicine’ and telehealth/telecare, which for convenience can be grouped under the general label of ‘remote care’:

- **Telemedicine** is essentially a ‘B2B’ (‘business-to-business’) application, i.e. in this context doctor—doctor/nurse; the patient may be present but the interaction is primarily professional-professional for purposes of diagnosis or triage. An example would be video conferencing in remote areas between a local nurse and distantly located doctor. The focus is essentially clinical, often addressing a single issue (such as ‘teledermatology’ or ‘telepsychiatry’). This is therefore inherently a simpler intervention to deploy and evaluate than



‘remote care’ (see below), and there are many more research publications about telemedicine applications than about remote care.

- **Remote care** is a ‘B2C’ (‘business-to-consumer’) application, i.e. care professional to end-user. It can be both clinical and non-clinical in focus, and this is usually (although not consistently) reflected in terminology: telehealth is health-focused and telecare is social care-focused. Remote care is much more complex to deploy than telemedicine: there are usually more and different types of setting and user, many organisations involved, and multiple objectives.

We shall be more focused on telecare than telehealth in this report, but we do need to emphasise that terminology is not consistent across health and care systems or across the research literature.

Limitations

There are limitations to what we have been able to achieve in four months. Our review of the international evidence on the use of digital and other technology in the health and social care fields has been rapid, and we have given most attention to the evidence in the dementia field, while ensuring that lessons have been learned from other areas. Our evidence reviewing was, of course, spanning many topics and fed into our work in pursuit of many aims, including: existence and deployment of technologies; effectiveness and cost-effectiveness; needs, preferences, assessment and matching; views of people with dementia and carers; economic modelling; and options for investing public resources to bring about improvements.

Another limitation on our work was that we could not collect primary data from people with dementia or carers, as this would have required ethical approval which can take many months. Nevertheless, we were able to access the views of people with dementia and carers through some of our other research (such as MODEM www.modem-dementia.org.uk), as well as from blogs and similar accounts in the public domain. Indeed, at a number of points in this study, we have benefitted from our ongoing work in the MODEM project (funded by ESRC and NIHR).

As will become clear later in the report, there is very little available evidence on effectiveness or cost-effectiveness of technologies in supporting either people living with dementia or their carers. This has put limitations on what it has been possible for us to explore in the economic analyses. We have, however, been able to further develop PSSRU’s dementia lifetime costs model to examine a number of economic questions pertinent to the study aims.

Structure of the report

The report is structured around the aims agreed with the DH. Our work in pursuit of the first and second aims – reviewing the available evidence – is conflated into section 2. We sought to cover all relevant technologies in the academic, policy, industry, third sector and other literature. In section 3 we then turn to the question of how technologies are matched to the needs and preferences of individuals – the conditions for successful adoption – for example, through better assessment and consultation and the consequences for outcomes and costs. Evidence to address this aim comes from previous studies and documents, and from interviews with a range of experts.



In section 4 we describe the current state of development of new technologies for care and support in the dementia field, based on our reviews and consultation with experts from industry, government, academic and elsewhere. Section 5 reports the views of some people with dementia, carers and representatives about the roles of digital, robotic and other technologies. We then turn to economic modelling of the lifetime costs of dementia, employing the evidence reported earlier to adapt the PSSRU dementia lifetime costs model; our analyses in section 6 are limited by the paucity of extant effectiveness as well as economic evidence. In section 7, we then consider the type of investment – action by the state – required to develop and deliver technologies in this field with the longer-term aim of achieving either savings or cost-effectiveness gains. This discussion builds on other material in the report, and includes information from interviews with a range of experts in the ICT field. We end with a brief concluding section that pulls together the main findings from the study.



2. Evidence review

Methods

A rapid literature review using a systematic approach was conducted to identify studies evaluating technological interventions for the use and care of people with dementia, unpaid and paid carers as well as clinicians. We covered the period from January 2000 to July 2015. The search terms employed were: dementia, Alzheimer, cognitive, impairment, care*, health, social tech*, robot*, tele*, ICT, app*, cost*, effectiveness, benefit. These search terms were developed into three research strings (see figure 1).

Articles included in this review are evaluations and economic evaluations of technological interventions which we have then organised using a typology consisting of five categories (defined and illustrated later):

- information and communication technology
- assistive technologies
- telecare and telehealth
- therapeutic technology
- and other

The typology was developed from a report by Stephanie Carretero (2015) and from categories used by AT Dementia (2015), and is in line with the definition quoted from Barlow and Knapp (2014) in section 1.

Detailed information on our typology can be found below. Relevant literature reviews were hand-searched and articles from these searches that met our inclusion criteria were added to the review. We have also included articles that were brought to our attention by members of the team or interviewees. We excluded literature that did not report the use of digital or other technology in health and social care for elderly people with dementia or cognitive impairment.

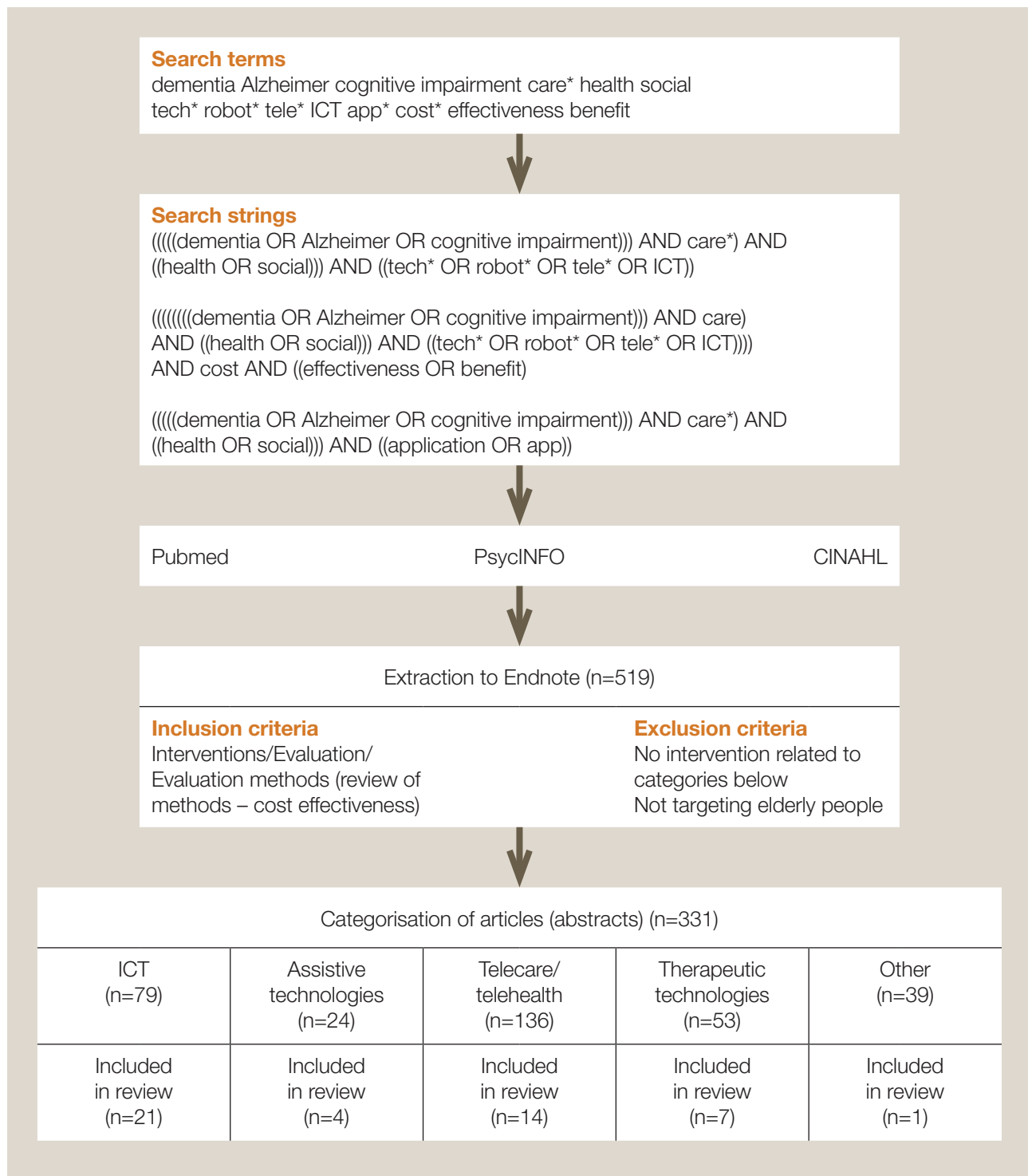
The search was conducted using three databases: Pubmed, PsycINFO and CINAHL. Initial results were selected by title according to the above inclusion and exclusion criteria. In total, 515 articles were extracted to Endnote. At the next step the article abstracts were evaluated. In total, 331 articles fitted inclusion and exclusion criteria applied to the abstracts. The review focused on studies reporting effectiveness, using randomized controlled trials, other robust designs or systematic reviews, and/or economic evaluations. After excluding the articles that were not reporting outcomes and only described technologies, 47 articles were included in the review and key information was extracted systematically from them. We also identified eight literature reviews.

Of the studies included, 28 focused on unpaid carers. Most of these studies were in the *information and communication technology* category, followed by studies in the *telecare/telehealth* category. Twenty-two studies focused on interventions targeting people with dementia directly. Most studies targeting people with dementia can be found in the category *telecare/telehealth*. Five studies in this review focused on paid carers or other professional staff; they can be found in the categories *information and communication technology* and *telecare/telehealth*. Four studies targeted clinicians. Some studies had multiple target groups (e.g. the person with dementia and unpaid carer dyad).

There are important variations in the robustness of the methods used, particularly with regard to the economic evaluations. The number of economic evaluations that we could find from this search was rather limited, but we are confident that our review provides a good overview of those economic evaluations that have been published.



Figure 1 Overview of the search strategy





Technology typology

We used the typology of five categories listed above, but there is of course substantial overlap between these categories. Moreover, as noted earlier, there is great variation in the way different authors categorise technologies.

Information and communication technology offers the possibility to communicate over distance using mobile phones or Internet applications. This can enable people to maintain their social network and personal interests despite limited ability to leave their home. It further allows people to participate in educational distance programmes, to obtain information and for unpaid carers to maintain their employment or other commitments (Carretero 2015 p19). To better reflect this diversity we distinguished two sub-groups for this category. One sub-group is *mainstream information and communication technology*. Interventions falling under this sub-category are communication devices (intercoms, telephones, other aids to communication), teleworking services, information and training platforms, social networking technologies, online service and dementia management tools for carers). The other sub-category is *mCare/mHealth*: it includes interventions on smartphone or tablet devices, such as mobile communication, apps, or prompts and reminders on the phone.

Assistive technologies cover technical devices with a digital or ICT component, such as digital memory aids or automated medication dispensers (Riikkonen et al. 2010, Bharucha et al. 2009).

The category **telecare and telehealth** covers a range of interventions such as interventions for the delivery of health and care from a distance, and the monitoring of a care recipient using technology or assistive robots (Carretero 2015, Barlow and Knapp 2014). To reflect the diversity of interventions falling under this category we further classified telecare and telehealth into sub-categories:

- Interventions focusing on the provision of **health care** include interventions falling under the telehealth umbrella.
- **Home care** includes interventions enabling the carer to provide better social care in the home.
- **Smart homes** cover interventions such as remote-controlled home automation systems (doors, gates, microwaves, stoves, lighting, on/off switch of appliances and home entertainment) (Allen et al. 1995, cited in Carretero 2015).
- **Assistive robots** are robots supposed to support people with dementia in their ability to carry out tasks and remain independent.
- **Safety and security** interventions focus specifically on the monitoring of a person with dementia and the possibility of setting off an alarm in the case of emergency (alarm and pager units, fall detectors, flood detectors, water temperature monitors, lighting), or they can be directed at the person with dementia to secure their wellbeing (activity monitors, wandering/safer walking technologies, telemonitoring). Smart homes, on the other hand, focus on the functioning of devices around the house, such as door sensors or 'remote-controlled home automation systems' (Carretero 2015 p20).

The fourth category identified comprises **technology-based wellness services/therapeutic technologies**; these include 'services for a healthier lifestyle of older people at home' (Carretero 2015 p21). Interventions and devices collected under this category are intended to contribute to the cognitive and physical fitness, entertainment, leisure and wellbeing of the person with dementia or their carers. Due to the number of articles focusing on *pet robots*, we established this as an additional sub-category.



We also used a category '**other**' for interventions and technologies that do not fall under one of the other categories described, but are considered relevant in the context of technology and dementia care.

Mapping the technologies onto the dementia pathway

While understanding the type of technology and the methods employed helps us map the coverage of the different types of technology, in order to move beyond the 'technical' characteristics and to focus on the role of technology in the dementia pathway, we attempted also to map the literature onto a framework that captures the different phases of dementia severity, who is potentially being helped by the technology, and the care setting in which the technology can be used.

This mapping is detailed in table 1 which maps the literature onto this framework; it appears in section 4 of this report as we will use other material to feed into it. As we describe there, we have divided dementia into stages (prior to the onset of dementia (or MCI), mild or early dementia, and moderate-to-severe dementia). The literature was further split into studies of individuals living in their own homes, and studies in formal care settings (e.g. day centres, care homes and hospitals). Thirdly, we distinguish between three groups of technology users: people with dementia, unpaid carers, and paid care professionals or clinicians.

We also identified six **functions** to provide a better overview of the purpose of the different technologies identified in the literature. We also included an 'other' option to be inclusive of interventions falling outside the scope of the identified functions. The functions are:

1. Memory and support of self-care and activities of daily living
2. Treatment and intervention delivery
3. Safety, security, monitoring and reassurance
4. Training
5. Care management and coordination
6. Social interaction and engagement
7. Other

Before people develop dementia: healthy or at-risk populations

While the search strategy employed for this literature review did not specifically target preventive or risk-modification measures, the search identified one study (Boot et al. 2013) comparing the effectiveness of cognitive training between an action videogame, a brain fitness game and no intervention, for people who were described as 'still cognitively intact'. This study did not find that engagement with the games led to improved cognition.

It is possible that some technologies, such as health apps on smartphones, may have a positive impact in modifying some of the known risks for dementia (for example, by encouraging people to be more physically active, or by offering tools to manage better some chronic conditions associated with dementia, such as diabetes). However, in order to assess the effectiveness of technologies to modify the risk of developing dementia, a more specific search would need to be undertaken than was possible in this short study. There are many apps and games available claiming to improve cognition and to protect against dementia.



Mild cognitive impairment (MCI) and ‘early-stage’ dementia

All studies identified to target people with dementia or their carers with MCI or in the ‘early stages’ of dementia focus on the individual’s home environment. One study by Pot et al. (2012) conducted in the Netherlands evaluated the impact of a GPS and communication device on people’s ability to go outside independently. The intervention targeted both the person with dementia and the unpaid carer. The device enables the carer to monitor the whereabouts of the person with dementia, but also both the unpaid carer and the person with dementia can use the communication tool to interact with each other. People with dementia reported that the device enabled them to leave the house independently, providing them with more personal freedom. Carers also showed positive outcomes by experiencing less worry. However, their feelings of role-overload did not change (Pot et al. 2012).

We identified three studies evaluating the *delivery of interventions* to the person with dementia and one intervention to the unpaid carer. One study targeting people with dementia evaluated the delivery of a memory clinic for the Choctaw Nation in the United States using videoconferencing (Weiner et al. 2011). This evaluation has some limitations, but the main barrier to access was problems with transport to the videoconference site (Weiner et al. 2011). A second study evaluated the delivery of cognitive training using computers, tablets and videogames (Tedim Cruz et al. 2014), and a third considered the usability of art therapy delivered with the help of artificial intelligence (ePad) (Leuty et al. 2013).

The study by Tedim Cruz and colleagues (2014) focused mostly on uptake and usage of a cognitive stimulation intervention. In comparison to groups with other conditions it was found that people with dementia spent the longest time training. Furthermore, best results in terms of training were gained by the group participating in face-to-face sessions.

We also found an example of the delivery of an intervention for unpaid carers, using an online videoconferencing system to conduct a psychotherapeutic support group (Marziali and Garcia 2011).

Moderate-to-severe dementia

The majority of technological evaluations in the literature target people with moderate-to-severe dementia and/or their carers. Most of the evaluations of dementia-specific technological interventions target people receiving and providing care in their own homes.

Use of technology at home

One Finnish study (Riikonen et al. 2010) evaluated the use of a number of assistive devices developed to support memory, *ability to self-care and to live independently*. The devices evaluated include memory aids, medication dispensers and easy-to-use desk phones. The study also evaluated other devices and will be referred to below. Another study assessed the usability of a dementia tablet with date diary and game functions. The evaluation reported the amount of interaction time as well as some carer feedback. Carers provided generally positive feedback, although it was highlighted that users had to learn to handle the system and clients reported concern about electricity costs and users being afraid of breaking the system (Nijhof et al. 2013). A very small study, with only six participants, examined the use of a computerized device (COACH) providing audio and audio-video prompts to lead a person with dementia through the process of handwashing. The authors report an improvement in the ability to independently perform handwashing among people with moderate dementia (Mihailidis et al. 2008).



Seven studies were identified that evaluated the *delivery of an intervention* using technology to the unpaid carer of someone with dementia. The interventions aimed to improve the unpaid carers' health and wellbeing through the delivery of psychotherapeutic support groups, telecoaching, cognitive behavioural therapy or stress management (Van Mierlo et al. 2012, Marziali and Garcia 2011, Marziali and Donahue 2006, Nichols et al. 2011, Gallagher-Thompson et al. 2010, Kajiyama et al. 2013). All studies reported some positive outcomes in terms of either competence (Van Mierlo et al. 2012), self-efficacy (Marziali and Garcia 2011), burden and depression (Nichols et al. 2011) or stress (Kajiyama et al. 2013, Gallagher-Thompson et al. 2010, Marziali and Donahue 2005). Two evaluations focused on a telephone-based carer education and training programme (Wray et al. 2010, Finkel et al. 2007). The study by Wray and colleagues found a short-term effect on costs, although the control group receiving care as usual also showed a reduction in costs associated with outpatient services. The study by Finkel and colleagues found reduced burden and depression among carers participating in the trial using the Computer-Telephone Integration System (CTIS).

One intervention targeted paid carers, clinicians and people with dementia by assessing the cost-effectiveness of delivering video-conferencing memory clinics in rural Australia. The study reports cost-effectiveness if clinicians would have to travel more than two hours to reach the place of the memory clinic (Comans et al. 2013).

Technologies to provide *safety, security, monitoring and reassurance* tend to target both people with dementia and their unpaid carers. Examples of evaluated assistive technologies directly supporting the person with dementia are cooker alarms, smoke detectors, fall detector alarms, locator systems and motion sensitive lights. Evaluation of these devices found that they can contribute towards a delay in care home admission and may enable people with dementia to stay in their homes longer. This evaluation also reported that passive devices that do not require programming or interaction were particularly well rated by users (Riikonen et al. 2010). Another study evaluating commercially available sensors reports that both people with dementia and their carers felt safer and more secure with the system in place (Nijhof et al. 2013b). Pilotto and colleagues (2011) tested the perceived usefulness of a hypothetical ICT-based intervention by showing a video to unpaid carers in three different countries. Carers noted the potential usefulness of the system, although there was a difference in perception of usefulness by age groups, with carers aged 50 years and older being more optimistic about the usefulness of the system than those aged under 50. An evaluation of a night-time monitoring system tracking care recipients' movements and giving alerts found that unpaid carers reported having better quality of sleep, even if devices used to track their sleep found no significant results (Rowe et al. 2010).

Technological interventions to *support carers and the delivery and management of care* target both unpaid and paid carers for people with moderate-to-severe dementia. We found six studies that evaluated interventions aiming to support carers in their caring role by providing them with access to therapists, professional carers or support groups using videoconferencing (Lundberg 2014; O'Connell et al. 2014), email or text messaging (Chiu et al. 2009), or offering web-based platforms providing information, or a combination of these (Torkamani et al. 2014). These studies showed that users of video-conferencing interventions appreciated the possibility of social interaction and enjoyed interaction with people in similar situations (O'Connell et al. 2014), and that they felt more aware about their rights in accessing services provided by the municipality (Lundberg 2014). Evaluation of the email or text message intervention showed that younger participants were more likely to engage with the



intervention; furthermore, participants used out of office times, such as early morning, late evenings and weekends to engage with the service (Chiu et al. 2009). The online platform was found to improve carers' quality of life (Torkamani et al. 2014). One study conducted in the Netherlands provided unpaid carers with customized e-advice on health and social support services: carers in the intervention group reported greater needs, and it was hypothesized that the system may increase carers' ability to recognize their needs (Van-Mierlo et al. 2015).

The PAL-4 system, offering videoconferencing and 'organiser functions' (Nijhof et al. 2013), and the Telehealth Education Programme evaluated by Wray and colleagues (2010) – both already referred to above – also have functions that support social interaction.

There are also interventions with a specific focus on the provision of support for carers dealing with challenging behaviour, such as an interactive voice response programme aiming to disrupt challenging behaviour through 'distraction calls' to the person with dementia. However, this was not found to have a significant effect (Mahoney et al. 2003).

Other interventions targeting people with moderate to severe dementia involve 'therapeutic' entertainment, as they target the wellbeing of the person with dementia. An example is a study evaluating the use of an MP3 player with individualized musical content: family carers showed decreased psychological distress and reported a 'respite' effect as a result of the person with dementia requiring 'less vigilance' (Lewis et al. 2015).

Use of technology in formal care settings

A number of studies found in our literature review evaluated the use of technological interventions in care homes (or other formal settings). Two interventions aimed to support *independence of daily tasks* for people with dementia. These focused on verbal, pictorial cues as well as light probes to direct participants towards their destination (Lancioni et al. 2012; Lancioni et al. 2013). Both trial studies showed an increase in the number of correct steps taken by participants.

Another study tested the usability of an anti-collision power wheelchair to provide people with dementia unable to walk by themselves with greater independence. Seven residents of a nursing home tested the wheelchair fitted with a sensor skirt. Several difficulties were observed due to the cognitive impairment of the participants, such as ensuring the safety of others, the need for support with use, and difficulties with the wheelchair when there were height differences in the floor (Wang et al. 2011).

Other interventions focused on targeting challenging behaviour or to increase interaction. Two studies evaluated the therapeutic seal robot Paro (Wada et al. 2005; Moyle et al. 2013). Wada et al. (2013) found improved EEG outcome among participants after having engaged with the robot. Moyle and colleagues (2013) also report positive outcomes, such as increased quality of life, reduced anxiety but also reported an increase in wandering. A meta-analysis evaluating Simulation Presence Therapy through the use of audio and videotape found a significant positive effect in reducing challenging behaviour (Zetteler 2008).

Two interventions specifically targeted members of staff in care homes. One intervention introduced a mobile phone app in two care homes that allowed staff to add comments to residents' notes on the phone. This led to an increase in note-taking, but also led to a situation where staff were expected to be up to date



regarding the current situation before the beginning of a shift (Pitts et al. 2015). The other intervention used ‘talking mats’ to enable conversation between care staff and people with dementia. The study showed that the use of talking mats enables people with moderate dementia to perform better in conversations (Murphy et al. 2010).

Another evaluation also focused on *social interaction*, specifically interaction between a person with dementia in a care home and their distant relatives. The Giraff telepresence robot is a device through which the person with dementia and their relatives can communicate using the tools of videoconferencing. Additionally, the Giraff can be moved around remotely by the distant relative, enabling them to see the environment in which the person with dementia is situated (Moyle et al. 2014).

Quality of evidence

It is important to note that most of the evaluations in this review are based on very small samples, and most have been conducted in an experimental fashion or environment (such as laboratory), which makes it difficult to infer the applicability of their findings to everyday situations. They would often have been conducted with carefully selected individuals, particularly those with more positive attitudes to the use of technology. Furthermore, studies have been conducted in different countries, and therefore in contexts that might reflect different cultural values, which may influence the study results or their interpretation.

Most of the studies are ‘before-and-after’ comparisons (before introduction of the technology, and some period after or during its use), and very few have control groups of people who do not get offered the technology. This makes it difficult to ascertain the degree to which any changes observed are due to the intervention (the technology); they could be due to other factors, including naturally occurring trends over time. Also, very few studies employ measures or report outcomes that are commonly used in the well-established clinical, health services or social care literatures on dementia, making it difficult to judge the effectiveness of these technological interventions in the context of other types of interventions (such as non-pharmacological interventions, medications, or carer support programmes). It also made it harder for us to be able to convert some of these outcome findings into resource and cost implications (see section 6 below).

There are studies in which a longer-standing or ‘standard’ intervention (such as a psychological therapy) is delivered using technology, but that do not test the technology as such. A good example is REACH (Resources for Enhancing Alzheimer’s Caregiver Health) in the United States (Mahoney et al. 2003). These tend to be of better quality, in general, than studies that focus on the evaluation of technology.

The few studies that include an economic evaluation highlight the difficulty of costing technological interventions appropriately (see Henderson et al. 2013 for discussion of these costing difficulties in the context of the WSD study).

In summary, the literature we have found mostly reports on technological interventions that target people with dementia and/or their unpaid carers. Notwithstanding the comments we have just made about research quality, there is some tentatively encouraging evidence. Technological interventions that enable unpaid carers to access information and exchange have resulted in overall positive outcomes. In terms of supportive devices to improve care recipients’ independence, self-care and



security, the evaluation of the GPS tracking device resulted in positive user feedback. This finding is in line with the finding that users find passive devices (cooker alarms, smoke detectors, etc.) to be most useful.

Literature reviews

Our search also identified eight previous literature reviews. Of those, two focus directly on the person with dementia. Büttner and Bürgener (2010) systematically reviewed the literature for technology advances in dementia care for people with mild cognitive impairment or early-stage Alzheimer's disease in the community. The systematic review and meta-analysis conducted by Zetteler (2008) focused on the 'effectiveness of simulated presence therapy' for people with dementia, analysing four studies, concluding that the suitability of people participating in simulated presence therapy may be important as findings only 'provide limited support' for the intervention (Zetteler 2008 p779).

Three reviews focus on unpaid carers. One looks at consumer health information technologies using mobile applications and internet-based approaches (Dyer et al. 2012), another reviews technology-based support groups (Lee 2015) and the third looks at technology-based cognitive behavioural therapy (CBT) for unpaid carers (Scott et al. 2015). Two other reviews focus on specific technologies: Bharucha and colleagues (2009) reviewed intelligent assistive technologies while Bemelmans et al. (2013) consider socially assistive robots. The seventh study reviewed the effectiveness of non-pharmacological interventions in preventing wandering. These included technology-based interventions (Robinson et al. 2006).

The authors from all but one review highlight the limited availability of evaluation evidence, the small sample sizes in those studies that have been conducted, and the fact that the majority of studies are of descriptive nature. These characteristics all limit the conclusions that can be drawn. Furthermore, these reviewers also concluded that the methodological rigour of studies remains limited, pointing towards the need for better research on the effectiveness of interventions (Bharucha et al. 2009, Bemelmans et al. 2013, Scott et al. 2015, Zetteler 2008, Dyer et al. 2012, Robinson et al. 2006, Büttner and Bürgener 2010). Additionally, Bharucha et al. (2009) argue that there is a need to consider the ethical implications of some technologies and to ensure that development of devices and applications does not forget to put users at the centre, making sure that the technologies are meaningful to them. (We come back to this question of ethics in section 3.) They also note that quality of life has many different aspects that need to be taken into account, and that improving an individual's functioning might not be enough. Nevertheless, the authors of these reviews conclude that early results have been broadly positive, and technological advances in dementia care may contribute to the wellbeing of people with dementia and their carers, as well as to a reduction in care costs (Büttner and Bürgener 2010, Lee 2015).



3. Evidence on matching technology to needs and preferences

Introduction

There is evidence from the Whole System Demonstrator (WSD) trial (discussed below) and other sources, that better matching of technology-based services to the needs, circumstances and preferences of individuals will increase the likelihood that the services will be seen as acceptable and hence used and potentially effective. Our evidence review therefore also considered what is known about how needs assessment and consultation can affect outcomes and costs, mindful of the considerable variation between localities in the nature and quality of assessment. In this way we will be trying to get a better understanding of (as noted in the scope) ‘the necessary conditions for successful adoption and any identified barriers.’

Telecare is now a key type of adult social care provision, with many adult social care departments (ASCDs) seeing it as a way to respond to the twin pressures of funding cuts and demographic pressure. It is now used as a ‘gateway’ service (the first kind of support offered to people with social care needs) in many ASCDs, and in some, there has been considerable local investment.

Early evaluations of telecare for people with dementia suggested that it could both prolong independent living by managing certain kinds of risk effectively, and save money by enabling people to retain optimal levels of independence, delaying admission into residential or nursing care and preventing unnecessary hospitalisation. These outcomes were also consistent with broader, value-based public sector reform initiatives designed to delay or prevent dependency, and promote independence, choice, and wellbeing.

These early studies were mostly based on project evaluations, usually small scale, and used research designs that meant the potential for generalisation was limited. Nonetheless, they contributed to the decision by the Department of Health (DH) to publish the ‘Building Telecare in England’ guidance (DH 2005). The subsequent Preventative Technologies Grant also set out guidelines for the infrastructure needed by local authorities to implement telecare services successfully, including training, equipment, 24-hour contact and response services, joined up working between different sectors, information and advice for service users, carers and professionals, and governance systems and procedures (DH, 2005a). It emphasised the role of telecare in enabling people to live independently for longer and providing service users with flexibility, choice and control. It described the aims of the Preventative Technology Grant as being to increase the provision of telecare support by at least 160,000 older people nationwide, provide service users with greater independence, reduce the need for residential care, reduce carer burden, and enable carers to have more freedom (DH 2005a p6). This was a clear policy commitment to telecare and new modes of care delivery into the 21st century. Although routed through social service departments, joint social and health planning and delivery of telecare policy/practice was assumed in allocating monies. Performance indicators were also introduced which encouraged local authorities to introduce technology into as many homes as possible over the funding period of the grant and beyond, with the aim of achieving ‘transformational change’ in the use of telecare.

Shortly after this, the DH announced an intention to fund a major study of telecare and telehealth, which became known as the ‘Whole System Demonstrator’ (WSD) trial. WSD looked at the impact of telecare and telehealth services (separately) in three local authorities (LAs). It was built around two parallel randomised controlled trials (RCTs), with a total of 2,903 individuals in the intervention groups and 2,901 in the control groups, spread over three English sites. It found some benefit in *telehealth* applications (where services are focused more narrowly on vital signs monitoring)



(Steventon et al. 2012, Cartwright et al. 2013) although these applications were not cost-effective (Henderson et al. 2013), but it found no evidence that *telecare* improved outcomes for those who used it (Steventon et al. 2013, Hirani et al. 2014) and again no evidence of cost-effectiveness (Henderson et al. 2014). Experiential evidence was also mixed (Sanders et al. 2012). These findings came from a well-designed and resourced study, and presented a significant problem for a number of key telecare stakeholders: first for the Government, because current policies support the development of forms of service provision which do not appear to offer any significant advantages over more traditional forms of care and support; second, for local authorities, many of which have invested very large sums in telecare at a time when their budgets have been cut to an unprecedented degree; and third, to manufacturers, whose ability to return a dividend to shareholders and to support further technological innovation would be jeopardised by dis-investment by the care industry.

Perhaps surprisingly, the findings of WSD do not (at least yet) seem to have led to a re-appraisal of the value of telecare in improving service efficiency and effectiveness by LAs, or any scaling back of investment. Indeed, referring to the findings of a recent Better Care Technology Survey (2014), David Pearson, then President of the Association of Directors of Adult Social Services, stated:

This is an important survey which ... will support members to generate further momentum in realising the potential for assistive technology. What is clear from the results is that we are a sector undergoing change, with a number of responses being qualified by comments relating to service reorganisation and Better Care Fund implementation planning. We hope our investment in resources to support members with their telecare service development can now be focused in the areas that make the most difference (ADASS, 2014).

WSD did not specifically set out to recruit people with disability to the trial; indeed, poor cognition was an exclusion criterion. A further pragmatic randomised controlled trial – ATTILA (Assistive Technology and Telecare to maintain Independent Living At home for people with dementia) – is underway at the time of writing, and aims to address this gap in research evidence (Leroi et al. 2013). However, even if the ATTILA trial, like WSD, finds no evidence of benefit, it is unclear whether it will stop the current momentum toward the use of telecare. Importantly, though it will address the question of whether or not telecare delays institutionalisation, the trial may not explain the reasons for these findings. We return to the question of research methodology and design later in the report.

In this section of the report, we explore some of the issues in the successful adoption of digital and other technology. In particular, and on the assumption that telecare devices, to be useful, should address defined needs, we focus on how assessments for technology for people with dementia are currently organised and conducted in England. We consider how assessment and other underlying factors that provide a context to assessment activity might affect the matching of need to telecare. Finally, we explore possible reasons for the apparent lack of agreement between DH policy and the current state of evidence of effectiveness, and what might be done about it.

One limitation of our study is that at present local authority eligibility criteria are such that some people with dementia will not qualify for care or support, and we think it would be unusual for this group to receive any kind of formal assessment of any needs for telecare. We are aware that there is a small but growing demand for telecare for this group and that devices of various kinds may be privately purchased, following what might be described as self-assessment. We can also make no claims for generalisability



for our findings, but they are intended to reflect indicative evidence that can inform policy and practice discussion and that may justify a larger study at some future point.

Methods

We followed two strands of inquiry. The first was a review of evaluations of various technologies used in connection with people with dementia and their carers. Among the studies included in the complete review (discussed in various parts of this report), there were five that included mention of assessment.

The second strand involved a small scale, qualitative study. Project team members identified a number of individuals prominent in the field of telecare and/or dementia in the UK and interviewed a number of them. The sample was opportunistic in that interviews were organised at short notice and based on the availability of those identified over the summer months. Interviews took place in July and August 2015. For this part of the study, we refer to 18 interviews which were carried out by three members of the project team. Interviewees came from a range of professional and occupational backgrounds. Seven were experienced academics specialising in social work, sociology and occupational therapy, each of whom had recognised expertise in the field of telecare, dementia, or both. Two worked in operational settings: one was a senior occupational therapist with extensive expertise in the field of both telecare and dementia, and the other a consultant old age psychiatrist specialising in dementia who had research interests in the field of telecare. The remaining nine comprised five commissioning managers, with particular interests in telecare and telehealth – three of whom worked jointly in adult social care and health settings, an equipment and technology enabled services project manager working for a large English council, one representative from a technology consulting company providing advice and guidance across a range of organisational sectors including local authorities, an employee from an ICT company supplying telecare equipment to local authorities, a senior manager from a large UK-based telecare manufacturer and the director of a national UK ‘think tank’ whose work embraces assistive technology and telecare.

All interviews were audio-recorded with the permission of interviewees and notes were also made during and immediately after the interviews. Recordings were listened to and notes re-read to ensure data familiarisation, before manual thematic analysis. Emerging themes were validated by a process of cross-checking among the three interviewers. The rapidity with which the report was prepared prevented full transcription of recorded interviews and instead the findings rely on notes, augmented by checks against the recording. Issues raised in the findings section reflect the views and perspectives of the interviewees, not the authors.

Findings

a. Themes from the literature

Several themes emerged from the review of evaluation studies that mentioned assessment and some other related articles. Franco et al. (2008) reported on a non-invasive monitoring of activities of people with dementia at home (e.g., eating and bathing). They found that daytime and nocturnal activity could be differentiated, providing a possible unobtrusive tool to facilitate a telecare package. There was no mention of a formal assessment. Dang et al. (2008) evaluated the effectiveness of a phone technology (using a text-screen phone with a handset and physical keypad) to support and educate caregivers of people with dementia. Baseline surveys covered



demographics and a wide range of outcome variables (e.g. burden, IADL, knowledge, etc.) but did not include any direct assessment as to the particular needs and desires of the caregivers, or whether these specific caregivers were open to this technology. The report notes that screen-phone use was limited, which suggests there may not have been a good fit between these participants and this technology.

Chou et al. (2012) evaluated a 'telecare medical support system' (TMSS) used in Taiwan. The study selected only those 30 households (out of an initial sample of 100) that were found to have the 'hardware and software infrastructure required for TMSS installation' and thus assumed an acceptance and familiarity with technology. (This sample selection strategy is important to note, because it emphasises that technological solutions cannot necessarily be seen as universally appropriate.) The authors reported that 'Case hospital IT technicians and medical personnel visited participating households to assess the home environments and care needs of each' (p174). Thus in terms of assessment, it would appear that some attempt was made to provide only those services within the TMSS model that might be required for each patient/carer situation. Despite the initial selection process, 40% of participants were later found to be 'invalid' either because the system was not necessary or not used because patient care was provided by a dedicated (paid) person, or because the lack of emergencies provided no opportunity to experience the higher functions of the TMSS – although the report does not record how many cases were in either of these situations. Results of qualitative interviews showed that after six months of using the TMSS, participants 'generally appreciated the ability of the TMSS to self-diagnose care recipient conditions; provide reminder, care, and emotional support; and help stabilize the care recipient's condition and emotion' (from abstract, p169).

Mahoney et al. (2003) reported on a randomised field trial of an automated telephone support system on carer burden and anxiety, with carers who managed people described as exhibiting disruptive behaviours arising from Alzheimer's disease. 'The intervention was designed to offer multiple components with flexibility in order to effectively appeal to a variety of users' (p558). There was no significant main effect from the intervention, but significant intervention effect for participants with low-to-mid mastery at baseline, and for wives, who made up about a quarter of the intervention group. One conclusion (from the abstract, p556): 'Findings suggest that, to optimize effects, similar interventions should be tailored to match the users' characteristics and preferences.'

In addition to these studies, the WSD trials already referred to are relevant to this discussion, even though they did not specifically look at people with dementia. Funded by the DH, WSD remains the largest and most expensive study of the impact of telecare and telehealth. Using a rigorous, cluster-randomised design in three purposively selected sites, 2,600 people were recruited from 217 general practices. Participants were randomly allocated to intervention or control group and followed up for 12 months. This trial found that the use of telecare did not lead to statistically significant reductions in service use – including community care, hospitalisation or admission into institutional care over the 12-month follow up period, nor was it cost-effective (Steventon et al. 2013, Henderson et al 2014).

Finally, we also found a number of published policy reviews or peer-reviewed papers offering practice guidance which considered the importance of assessment from a clinical and/or policy perspective, and a small number were reviewed for this report. Woolham and Frisby (2002) noted the relative absence of services for people with dementia using technology by local social care and health service providers, and described in detail a step-by-step process for 'Developing quality assured and



person-centred use of technology within dementia care.’ The process they described begins with an assessment of the needs of the individual, identifying potential technology solutions, considering the ethical issues that might be involved, and then moving forward to implement the appropriate plan.

Wey (2006) describes a theoretical framework for dementia rehabilitation that builds on an assessment of both the limitations and the strengths of the person with dementia and his/her social and physical environment – a set of variables that must be seen as changing over time – and from this assessment identifies appropriate interventions that may include technology-supported tools and services when and where appropriate. Woolham et al. (2006) note that the expanded interest in assistive technology and telecare for people with dementia has been accompanied by a number of significant policy and practice challenges that may make it more difficult for the needs of the user to actually drive the technology received despite the current focus on person-centred care. A good assessment is a necessary condition for quality care, but it is by no means sufficient.

In conclusion, the evaluations identified, particularly those by Dang (2008), Chou (2012), and Mahoney (2003), suggest the importance of assessment, although none of these studies incorporated sufficiently good quality assessment data to judge the value and importance of the link between the needs and preferences of people with dementia and the effectiveness of technology-related tools and services. The reviews and thought pieces in this area, however, strongly suggest that this is the clinically and ethically appropriate approach for people with dementia, and no studies were found that argued against this proposition.

b. Expert views on assessment for telecare: the ideal and the reality

Interviewees to whom we spoke who were working as academics, and especially those with a professional background in occupational therapy, placed considerable importance on the need for high-quality assessments of need for telecare recipients with dementia. Asked about the kinds of qualities an ‘ideal’ assessment should contain, they frequently mentioned the terms ‘person-centred’¹ (the person with dementia should be at the centre of all assessment activity, and involved as much as possible) and ‘holistic’ (briefly, taking into account social, psychological, physical environmental and emotional factors impinging on the life of someone with dementia). A diagnosis of dementia made the process of assessing need less straightforward. There was a general view that although the *principles* of the assessment should be maintained (broadly, finding out about the goals of the individual, about how they might want to live their life), the way in which an assessment (for telecare or any other form of provision) should be carried out might be different from an assessment with someone who was not cognitively impaired.

The focus of the assessment. Interviewees emphasised the need for assessments ‘to start with the person’ – identifying their strengths (rather than just their weaknesses) and working to build on these strengths and skills in a nuanced way. Many interviewees strongly felt that it was important that the telecare assessment was an integral part of a wider, holistic assessment of the needs of someone with dementia.

‘Holistic’ and ‘person-centred’ had similar meanings for interviewees. One referred to the importance of the focus of the assessment ‘embracing complexity’. This might mean, for example, assessing whether the person being assessed had insight, a realistic understanding of their own abilities, their cognitive, communication, and motor skills; their level of mobility, their habits and lifestyle, their physical environment

¹ The terms ‘person-centred’ and ‘personalised’ are frequently used interchangeably by care professionals. Some authors have argued that the two terms are conceptually distinct and embody rather different values. For a fuller discussion see Woolham et al. (2015).



(both in the home and outside), and their social network. Another interviewee illustrated this by pointing to the absurdity of offering or providing a falls detector without also considering the person's mobility and trying to find ways to improve this. Another emphasised the importance of tailoring the solution to the individual – so, for example, although the installation of door sensors linked to a pre-recorded message advising the person with dementia not to leave their home might offer a technological solution to a problem of 'wandering', it was essential to consider the impact this might have. The message might be ignored, or it might lead them to think there was someone in their home which could produce feelings of great anxiety.

The style of the assessment. There was also some reflection on the style as well as the content of an assessment for telecare for people with dementia. Interviewees felt that it was important that assessments – particularly first assessments – should always be conducted in the home environment of the individual (rather than, for example, over a telephone or in a clinic) because of the importance of drawing on observation to obtain an understanding of the physical and spatial aspects of the home environment. Home visits were seen as a way in which the skills of the individual could be properly assessed. Interviewees also felt that although the assessment should always be person-centred it was also recognised that it might be necessary for people with dementia to have the support of a close relative or someone who knew them well to augment their responses. 'Firing questions' at people with dementia, or rushing through questions without allowing sufficient time for them to consider their responses, or failing to check whether they understood questions, were considered poor practice. Some interviewees also emphasised the need not to be prescriptive in the approach to the assessment, e.g. assessing 'for' a particular piece of technology or equipment, and to offer choices (not necessarily of different kinds of telecare equipment: one interviewee suggested that depending on need, it might require 'hi-tech, low-tech or no tech').

Who should do the assessment? Many interviewees felt strongly that it was important that the telecare assessment was an integral part of a wider, holistic assessment of the needs of a person with dementia rather than a specialist assessment divorced from an assessment of need that might be carried out by, for example, a care manager, social worker or occupational therapist. One interviewee described this pithily as 'barking mad'. Several interviewees described a lack of understanding of telecare, leading to a sense that it was the provenance of technical rather than care professionals. One interviewee felt strongly that national policy, and national training organisations and universities, were not properly aligned to, or supportive of, telecare. They commented that there appeared to be a 'massive workforce skills gap' in that both Skills for Health and Skills for Care reflected the needs of the existing workforce but had not embraced the future, and in particular 'the need to bridge the gap between ICT and care staff, so there are people possessing both sets of skills – technical and social/care-related – to match people to technology'. However, rather than acknowledge this need – perhaps because of the risks involved, perhaps because of concerns about the capacity of ASCDs to 're-skill' their workforce, or the diffuse and fragmented nature of the social care workforce itself – many ASCDs had contracted out telecare services entirely to manufacturers or suppliers.

According to some interviewees, this was a significant contributor to poor assessment practices. Telecare assessors, often local sub-contractors of telecare companies though (presumably) technically competent, were not seen as possessing the skills of experienced care professionals in assessing complex cases. Furthermore, they were regarded as being more likely to take a technology-focused – rather than person-



centred – approach to received referrals: for example accepting prima facie requests from a referrer for a specific item of technology rather than ‘embracing complexity’ – looking at needs in a wider, more holistic and person-centred way. Emphasising the importance of clinical (or practice) reasoning, one interviewee said ‘referrals can be complex but the technology solution may be simple and vice versa.’ Compounding these issues, one interviewee also suggested that many ASCD assessment protocols for telecare ‘might be OK for people without dementia but not for those with.’

Who should be involved in the assessment? Interviewees also considered who might be involved in the assessment process besides the person with dementia. A number drew attention to the marginalisation of unpaid carers – usually relatives, and often also elderly themselves – whose role in the assessment was to act as an amanuensis, or facilitator for the interview process with the person with dementia rather than someone who might have needs in their own right. The 2014 Care Act – which offers carers new statutory rights – may change this situation over time, but a number of respondents felt that another, particular reason for including unpaid carers fully in the assessment was that many of them would become the ‘social response’ – the person who would be the first to be contacted by a call centre if a telecare device generated an alarm signal. There was concern that even where carers were involved more fully, their potential role as ‘responders’ was not always made clear, and sometimes involved more responsibility than was immediately apparent. One interviewee referred to the importance of paying attention during the assessment to how devices would be used, and the nature of the care relationships needed to make them work: for example, in encouraging the ‘habitual’ use of telecare by people with dementia, or (depending on the kinds of technology used) making sure batteries were charged every night. One interviewee felt that ideally, all those involved in delivering support or care to the person with dementia should be involved so there was a full awareness by all of what was being installed, for what purpose, and how it worked.

Some interviewees also strongly felt that there were real advantages to joint assessments – where front-line professionals from different disciplines each participated where the person with dementia had complex needs. Several interviewees also noted that the needs of the individual could change very rapidly and therefore that regular reviews and reassessments were important.

Interviewee views on existing telecare assessment practice

There was a high level of agreement among interviewees that standards of assessment practice for telecare in ASCDs were not uniformly high. Though in some local authority areas assessments were detailed and holistic, in others, they were seen as superficial and fragmented. One interviewee felt that a ‘minimalist’ approach to assessment might be appropriate for some people with dementia – specifically, people at an early stage in the disease process, who retained mental capacity, or people with simple rather than complex needs. Others felt that dementia created multiple needs, and therefore complexity, but despite potential for rapid changes in need (often characteristic features of the disease) regular reassessments were not always scheduled, and neither were scheduled checks on the installed technology to ensure it still worked, and that it was still meeting the needs for which it was intended, etc. Telephone-based reviews were not frequently mentioned, but according to some interviewees, did occur.

Nearly all interviewees referred to the negative consequences of austerity policies on the assessment process: specifically, the lack of time available in busy operational teams to conduct detailed assessments (when staff often knew these were needed) and a widespread ‘narrative’ in ASCDs about using telecare to save money. This



narrative reportedly created concerns among people with dementia and their relatives and unpaid carers that telecare was about ‘cuts’ rather than an opportunity to deliver services that could compensate for impaired cognition, or to help people with dementia maintain preferred lifestyles: self-care, social contact, hobbies, habits and routines. Some interviewees also felt that the same contextual factors created suspicion among *paid* carers – care workers rather than relatives – that telecare would be used instead of hands-on care, placing their continuing employment, or conditions of employment, in jeopardy.

Interviewees also commented on ways in which commissioning behaviour affected practice, citing examples in which ASCDs purchased very large quantities of equipment which was subsequently used as a prophylactic without any real regard to its usefulness in the homes in which it was installed. This was attributed to commissioning decisions (we refer below in more detail to commissioning) in which contracts were signed with single manufacturers, leading to situations in which not all needs for which a telecare solution might be found were addressed due to limitations in the product range from the manufacturer. One interviewee commented that this also led to situations in which someone making a request for support which could be addressed by some technology might be told ‘we don’t do that’ and not always be signposted on to organisations that might be able to provide advice or access to technology that could help.

Limited understanding of telecare’s potential also affected the ways it was used. Some interviewees commented that if referrals for telecare were made, they often tended to be unhelpfully prescriptive, requesting that the patient or service user be assessed for a specific device, often as a result of a superficial understanding of the needs of the person referred. These interviewees were concerned that this approach led to a ‘tick-box approach’ rather than a deep understanding of the needs and aspirations of the individual with dementia. One interviewee provided an example of situations in which telecare was installed in the home of someone with dementia while they were in hospital. Because there had been no possibility of understanding how the person interacted with their home environment, unsurprisingly, the installed devices proved to be of little value when the person was discharged. A number of interviewees drew attention to situations in which the assessment was ‘for’ a specific device available from the commissioned manufacturer, and for the need for ASCDs to ‘look beyond what was available in the [provider] catalogue’. This may also have contributed to a tendency, noted by some interviewees, for ASCD staff or contracted telecare assessors not to utilise technologies that could potentially be useful.

Concerns about ethical issues in the use of technology were not strongly reflected in interviews, though their importance was acknowledged. One or two interviewees were, though, at pains to point out that when ethical issues surfaced (as inevitably they would from time to time), ‘ethics means consideration of how to act: it doesn’t mean not acting’ – implying perhaps that ethical concerns might sometimes have been used to ‘close down’ discussion about the use of telecare or prevent its use altogether rather than to consider how to use it appropriately. This might reflect another ‘gap’ in practitioner knowledge. Another interviewee – who regularly came into contact with front-line staff – observed that some of these seemed to lack confidence in applying the Mental Capacity Act (MCA)² and sometimes Deprivation of Liberty Safeguards (DOLS) in relation to the use of some telecare devices.

Our interviewers offered insights into ways in which telecare could potentially have positive and negative impacts on key stakeholders: people with dementia, their unpaid carers, and ASCDs.

² The Mental Capacity Act (2005) provides a statutory framework for people who lack capacity to make decisions, or whose capacity is impaired and therefore require support in making decisions. People with dementia may lack capacity to decide whether to agree to use telecare in their home. The Act requires professionals to assess capacity to determine if the person is able to make a decision.



Impacts on people with dementia

(a) Positive impacts. Little mention was made by interviewees of the importance of technologies most frequently used: pendant alarms (only useful for people who would remember to press the button) and telecare intended to manage risks in the home. However, it is important to acknowledge the contribution these may make to maintaining independence. Interviewees did offer several examples of how telecare, if used appropriately, could bring about positive benefits. Though these might sometimes be straightforward, an understanding of the social and environmental context in which telecare was used was often vitally important. One interviewee described a case in which the real needs of a person with dementia were not immediately apparent. This person ‘went out at night’³ – behaviour that eventually led to admission into a nursing home. He did not thrive there, refusing to eat. His brother took him home on Christmas day and he subsequently refused to return to the care home. This presented significant risks: the interviewee explained that if he left his brother’s home at night, he could potentially have died of hypothermia. Door sensors and a wrist alarm were installed to address this issue, but as the interviewee pointed out, ‘the really interesting thing was, he stopped going out. This wasn’t to do with the door sensor: having someone to talk to gave him contact with someone else, and orientation ... putting in telecare that was less intrusive met his real need – which was for social contact.’

Other interviewees referred to the emergence of new technologies that moved telecare away from home-based risk management and enabled more independence: for example worn GPS devices made it possible for some people with dementia to go outdoors without becoming disoriented. Other interviewees drew attention to technologies for communication – seldom used by ASCDs for any telecare users – that had considerable potential to support leisure time activities and social contact for people with mild to moderate dementia. These included iPads and mobile phone applications which could support independence: hand-held GPS, and digital photography (enabling the individual to photograph an environment so they could remember where they had been). Another interviewee also referred to the potential of video, music, and electronic life story books in supporting wellbeing among people with moderate to more severe dementia by facilitating contact with people no longer present (both those alive but living elsewhere, or people now deceased).

(b) Negative impacts. Some interviewees felt the lack of access to these ‘newer’ devices (either because the person with dementia did not meet eligibility criteria or because the ASCD did not provide the technology as it focused on risk management and safety only) were seen as a significant issue and unlikely to change because of the very constrained budgets available to ASCDs. This created a situation in which the ASCD might increasingly become an ‘enabler’ rather than a direct provider of telecare: signposting people with dementia and their unpaid carers and relatives to places where they could purchase these devices themselves. As many ASCDs had introduced charges for the use of telecare, interviewees who raised this issue did not feel it crossed any wide Rubicon.

Interviewees also referred to other less positive outcomes for people with dementia, such as devices that were not configured to work correctly. For example, reminder devices that offered a ‘reminder’ only after the activity for which the reminder was designed had been completed, or automated lighting (designed to help someone getting up at night to find their toilet) that switched off either too soon (leaving the person on a dark landing) or too late (not switching off after the person had returned to bed). Also problematic was the provision of devices that required user activation of some kind (e.g. a button to press), when the level of cognition of the person with

³ The label ‘wandering’ is frequently applied to this kind of activity but many people who work in dementia care settings feel it is an unhelpful label, discouraging a further consideration of causes, or the reasons someone with dementia might leave their home in circumstances that may but them at risk.



dementia meant that appropriate use was unlikely or inconsistent. One interviewee also recalled an incident in which automated lighting was physically destroyed because the recipient had failed to remember what the telecare device was for. By contrast, another interviewee suggested that configuration problems (technology not operating in phase with the individual's activities) which from a technical perspective might be fairly minor, could commonly cause anxiety and distress: 'If telecare misbehaves (or is wrongly installed) people will tend to blame themselves rather than the technology.'

Impacts on unpaid carers

(a) Positive impacts. Many interviewees tended to feel that unpaid carers and relatives were more enthusiastic about telecare and that people with dementia 'went along with' their relatives. Others felt that carers either rejected the whole idea of telecare at an early stage, or went 'completely overboard' for it. In such cases, some interviewees felt that a focus on the prevention of harm sometimes blinded them to ethical issues: for example, such as those arising from the installation of video cameras in the bedrooms of the person with dementia, or their bathroom.

Interviewees presented numerous examples of ways in which telecare had helped carers: enabling them to lead a more normal life by reducing the frequency of visits to the home of the person with dementia (by non-resident carers) and enabling those who lived with the person with dementia to get more sleep as they did not have to be in a state of constant vigilance. As one interviewee put it,

Assistive technology in the home, if well-matched to need, can have huge psychological benefits: carers can be less 'tied' to a loved one, and it reduced the constant need to be checking on them...

(b) Negative impacts. 'Invisible' additional work for carers in ensuring that the technology worked effectively has already been noted. Additional unwelcome impacts were also mentioned. One interviewee commented that though carers might be comfortable about responding to alarm signals generated by technology, frequent false alarms might quickly lead to disillusionment.

Some interviewees also pointed out that some technologies – for example, those designed to support assessment of patterns of behaviour, or those which used GPS to prevent someone with dementia from becoming lost – might raise anxiety levels as well as offer reassurance: one interviewee referred to a carer who discovered, when using GPS-based tracking systems, that the person they cared for travelled (by public transport) many miles further from home than they had anticipated.

Impacts on ASCDs

(a) Positive impacts. The current interest by ASCDs in telecare arises from a need to find cost-effective, affordable solutions to rising demand and shrinking resources. Interviewees drew attention to the *potential* of telecare to offer cost-effective new approaches to service delivery – delaying or preventing admission into care or hospital, and using technology as a substitute for some social care tasks while supporting independence.

(b) Negative impacts. Interviewees referred to multiple challenges faced by ASCDs. Several emphasised the need for ASCDs to adapt their telecare arrangements – protocols for assessment, telecare installation, review and maintenance – to meet the needs of people with dementia. As one interviewee put it: 'Standard packages are easy, but they don't work'. A need for the integration of telecare with general



social work/care management assessment, and for a more nuanced understanding of need – particularly for people with moderate or severe dementia – were seen as essential for telecare to fulfil its potential for people with dementia. One interviewee felt ASCDs needed to consider different technologies, and adopt a different focus, depending on a person's level of dementia. The interviewee pointed out, for example, that risk management was less of an issue for people at an early stage of the disease, and that assessing whether someone with dementia could respond to, or interact with, technology was essential in determining what might be installed. There was wide agreement that telecare could only work well when seen as part of a wider local infrastructure within which it was deployed. However, in practice it was also described by some interviewees as a 'bolt-on': these interviewees felt that service re-design was needed to make it work effectively.

Attention has already been drawn to places in which telecare manufacturers have been commissioned to supply and install telecare. Though potentially addressing capacity problems and skill deficits within the ASCD workforce, it may also have contributed to technology rather than person-centred approaches to telecare delivery, with telecare staff trained to assess for 'specific items of kit, nothing more'. We have also already drawn attention to reported shortcomings in maintenance arrangements, and a failure to review the impact of the technology.

Commissioning of telecare and impact on assessment and matching of need to technology

The local authority context for telecare delivery in England is characterised by a great deal of diversity in commissioning arrangements, though our findings suggested that there may have been a shift away from local authorities directly providing telecare services 'in-house' to the commissioning of the various elements (assessment, installation, maintenance, reassessment, monitoring, response) of their services in part or wholly to external private and/or third sector organisations. A separate study would be required to assess the extent to which this might be occurring, and the consequences. Cuts in funding have also meant that some local authorities appeared to be moving away from directly funding or subsidising telecare services, instead signposting service users to particular providers. One local authority commissioning service which had moved to this model felt there were some benefits. Under the previous system where service users were subject to FACs assessment, people in the early stages of dementia were not deemed to have sufficient need.

Several interviewees also drew attention to the importance of early access to telecare because it enabled people with dementia to become familiar with technology and comfortable about it being used to provide support, and this interviewee commented that now they were able to assist people in locating technological solutions for purchase at an earlier stage, based on their needs and aspirations. Another remarked that simple pieces of equipment and adaptations early on make it more likely that individuals would accept more advanced technology later on. Early adoption was identified as important but challenging as there was a fine balance, as one interviewee identified: 'none of us want to think: 'I am going to need that'. 'Selling on the basis that you'll need it later is frightening.' Instead they advocated 'selling' telecare on its ability to help people remain independent as 'there is a slippery path to dependency'. Other respondents also referred to the use of 'private' arrangements – including the use of direct payments – to choose, buy, and use telecare; although we were unable to establish the full extent to which this was occurring. (One telecare manager interviewed felt that though at present the private segment of the telecare market was small, it was expected that it would grow very rapidly with the contraction of the state sector.)



We were also made aware that removing the subsidy for telecare provision and the subsequent introduction of charges (and perhaps more choice) in ASCDs, may have led to situations in which people with dementia and their relatives/unpaid carers might elect to purchase different devices to those offered. This might be wholly beneficial in some cases, as interviewees felt eligibility criteria prevented access to telecare for people at an early stage of dementia, and the technologies on offer by the ASCD were not really needed by this group. However, there was a fairly widely held assumption that by helping people with dementia to get familiar with having technology in their lives from an early stage made it easier for them to accept other kinds of telecare as their dementia progressed. Interviewees also pointed out, however, that without clear, reliable and unbiased information about telecare, there was a risk that private purchasers might choose the wrong kinds of technology to address their needs. This model of provision reflected wider tensions in adult social care and NHS settings between needs-based approaches to service provision and those designed around *demand*, and ability to pay.

Some concern was also expressed at the extent to which commissioning arrangements for telecare were able to support the goal of using telecare in person-centred ways. Patterns of commissioning impacted on the availability of equipment. One commissioner's ASCD had commissioned a particular technology manufacturer to provide all equipment for this ASCD, and as this provider did not have a great deal of equipment with a dementia focus, the equipment that could meet the needs of someone with dementia was limited to what could be provided by the LA through smaller projects and pilots. Needs assessments therefore were to a degree related to the practical realities of what equipment had been commissioned.

A further barrier to delivering person-centred telecare identified by the commissioning interviewees was related to scepticism of its benefits, in particular from within the health sector. Several interviewees who worked in commissioning settings felt that there was a lack of enthusiasm for telecare among clinical colleagues, because of the lack of evidence for patient/service user benefit. Some of our interviewees argued that there was a need for 'cultural change' and change of mind-set. Though our evidence indicated that commissioning is increasingly 'joined up' across health and social care, in practice, interviewees also drew attention to the continuing existence of silo-based thinking. ASCD commissioners said they found it difficult to persuade health professionals about the benefits of telecare. This appeared to be not only a cultural issue around evidence ('GPs want cold, hard facts'), but also concerns among health professionals that their older patients were too old to learn or adapt to telecare. Clinicians were reportedly more used to evidence in the form of RCTs, and interviewees commented that existing evidence for telecare tended to be short-term and social care-based. As a result, in one LA the interviewee said that 95% of those who had received an AT assessment were referred from social care, not health. Time was reportedly an additional factor; in a 10-minute appointment, it was said to be difficult for a GP to also include a referral for AT.

Discussion: The necessary conditions for successful adoption of telecare and identified barriers

- 1. The legacy of 'Building Telecare' Policy Guidance.** ASCDs have been encouraged by the DH to make the use of telecare widespread and their efforts have been assessed by the use of performance indicators. A stated intention of the 'Building Telecare Guidance' was to 'pump-prime' the manufacturing sector, and little guidance was offered to ASCDs by the DH about 'best practice' in the use of telecare in general or for people with dementia. Though there was some awareness, arguably,



little attention was paid to the complex professional and organisational arrangements needed to construct viable local infrastructures to support its use (Woolham and Frisby 2002, Woolham et al. 2006). These arrangements seemed to have been presumed to exist when in practice this generally seemed not have been the case. Arguably, this may have led to an excessive preoccupation with the commissioning and use of telecare equipment – the technology itself – and much less focus on how to use these devices sensibly and appropriately, matching the technology to need. This, in turn, might explain why, although early telecare project evaluations (Mitchell 1996, Alaszewski and Cappello 2006, Woolham 2006, Newton et al. 2008) demonstrated good outcomes, the WSD trial – focused on the impact of telecare as a large service rather than smaller scale projects – did not.

2. **Wider policy considerations.** Over the last quarter of a century there has been cross-party support for social care policies that encourage people who use social care services to be independent (DH 2005b). Terms such as autonomy, empowerment, choice, are seen as synonymous with health and wellbeing. However, there is also a view, expressed in the field of social gerontology, that such policies and the values that underpin them do not serve frail older people well. They are not unrealised aspirations: most older people with dementia will have led independent, productive lives (Orellana, 2010), but are now much less able to fulfil policy aspirations of independence and autonomy. Advocates of this view argue that independence may not only be unachievable, but may even be undesirable as in a pure form it might represent a state of isolation and singularity (Lloyd 2010, Barnes 2011, Lewis and West 2014). Instead, they argue that citizens exist in relationships of inter-dependence or ‘nested dependencies’ (Fine and Glendinning 2005) in which people might trust and depend on others in many areas of their lives yet be independent in others. This has profound implications for the way in which support and care is provided for older people in the UK.

There are several implications for telecare. First, it affirms a view that it should not generally be used as a substitute for social care (as is increasingly the case due to austerity) but that if telecare is used to save money, for people with dementia this might be better achieved through delaying need for residential care and reduced levels of hospitalisation (Woolham, 2006). Second, it supports the idea of person-centred rather than technology-focused approaches to telecare. Third, it challenges the idea that care (and telecare) is simply a ‘commodity’ that can be subject to a consumer transaction. It is, instead, rooted in the idea that care – both given and received – is a fundamental human need (Milne et al. 2014, Ray et al. 2014).

3. **Consumer or needs led approaches to care delivery.** The introduction of care management, service brokerage, local care markets and most recently personal budgets and direct payments have all successively transformed the way care and support is allocated from arrangements based on need (sometimes pejoratively referred to as the ‘professional gift’ model; Duffy 2008) to ones in which service users are seen as consumers or customers, and with purchasing power conferred by personal budgets, able to exercise choice (Leadbeater 2004, Boyle 2013). There is a far from settled consensus about the advantages and shortcomings of either approach; see, for example, discussions in relation to choice (Schwartz 2005, Salecl 2010), personal budgets and direct payments (Beresford 2008, 2009a, 2009b, 2011, Slasberg et al. 2012). There is, however, little evidence to date that in adult social care a demand-led rather than needs-led approach to service delivery is producing better outcomes for older social care ‘customers’ – in this case, people with dementia who are at an early stage of the disease or relatives



who are carers. There is also an alternative narrative which argues that public services are not, in any event, about delivering choice, but about rationing scarce resources: a role which, some have argued, they have fulfilled very effectively until recently (Clarke 2007, Clarke et al. 2006, 2008, Daly 2012). The implications of this perspective in relation to telecare's role are undeveloped but would support rigorous person-centred assessments carried out by professional staff with the necessary skills and competence, and for telecare to be used to support more meaningful kinds of contact with the person with dementia rather than short-duration visits (so-called 'check visits') and not to be used as a substitute for social care, unless this was what the individual, who had capacity to decide, chose.

Leaving aside policy controversies, however, regardless of whether the future service delivery model for telecare in England is one that is built on professional definitions of need or consumer demand, telecare users – managers, professionals, paid and unpaid carers, relatives and people with dementia – will all need more information about products and services to inform decisions about what technology to deploy.

4. **The need for information.** Information and guidance about telecare is an important precondition of successful use. This information needs to be independent of the manufacturing sector, easily accessible, easy to understand, and regularly updated. The AT Dementia website (www.atdementia.org.uk) meets all of these criteria at the present time but may need to be appropriately (but independently) funded to continue to update and develop. However, internet-based sources of information are unlikely to reach many older people with dementia and elderly carers at the present time, as internet use, though increasing, is by no means universal among older people, and many challenges remain to be overcome (Damant and Knapp 2015). Information about telecare also needs to be available where older people in particular are most likely to see it: post offices, GP surgeries, libraries, cafes, bus stations as well as through other media: newspapers and magazines, radio and television. Information currently provided by public sector agencies is often rather general (presumably to give it the longest possible shelf-life) and invites the reader to either email or telephone for further information. Those responding to such enquiries need to be fully informed and have access to detailed and constantly updated information, and be able to either signpost callers effectively (perhaps following up on a proportion of calls) or refer on for social services assessment.

Interviewees commented that although a great deal of information is provided by telecare manufacturers and suppliers about their products, much of this is designed to win market share rather than just provide information.

5. **Aesthetics.** Another way in which any 'stigma' attached to using telecare technology could be reduced – particularly for wearable devices – is to make them attractive. Though manufacturers have made considerable progress in making these devices smaller and less cumbersome, more could be done: perhaps designing some items as jewellery, for example. The recent development of smart watches and wrist-borne fitness devices – more likely to be seen as status symbols than stigmatising – might be helpful in this regard.
6. **Training.** There was wide support for the need for telecare assessments to be integrated with social care assessments of need. Achieving this in practice presents formidable obstacles but without integrated assessments, there is a much greater likelihood of a technology-based rather than user-focused approach, which is likely to be wasteful and deliver poorer outcomes for people with dementia. It is essential,



in the medium term, that social care and telecare assessment are integrated so that the assessment is both holistic and person-centred. Where necessary, protocols may need to be developed to enable minimum standards to be achieved in the quality of assessments. In the medium term, too, telecare assessors should receive accredited training. Useful thinking about the contents of potential training and the creation of a new, hybridised professional group has already been carried out (FAST 2005) and some universities – for example, Coventry University – offer well-structured advanced level qualifications in the use of electronic assistive technology and telecare.

- 7. Referral waiting times and assessment quality.** Occupational therapy services in the UK introduced streamlined arrangements for access to minor aids and equipment several years ago to try to address the long waiting times experienced by people referred, frequently for simple devices such as walking frames or toilet seat raisers. Though the introduction of ‘up-stream’ screening to triage ‘simple’ from ‘complex’ cases might prevent similar delays in access to telecare, the parallels are not exact. Telecare (rather than stand-alone electronic devices) is often complex, potentially expensive, and for people with dementia not so easily matched to need. Expert opinion from our interviewees has suggested a greater likelihood of complexity, even if the eventual solution is relatively simple, and that superficial, fragmented, or technology-based assessments are much less likely to be effective.
- 8. Affordability.** Cost is a barrier to the provision of telecare services. Local authority ASCDs have recently faced unprecedentedly deep cuts in central government funding which has effectively destroyed support for training and education (Rainey et al. 2015). However, if telecare is used appropriately, and can reduce the prevalence of institutionalisation, this creates savings which could be used to offset the increased cost of more rigorous and dementia-friendly assessment. Some commissioners working in ASCDs and interviewed for this report felt that the findings from the WSD trials were ‘unhelpful’ and that evidence was needed to demonstrate a return on investment. Although this raises some interesting questions about relationships between research evidence and practice, commissioners also felt that the preventative nature of some of this equipment made it difficult to demonstrate true cost savings as opposed to cost avoidance. Although cost savings might be demonstrated in relation to independent living, there was also a time-lag in this situation.
- 9. Issues in commissioning telecare for people with dementia.** Our findings suggest that commissioning activity may have been a significant reason for technology-focused rather than person-centred assessments, because a limited range of technology defined what was ‘on offer’. Desired objectives and outcomes for people with dementia were therefore only partially met by what it was possible to provide. Interviewees felt that access to a wider range of technologies, from different manufacturers, would improve the matching to need. Though some interviewees suggested inter-operability was a barrier, others tended to reject this idea, arguing that common electronic communication protocols were now widespread. An underlying issue may be concerns about potential product liabilities which may particularly affect ASCD commissioners. Many telecare systems comprise a range of sensors, activators and alerts. If one of these individual components malfunctions the consequences could be very serious. Commissioners may seek to avoid situations in which the attribution of responsibility becomes less straightforward, as for example when components in a system have different manufacturers. No-fault insurance and common product reliability standards (equivalent to a ‘kite mark’) could help in encouraging the use of a greater range of technologies.



-
- 10. ASCD eligibility criteria.** Some interviewees also felt that a specific challenge related to dementia was that local authority eligibility criteria meant that people with dementia and their families were introduced to technology ‘late in the day’ which made it harder for them to adapt to using telecare. Interviewees said that by the time people were eligible for care it was often too late to introduce technology in a positive way due to the progress of the illness. However, this perspective seemed to be based on assumption that skills and awareness acquired at an early stage in someone’s dementia will be retained as the dementia progresses. No evidence was presented by interviewees to support this claim and it is often more likely that skills and memories acquired *earlier* rather than later in life are the ones retained for the longest as the illness progresses. It also seemed to assume a need for the person with dementia to ‘adapt’ to the technology. Other interviewees – particularly specialists in the field of dementia and telecare – took the view that as a person’s dementia progresses, the telecare used would normally need to be ‘passive’ (i.e. working around the individual, and requiring no input from them) rather than ‘active’ (e.g. button-operated). If telecare is to be appropriately matched to need, the assessment will also need to take into account the capacity of the individual to use any equipment that is consciously user-activated and periodic re-assessment will be needed.
- 11. The role of unpaid carers and relatives: transferring responsibility from the state to vulnerable individuals?** Interviewees drew attention to ‘invisible’ work for unpaid carers in ensuring that telecare devices worked properly when installed, as well as being the first point of contact when an alarm signal was triggered by installed devices. They also commented on the potential for telecare to reduce stress and improve wellbeing among carers. To minimise the potential for telecare to exploit and maximise its potential to offer support to carers, interviewees felt that carer needs should be included in assessment activity, that the full implications of using telecare were explained, and that reviews be conducted shortly after installation and in the home of the individual with dementia, and with relatives or unpaid carers present, to address any unforeseen issues. A named individual, readily accessible by telephone and equipped with the knowledge and power to address carer concerns, might also help.
- 12. Ethics.** Though the ethical use of telecare was considered important by interviewees, none drew particular attention to outstanding ethical issues, other than one interviewee who felt that ethical concerns were often used inappropriately to prevent the use of telecare. A potential but unexplored issue may relate to the deployment of some forms of telecare devices by relatives of someone with dementia. Restrictions in eligibility criteria may mean that the private market for telecare will grow. The kinds of technologies that are available may be restricted unless the private purchaser is able to buy call centre time, but off-the-shelf technologies have the potential to be used appropriately or inappropriately. The siting of CCTV cameras in bedrooms or bathrooms of people with dementia may provide information to relatives that allay fears about problems with day and night routines, falls, etc., but they also represent a major breach of an individual’s privacy, and may contravene human rights legislation. A more general concern is that the technology may be used as a means of addressing behaviours that others find troublesome but which curtail or restrict activity by the person with dementia rather than support their independence. At the minimum, clear guidance should be made available to relatives who are contemplating the use of telecare technologies to help them select and use these tools sensibly.



4. Current state of development of new technologies

The fourth aim of the study was to liaise with industry, government, academic, third sector and other experts to understand the current state of development of new technologies for care and support in dementia, and the possible new technologies that could become available very soon. In pursuit of this aim we drew on a number of sources. As well as the rapid review of the peer-reviewed and grey literature described in section 2, we conducted interviews with experts from different sectors. We also obtained experiential evidence from carers, people with dementia and a formal care setting, which we will describe in section 5.

Here we report on the interviews, with a focus on the technologies that were discussed by interviewees. We also develop a table that maps the technologies identified in the project via the interviews, literature review and the experiential evidence onto the 'dementia journey.' The mapping organises the technologies according to their function, the stage of severity of dementia for which they can be useful, which individuals are potentially helped by the technology, and the care setting in which technology can be used. The framework used has been described in more detail in section 2 above.

Overall, we conducted 24 interviews with experts from different sectors including academic researchers (7), technology developers based in the UK (3) and Spain (1), city and county council adult social services' commissioners (6), independent ICT-based care service commissioner (1), NHS Trusts (2), and an independent home care provider (1). We also consulted experts from a number of third sector organisations including a leading dementia charity (1), an independent government agency for technology innovation (1) and an independent think-tank for ICT solutions for care (1).

Current business-to-business technologies for dementia care

Interviewees discussed the technologies which are deployed as telecare services (as defined in section 1) for people with dementia and their family carers. Telecare services for dementia care include technologies such as pendant alarm systems, medication reminders and geo-fencing localisation services (e.g. buddi, loc8tor). Interviewees also discussed the growing use of more advanced monitoring systems for dementia care which largely consist of sensor devices placed around the home to detect 'unusual' home conditions (e.g. extreme temperature, flood) or activity patterns (e.g. fall monitors, bed sensors or door exit monitor). Telecare commissioners suggested that these monitoring services can provide people with dementia with 'peace of mind' and help prevent '[unpaid] carer breakdown'.

One technology developer described their latest telecare service, a bespoke mobile phone which sends information about the service user's precise location (using GPS technology) at regular intervals. The phone is designed specifically to be accessible for people with dementia by having a single 'SOS button' and a large display, as well as a two-way communication function. To guarantee the reliability of the mobile signal, the mobile telecare service includes a roaming SIM card with a private APN (access point name).

The features of the phone allow people with dementia to raise an alert easily, both when they are at home or out and about. When responding to an alert, the call centre (or designated family carer) can immediately identify the location of the service user (using GPS technology) as well as speak to the service user; this enables the respondent to gain a better understanding of the service user's immediate needs and to arrange an appropriate response.



Technologies generally described as ‘telehealth’ were not frequently mentioned by our interviewees. One county council service commissioner referred to the NHS Health and Symptom checker app⁴ to discuss the emergence of services which enable self-managed care. Another social care commissioner mentioned a trial of a telehealth texting service, where service users are reminded by SMS to text their vital sign readings. Although the trial included service users with long-term conditions more generally, the interviewee suggested that the telehealth services could be relevant to people with dementia.

Similarly, there was little discussion around ‘telemedicine’ services, which consist of the use of ICT (often videoconferencing equipment) by care professionals to deliver a care service (e.g. consultation, diagnosis). One service commissioner referred to the Red Embedded service, a secure videoconferencing service designed to bring together the expertise of care practitioners from both the health and social care sectors, patients/users and their family carers. The lack of direct references to telehealth and telemedicine services in the context of dementia care is probably because most of the statutory care services for people with dementia (and who are eligible for state-funded care) are provided by adult social services, rather than by the NHS.

Interviewees discussed ways in which technologies are used by care staff to provide care for people with dementia. One interviewee, from a large care facility, noted that care homes (mainly large, private care homes) are increasingly using telecare devices, such as enuresis pads and bed sensors, arguing that these devices permit care home staff to provide a less intrusive and more personalised level of service.

Another example of care staff using technology to deliver care was given by an interviewee from the independent home care sector. This interviewee described a pilot scheme currently underway in Wales, where front-line carers use a smartphone application to log their visits with service users (by scanning their phone over a small electronic tag placed discretely in the service users’ home). Early anecdotal evidence suggests that the majority of service users and care staff are very positive about the ICT service: there have been several expressions of interest in the technology from carers outside the pilot region. Also, both service users and care staff reported that using the smartphone reduces the time carers have to spend filling in paper forms and obtaining signatures, giving them more time during the visit to engage in face-to-face care. An alternative view would be that telecare becomes a substitute for social care, but we have not seen evidence from research to substantiate either of these arguments.

Current business-to-customer technologies for dementia care

Several experts discussed the range of technologies currently available on the consumer market that could be used by people with dementia and their family carers. Interviewees referred to bespoke devices, including reminder and reminiscence services. The reminder devices, such as the Memo Minder or Voice Cue, include a sensor and a voice recording which plays a message, which prompts the service user about activities, appointments or tasks. The reminiscence devices, such as Talking Photo Albums, consist of a screen which displays photos of people, places and important events that are relevant to the person with dementia and play recorded messages which explain the context of the photos.

Telecare commissioners and technology developers mentioned that some of the monitoring devices noted above under ‘telecare services’ (e.g. door exit services, pressure mats, bed sensors) are also available on the consumer market.

⁴ <http://apps.nhs.uk/app/nhs-health-and-symptom-checkers>, accessed on 23 September 2015.



Interviewees also mentioned a number of online tools developed for dementia care. For instance, MyBrainBook is designed as an individualised service that allows a person with dementia to take decisions about what information they share with the people who care for them, including health, social and informal carers. It is also designed to facilitate communication between carers, as well as between carers and the people they support. The About me e-learning service course was also mentioned as an online service that provides information to carers (not dementia-specific). One service commissioner referred to an online interactive ‘assessment’ game, which allows service users to identify their care needs and obtain information about how to access services that can help them live independently in their own homes.

Many interviewees discussed the growing use of tablet computers and smart phones in dementia care. Interviewees from an independent think-tank and innovation agency suggested that these technologies will be instrumental in shaping access to social care in the future. They explained that people with mild cognitive impairment and early-stage dementia – and their family members – many of whom have already incorporated these ICT devices into their daily lives, have access to the growing number of iOS and Android apps, which are designed specifically to support their needs. In particular, interviewees referred to a number of reminder and reminiscence apps designed to stimulate cognitive function for people with dementia. For instance, the Remind Me app provides reminder alerts (similar functions to the bespoke reminder devices mentioned above). The House of Memory app allows a person with dementia to look at images that evoke good memories, as well as incorporates an audio function that allows them to incorporate familiar sounds and music.

Interviewees also stressed that there are number of apps designed to support family carers of people with dementia: apps such as Jointly, Rally Round, Finerday are designed to assist family carers to coordinate – and to harness support from – the wider care network. There was also mention of apps designed as information and support resources for family carers (Talking Point, Assisted Living app).

State-of-the art in technology for dementia care

One interviewee from an organisation specialising in technology innovation explained some of the latest developments in technology for dementia care research. The first area of interest consisted of analytics technologies, which include ‘stratified medicine’ and diagnostic tools designed to identify those people at risk of dementia or in its early stages. The motivation behind this stream of research and development is the assumption that intervening in the early stages of the ‘dementia pathway’, while people have relatively few care needs, will translate into lower costs in the long run.

A second area of research and development is around the integration of ‘digitalised care pathways’ of long-term conditions, including dementia, into mainstream care systems. The digital care pathways are designed to join-up information from different care agencies in order to improve access to relevant health and other information by people with dementia and carers, enabling them to take more control over their care, and ultimately improving their care experience. An example of an integrated service generated from this stream of research initiatives is the electronic health records developed by the *delivering assisted living lifestyles at scale* (DALLAS) programme.

A third area of growing interest is in gaming technologies. According to one interviewee, products such as Xbox, WiiFit, brain teasers and other apps are being used increasingly in health and social care to support the management of long-term



needs and to maintain health, although we are not aware of evidence to support this view. The interviewee mentioned that research is being carried out on gaming technology, such as brain training, which is designed to support and stimulate brain function to help maintain – or to slow the rate of decline of – cognitive function in people with early stage dementia. Another interviewee, representing a leading technology development company, confirmed that entertainment and leisure apps for people with cognitive impairment are currently being developed for similar purposes.

Gaming technologies are also being developed as tools to elicit behaviour change, particularly in terms of medicine compliance. An interviewee explained the research being carried out on an interactive game for people with dementia, which reminds players to take their medication and displays the potential health and social outcomes of their choice to take or not to take their medication.

The final area of research and development is in memory and augmented reality technologies. These technologies are designed to help carers understand, in a virtual world, the experiences and needs of people with dementia. The technologies can also be used to train carers in dementia care by suggesting ways to help reduce levels of confusion in people with dementia and help them manage their condition.

The use of robots in dementia care attracts much attention in the media. While their use is not yet widespread, some robots, such as the pet seal Paro, are being tested in care homes in various countries and have been evaluated (Wada et al. 2005, Moyle et al. 2013). Other robots are being tested, mostly in Japan. An example is Papero (Inoue 2014), a small robot that delivers verbal messages (which can be inputted via a tablet by relatives) such as reminders about medication and activities. Humanoid robots such as Paro and Pepper have been tested in day care centres and nursing homes with the aim of providing stimulation and encouraging social interaction. Pepper has been developed to ‘read’ emotions and has specific apps to support independent living by people with dementia (Japan Times 2015). Finally, we sought the views and experiences of people with dementia and unpaid carers with regards to technology. We did this through consulting with a group of carers and conducting an internet search for published accounts of technology-use by people with dementia and their family carers. We present the details in section 5.

Table 1 below provides a list of the technologies according to their functions, which were mentioned in the literature, by interviewees, or on online forums. In the next subsection we provide a brief overview of the findings from the literature search and interviews with experts.

Mapping the technologies

In table 1 we have mapped the technologies using a framework that focusses on their function in the context of the ‘dementia pathway’, distinguishing the different phases of dementia severity, which individuals could potentially be helped by the technology, and the care setting in which the technology can be used.

As described in section 2, the framework distinguishes between six key functions of technology: memory and support of self-care and activities of daily living; treatment and intervention delivery; safety, security, monitoring and reassurance; training; care management; and supporting social interaction and engagement. We have also used an ‘other’ category for technologies that fall outside the scope of the identified functions.



In terms of the stages of dementia, we have included a stage prior to the development of dementia or cognitive symptoms, because, although this is not an area that we have had time to explore fully in this project, there are technologies that might have *potential* in influencing the risk of developing dementia, or delaying onset, either by encouraging lifestyle changes (encouraging exercise or changing diet), or by supporting the treatment of specific conditions that increase the risk of dementia, such as diabetes or high blood pressure. In the framework we group together mild cognitive impairment (MCI) and the earlier, or mild, stages of dementia, and we also group together moderate and severe dementia, as there is substantial overlap between the care needs of these groups. It should be noted that not all sources of information that we pulled together had specified explicitly the severity of dementia; in those cases we have assumed that more ‘care-intensive’ types of technology would be targeted at people in the moderate to severe stages.

The literature has further been split into two types of care settings: people’s own homes and formal care settings, such as day centres, care homes and clinical settings.

Thirdly, we distinguished the technology by the target beneficiary or user. Here we divided users into three groups: the person with dementia, their unpaid carers and paid care staff or clinical professionals. Some technologies only target one user group, others target two or more.

What technology functions are used when, where and by whom

Our mapping (detailed in the table) suggests that there is a role for preventive technology before people develop dementia.

Technology in MCI and early stages of dementia: Once people have MCI or are at the early stages of dementia, much of the technology is focussed on the person with dementia, supporting their ability to live independently with GPS and communication devices, technology that helps mitigate memory problems (such as medication reminders, locators, voice and visual cues to help perform daily activities, ‘dementia-friendly’ versions of household gadgets (such as adapted TV remote controls, etc.), and promoting self-management of health.

Technology can also facilitate the delivery of care, for example using videoconferencing to run memory clinics in rural areas, or delivering cognitive training or even art therapy.

People at the early stages of dementia or with MCI can also benefit from technologies to improve safety at home. Particularly because at this stage of the dementia pathway many people are able to live on their own, systems that monitor activity using sensors can also help relatives by reducing their anxieties.

We have found many examples of people with MCI or dementia using social media and the internet to obtain information about their conditions, share experiences, and obtain support and to facilitate an advocacy role.

Technology in moderate and severe dementia, when people live at home: In the moderate to severe stages, technology can play a role in supporting people’s ability to remain independent and maintain their skills, and therefore assistive and safety technology continues to play an important role, particularly in the moderate stages.



Unpaid carers often face huge demands at this stage, and may find it difficult to access support services outside their home. Technology can play a crucial role in delivering interventions to improve their health and wellbeing through the delivery of psychotherapeutic support groups, telecoaching, cognitive behavioural therapy or stress management (as discussed in more detail in section 2). Technologies such as baby monitors or more sophisticated night-time monitors can also help carers sleep better.

There is also an important role for technology as a means to coordinate care, either between different unpaid carers, or between unpaid carers and professional health and care services.

Technology is also used to deliver training, both to unpaid carers and professional care staff. Both people with dementia and carers can also benefit from technologies that facilitate social interaction and networking.

There is a growing 'therapeutic role' for technology, often used with devices such as tablets or digital music players, to help people with dementia reminisce and experience pleasure from their favourite music or films, and from looking at photographs (sometimes accompanied by verbal explanations). There is also evidence that some of these activities have benefits for unpaid carers, decreasing their levels of distress and offering some 'respite'. For example, the START intervention for family carers includes relaxation CDs (Livingston et al. 2014).

Technology in moderate and severe dementia, in formal care settings: We have found examples of technology being tested to help people in formal care settings, such as day care or care homes, to remain as independent as possible. In care homes in particular there is more emphasis on technology with therapeutic effects, such as pet robots, or simulated presence therapy, and therapeutic 'entertainment and reminiscence' delivered with technology, for example photo albums, music, games, films, karaoke-style apps, and so on.

Technology is used to link with the person's relatives, and in some cases, to help the relatives be more involved and understand better the care of their family members in the care home or day centre.

A growing number of care homes and day centres are using mobile technology to facilitate person-centred care and to take notes 'on the spot', to carry out risk assessments, and to coordinate with other professionals involved in the care of an individual outside the care setting. We have also found examples of technology being used to facilitate communication with people with dementia, including robot interpreters for people who speak a different language.

There are a number of practical care tools that are becoming widely used, such as sensor mats and movement sensors that reduce the need for checking on people at night.

**Table 1 Mapping technology onto the 'dementia journey': technologies identified in the literature and the interviews**

Stage of dementia	MCI/'early stages' of dementia (has diagnosis of dementia, but mild cognitive impairment as measured, for example, by MMSE)		
	Setting	Home	
Target user	Person with MCI or mild dementia	Carer	Paid carer/other professional
Tech function:			
Memory and support of self-care, daily living			
	<p>GPS and communication systems to support independence</p> <ul style="list-style-type: none"> • <i>GPS and communication device linked to unpaid carer</i> (Pot et al. 2012) [before & after pilot study, reports of increased ability to go outside on their own and more 'freedom from carer']. • <i>Wrist pager solution</i> (Tunstall Healthcare (UK) Ltd 2012b): Confidence/reassurance for service user they can call for help. Alert for family member. • <i>GPS functions in smartphones</i> (accessed verbally using Siri when getting lost), described by person living with dementia (LeBlanc 2015a). <p>Support with memory problems:</p> <ul style="list-style-type: none"> • <i>Medication reminders</i>: Reminder; alert for family network if medication not taken. (Alzheimer's Society 2014). • <i>(Dementia) Day clock</i> (Tynetec 2015). • <i>Loc8tor</i> (Loc8tor healthcare 2014): Helps service user find objects (e.g. wallet, keys). • <i>Voice Cue</i> (Attainment Co Inc) (Living made easy 2015b): Voice prompts remind of appointments, tasks. • <i>Memo Minder</i> (Gardener 2015): Recorded message reminds users to complete tasks as they walk past sensor (e.g. remind to bring keys). • <i>Remind Me App</i> (Aida Reminder Lite) (Licea 2015): reminder service. • <i>Smartphone alarms</i>: (Aida Reminder Lite) (Licea 2015): reminder service. 	<p>GPS and communication systems to support independence</p> <p>Examples:</p> <ul style="list-style-type: none"> • <i>GPS and communication device linked to unpaid carer</i> (Pot et al. 2012) [before & after pilot study, reports reduction in worry for carer, no change in burden]. • <i>Wrist pager solution</i> (Tunstall Healthcare (UK) Ltd 2012b): Confidence/reassurance for service user they can call for help. Alert for family member. • <i>Loc8tor</i> (Loc8tor healthcare 2014): GPS service allows family network to identify location of service user. • <i>buddi</i> (buddi 2014): Location service that allow carers to know where people are and speak to them. Also detects falls and sends alerts. <p>Own health checker:</p> <ul style="list-style-type: none"> • <i>NHS Health and Symptom checker app</i> (NHS choices health apps library 2013): Mobile advice, promotes self-managed care. 	



Target user	Person with MCI or mild dementia	Carer	Paid carer/other professional
Tech function:			
Memory and support of self-care, daily living			
	<p>Support with memory problems:</p> <ul style="list-style-type: none"> • <i>Automated Pill Dispenser</i> (York Health Economics Consortium 2013): supports compliance with medication by automatically distributing right amount of medication and setting of alarm to remind the person with dementia. • <i>Papero Robot</i>: small robot linked to a tablet that gives verbal reminders about medications and activities (Inoue, 2014). • <i>Pepper Robot</i>: humanoid robot with specific apps to support people with dementia with reminders, etc. (Japan Times, 2015). <p>Dementia-friendly versions of household gadgets:</p> <ul style="list-style-type: none"> • <i>HandleEasy TV remote control</i> (Doro) (Dementia Circle 2015): Simplified remote control, can help reduce confusion caused when using 'standard' remotes, allows people to continue using TV. <p>Own health checker:</p> <ul style="list-style-type: none"> • <i>NHS Health and Symptom checker app</i> (NHS choices health apps library 2013): Mobile advice, promotes self-managed care. 		
Treatment/intervention delivery			
	<p>Diagnosis and treatment via videoconference:</p> <ul style="list-style-type: none"> • <i>Memory clinic</i> for the Choctaw Nation (Weiner et al. 2011) [reports uptake, usage and intervention costs]. <p>Cognitive training delivered with computers, tablets or videogames:</p> <ul style="list-style-type: none"> • Combination of 27 independent <i>cognitively stimulating games</i>, but weak evidence, particularly with regards transferability. (Tedim Cruz et al. 2014) [evaluates uptake & usage, not effectiveness]. 	<p>Stress reduction interventions delivered through technology:</p> <ul style="list-style-type: none"> • <i>Online video conferencing psychotherapeutic support</i> (support group intervention facilitated by a clinician (appears to reduce improve mental health-related outcomes for carers: Marziali and Garcia 2011). Also text based chat group (comparison) showed significant improvement in self-efficacy. [evaluated not RCT, compared to other intervention]). 	



Target user	Person with MCI or mild dementia	Carer	Paid carer/other professional
Tech function:			
Treatment/intervention delivery			
	<p>Art therapy delivered via technology:</p> <ul style="list-style-type: none"> • <i>dPAD: art therapy platform</i> that uses artificial intelligence to engage users (Leuty et al. 2013) [small study evaluation usage and usability]. 		
Safety, security, monitoring, reassurance			
	<p>Home safety technologies:</p> <ul style="list-style-type: none"> • <i>Gas shut-off valve</i> (Tunstall Healthcare (UK) Ltd 2012c). • <i>Call blocker</i> (of unwanted and nuisance calls) (Tunstall Healthcare (UK) Ltd 2012c) Reassurance/confidence to service users that they can maintain privacy, feel less vulnerable while living at home. • <i>Carbon monoxide detector</i>: to detect and raise alarm in case of defective gas boiler (York Health Economics Consortium 2013). • <i>Smoke alarm</i>: setting off alarm in case of smoke from fire in the house (hob, cigarette) (York Health Economics Consortium 2013). • <i>Carbon monoxide monitor</i> (York Health Economics Consortium 2013). • <i>Heat extreme detector</i> (York Health Economics Consortium 2013). <p>Security:</p> <ul style="list-style-type: none"> • <i>Door contacts</i>: providing evidence of people leaving room or house at inappropriate times (night) (York Health Economics Consortium 2013). • <i>Flood detectors</i>: helps to detect water leakages or spillages (York Health Economics Consortium 2013). • <i>Natural gas sensors</i>: set off alarm if unlit gas detected (York Health Economics Consortium 2013). • <i>Bed monitors</i> (York Health Economics Consortium 2013): sets off alarm if a person gets out of bed and does not return after preset time; can switch on light when person gets out of bed. 	<p>Activity monitoring using sensors:</p> <ul style="list-style-type: none"> • <i>Just Checking</i> (Just Checking 2015): sensors feed information to an activity monitoring app on a tablet computer, showing daily routine. • <i>Pressure mats</i> (York Health Economics Consortium 2013): can indicate to carers when person with dementia gets up at night. <p>Monitoring alarms:</p> <ul style="list-style-type: none"> • <i>Just In Case</i> (Oysta Technology 2012): GPS and 2-way call features allow call centre/carer or family network locate service user and identify precise need of alert. 	



Target user	Person with MCI or mild dementia	Carer	Paid carer/other professional
Tech function:			
Training			
		<ul style="list-style-type: none"> Assistedliving app (ALT) (Virtual College 2015): resource about what, how and who ICT can help. 	<ul style="list-style-type: none"> Assistedliving app (ALT) (Virtual College 2015): Information resource about what, how and who ICT can help.
Care delivery, management and support			
	Recording care preferences: <ul style="list-style-type: none"> MyBrainBook (MyBrainBook 2015): Helps people record their needs, preferences and routines. 	Care coordination: <ul style="list-style-type: none"> Jointly (app) (Carers UK 2014b): Carers create network which facilitates communication and coordination of care. Rally Round (Rally Round 2015): Online service which helps coordinate informal care network. 	
Social interaction/networking			
	Social media: <ul style="list-style-type: none"> Use of social media, Twitter and Facebook, to share experiences, find information, obtain support and advocate (Clasper 2015b). 		
Other			
	<ul style="list-style-type: none"> Context-aware life logging: the application enables storage of information and can be used for reminiscence or memory support at later stage. (Kikhia et al. 2010). 		



Moderate to Severe dementia (1)			
Stage of dementia	Setting	Home	
Target user	Person with dementia	Unpaid/family carer	Paid carer/other professional
Tech function:			
Memory and support of self-care, daily living			
	Assistive technology to support living at home: <ul style="list-style-type: none">• <i>Memory aids</i> (Riikonen et al. 2010) [Before & after, mixed methods, small sample multi-technology study. Outcomes: potential delay in care home admission].• <i>Medication dispensers</i> (Riikonen et al. 2010) [Before & after, mixed methods, small sample multi-technology study. Outcomes: potential delay in care home admission].• <i>PAL 4-dementia tablet date/diary functions</i> (Nijhof et al. 2013a) [Before & after study, establishes usability, potential care burden reduction].• <i>Devices using audio/video prompts</i> (with artificial intelligence) to guide through performance of ADL activities (Mihailidis et al. 2008) [Efficacy study, six people, showed some increases in independence].	Own health checker: <ul style="list-style-type: none">• <i>NHS Health and Symptom checker app</i> (NHS choices health apps library 2013) Mobile advice, promotes self-managed care.	
	Dementia-friendly versions of household gadgets: <ul style="list-style-type: none">• <i>Easy to use desk phone</i> (Riikonen et al. 2010) [Before & after, mixed methods, small sample multi-technology study. Outcomes: potential delay in care home admission].		
Treatment/intervention delivery			
	Delivering dementia clinics via videoconference: <ul style="list-style-type: none">• <i>Dementia clinics delivered via videoconference</i> in rural Australia. (Comans et al. 2013) [comparison with 'conventional' face to face clinic, related papers established effectiveness. Cost-effective if travelling more than two hours].	Interventions delivered through technology: <ul style="list-style-type: none">• <i>Dementelcoach</i>: telecoaching intervention for carers (Van Mierlo et al. 2012) [before & after, controls, found carers who received telecoaching & day care reported greater feeling of competence than those who only received telecoaching].	



Target user	Person with dementia	Unpaid/family carer	Paid carer/other professional
Tech function:			
Treatment/intervention delivery			
		<p>Interventions delivered through technology:</p> <ul style="list-style-type: none"> • <i>Online video conferencing psychotherapeutic</i> support group intervention facilitated by a clinician (Marziali and Donahue 2006) [small pilot RCT, found reduction in stress compared to control]. Also, Marziali and Garcia (2011), where, compared to text based chat group, showed significant improvement in self-efficacy, [evaluated not RCT, compared to other intervention, shows improved mental health outcomes]. • <i>Telehealth Education Program (TEP)</i>: telephone-based information for carers, self care/caring advice and support group (Wray et al. 2010) [RCT on US Veterans, compared to usual care, outcomes: 10 week intervention, reduces formal care costs at 6 months but not at 12 months]. • <i>REACH (Resources for Enhancing Alzheimer's Caregiver Health)</i> intervention, delivered via telephone (Nichols et al. 2011) [extensively evaluated inc. RCTs, although evaluations of intervention, not technology]. • <i>Cognitive Behavioural Therapy: Delivered via DVD</i> to Chinese carers in the US (Gallagher-Thompson et al. 2010) [RCTs, but evaluation of intervention, not technology]. • <i>Icare stress management programme for carers.</i> (Kajiyama et al. 2013). [RCTs, but evaluation of intervention, not technology]. • <i>E-care technology-based psychoeducational intervention</i> for carers, based on REACH (Finkel et al. 2007) [small RCT, found dec. carer burden and depression]. • <i>Research into cognitive behavioural therapy</i> (Alzheimer's Society 2013). 	



Target user	Person with dementia	Unpaid/family carer	Paid carer/other professional
Tech function:			
Safety, security, monitoring, reassurance			
	<p>Safety technology:</p> <ul style="list-style-type: none"> • Various home safety: <ul style="list-style-type: none"> – Cooker alarms (Riikonen et al. 2010) [Before & after, mixed methods, small sample multi-technology study. Outcomes: potential delay in care home admission]. – Smoke detectors (Riikonen et al. 2010) [Before & after, mixed methods, small sample multi-technology study. Outcomes: potential delay in care home admission]. – Fall detector alarms (Riikonen et al. 2010) [Before & after, mixed methods, small sample multi-technology study. Outcomes: potential delay in care home admission]. – Locator systems (Riikonen et al. 2010) [Before & after, mixed methods, small sample multi-technology study. Outcomes: potential delay in care home admission]. – Motion sensitive lights (Riikonen et al. 2010) [Before & after, mixed methods, small sample multi-technology study. Outcomes: potential delay in care home admission]. – Flood detector (Alzheimer's Society 2014, York Health Economics Consortium 2013). – Property exit sensor (Tunstall Healthcare (UK) Ltd 2012c): Alerts family network if service user leaves home unexpectedly. – Temperature extremes sensor (Tunstall Healthcare (UK) Ltd 2012c). – Carbon monoxide detector: to detect and raise alarm in case of defective gas boiler (York Health Economics Consortium 2013). – Smoke alarm: setting off alarm in case of smoke from fire in the house (hob, cigarette) (York Health Economics Consortium 2013). 	<p>Night time monitoring system:</p> <ul style="list-style-type: none"> • Night time monitoring system, tracking movement and giving alerts (Rowe et al. 2010) [pretest-posttest controlled study, carers report better sleep but not observed by sleep monitoring technology]. • Bed sensor (Tunstall Healthcare (UK) Ltd 2012c): Alert family member when person with dementia does not return to bed after prolonged period. <p>Safety monitoring:</p> <ul style="list-style-type: none"> • SeNCit (SeNCit 2013) Monitoring device that sends family members SMS alerts about adverse events in the home. • Just In Case (Oysta Technology 2012): GPS and 2-way call features allow call centre/carer or family network locate service user and identify precise need of alert. • Canary (Canary 2015): monitoring and notification system to alert unpaid carers to unexpected events; also visitor card system which logs the time paid careworker arrives. 	<ul style="list-style-type: none"> • Information Management System to assess risk. Staff can enter notes related to safety and risk. The system enables sharing that information, alert to and remind of specific information entered (Riskman 2012).



Target user	Person with dementia	Unpaid/family carer	Paid carer/other professional
Tech function:			
Safety, security, monitoring, reassurance			
	<p>Safety technology:</p> <ul style="list-style-type: none"> • <i>ADLife preventive sensor technology</i> (Nijhof et al. 2013b) [Before & after, usability. Qualitative evidence of reduced carer worry]. • <i>HOPE-ICT</i>: integrated smart platform to support independence and monitor conditions. (Pilotto et al. 2011) [Survey asking people if they would find it useful after watching a video about it]. • <i>Panic button: Just In Case</i> (Oysta Technology 2012) allows service users to contact call centre or family member when in distress when out and about. • <i>Pendant telecare alarm</i> (e.g. MyAmie): Provides service user with reassurance that they can get help when needed. (Tunstall, 2012a). • <i>Baby monitors</i>: reported use by unpaid carers. 		
Training			
		<p>Training for carers about dementia and caring role:</p> <ul style="list-style-type: none"> • <i>Telehealth Education Program (TEP)</i>: telephone-based information for carers, self-care/caring advice and support group (Wray et al. 2010) [RCT on US Veterans, compared to usual care, outcomes: 10 week, reduces formal care costs at 6 months but not at 12 months] • <i>Assistedliving app</i> (ALT) (Virtual College 2015): Information resource about what, how and who ICT can help. • <i>About Me e-learning</i> (Carers UK 2014a): Course modules on building networks, finding support and taking care of carers. 	<ul style="list-style-type: none"> • <i>Assistedliving app</i> (ALT) (Virtual College 2015): Information resource about what, how and who ICT can help. • University of Salford (University of Salford 2015): <i>Dementia Care and the Enabling Environment</i> (MSc, Pg Cert, Pg Dip): certificate and degree course.



Target user	Person with dementia	Unpaid/family carer	Paid carer/other professional
Tech function:			
Care delivery, management and support			
	<p>Recording care preferences:</p> <ul style="list-style-type: none"> • <i>MyBrainBook</i> (MyBrainBook 2015): Helps people record their needs, preferences and routines <p>Care assessments:</p> <ul style="list-style-type: none"> • <i>Interactive games online</i> (Staffordshire Cares 2015): Online needs assessment presented as interactive game can assist service users to access services they need which will help them live independently at home. 	<p>Supporting carers with dealing with challenging behaviour:</p> <ul style="list-style-type: none"> • <i>Interactive Voice Response</i>: to help carers manage disturbing behaviours commonly associated with caregiver stress, also 'distraction calls' for care recipient (Mahoney et al. 2003). [RCT, no significant overall effect] <p>Supporting carers in caring role:</p> <ul style="list-style-type: none"> • <i>Internet-based Caregiver Support Service (ICSS)</i>, connects Chinese Canadian carers to therapists who support via email or text message. (Chiu et al. 2009). [Before & after, usage/uptake, reports carer burden but no control]. • <i>ACTION ICT system</i>: software package with info on dementia and caring and videophone with contact to trained personnel in call centre and other carers (Lundberg 2014) [before & after study, only usage]. • <i>ALADDIN</i>: pc-based platform including education material, contact with other carers & clinicians and telehealth features (Torkamani et al. 2014) [multi-centre RCT, small numbers, country differences not explored, outcomes: small differences in carer burden & carer QoL]. • <i>PAL 4-dementia tablet</i> (Nijhof et al. 2013a) [Before & after study, establishes usability, potential care burden reduction]. • <i>Video conferenced support group for carers in rural settings</i>, with professional facilitator (O'Connell et al. 2014) [Before & after: usage, usability, some carer wellbeing feedback]. • <i>DEM-DISC</i>, customized e-advice on health and social support services for informal carers and case managers of people with dementia (Van-Mierlo et al. 2015) [cluster RCT, system may make carers more aware of their needs, carers with higher needs use system more]. 	<p>Care coordination:</p> <ul style="list-style-type: none"> • <i>PAL 4-dementia tablet</i> care coordination function (Nijhof et al. 2013a) [Before & after study, establishes usability, potential care burden reduction]. • <i>Red Embedded Systems</i> (RED Embedded Systems 2014): Managed video care system that links carers from different sectors using TV. <p>Care assessments:</p> <ul style="list-style-type: none"> • <i>Interactive games online</i> (Staffordshire Cares 2015): Online needs assessment presented as interactive game can assist service users to access services they need which will help them live independently at home. <p>Supporting personalised care:</p> <ul style="list-style-type: none"> • <i>MyBrainBook</i> (MyBrainBook 2015): Helps carers deliver personalised services.



Target user	Person with dementia	Unpaid/family carer	Paid carer/other professional
Tech function:			
Care delivery, management and support			
		<p>Supporting carers with dealing with challenging behaviour:</p> <ul style="list-style-type: none"> Tablets and computers: used by carers to find information and resources on the internet to support their caring role. <p>Care coordination:</p> <ul style="list-style-type: none"> <i>Jointly (app)</i> (Carers UK 2014b): Carers create network which facilitates communication and coordination of care. <i>Rally Round</i> (Rally Round 2015): Online service which helps coordinate informal care network. 	
Social interaction/networking			
	<ul style="list-style-type: none"> <i>PAL 4-dementia tablet</i> (Nijhof 2013a) [Before & after study, establishes usability, potential care burden reduction]. <i>Talking Point (app)</i> (Alzheimer's Society 2015a): Support forum and information resources for service users. <i>Finerday</i> (Finerday 2015): Social networking tool for service users, formal carers and family networks. <i>iPad</i>: device can support reminiscence, enhance interaction and communication and contribute to recall. (Upton et al. 2011). 	<p>Video communication:</p> <ul style="list-style-type: none"> <i>PAL 4-dementia tablet</i> (Nijhof 2013a) [Before & after study, establishes usability, potential care burden reduction]. <p>Other networking:</p> <ul style="list-style-type: none"> <i>Telehealth Education Program (TEP)</i>: telephone-based information for carers, self-care/caring advice and support group (Wray et al. 2010) [RCT on US Veterans, compared to usual care, outcomes: 10 week, reduces formal care costs at 6 months but not at 12 months]. <i>Finerday</i> (Finerday 2015): Social networking tool for service users, formal carers and family networks. 	<ul style="list-style-type: none"> <i>PAL 4-dementia tablet</i> (Nijhof 2013a) [Before & after study, establishes usability, potential care burden reduction]. <i>Finerday</i> (Finerday 2015): Social networking tool for service users, formal carers and family networks.
Other			
	<p>'Therapeutic' entertainment: games, music, films, photos:</p> <ul style="list-style-type: none"> <i>PAL 4-dementia tablet</i> (Nijhof et al. 2013a) [Before & after study, establishes usability, potential care burden reduction]. 	<p>'Therapeutic' entertainment use by the person with dementia: games, music, films, photos (potential respite effect for carer):</p> <ul style="list-style-type: none"> <i>MP3 players loaded with individualised musical content</i> (Lewis et al. 2015) [Before & after study, no control, outcome: decreased psychological distress for family carers, offered some 'respite']. 	



Target user	Person with dementia	Unpaid/family carer	Paid carer/other professional
Tech function:			
Other			
	<p>‘Therapeutic’ entertainment: games, music, films, photos:</p> <ul style="list-style-type: none"> • <i>MP3 players loaded with individualised musical content</i> (Lewis et al. 2015) [Before & after study, no control, outcome: decreased psychological distress for family carers]. • <i>Photo Album</i> (Lifemax Ltd) (Living made easy 2015a, ABC News 2010): Helps service users reminisce about past events with photos and a descriptive recorded message. • <i>House of memories (app)</i> (National Museums & Galleries on Merseyside 2015): Allows service users to look at images that evoke good memories. Family members can help build ‘memory box’. • <i>Use of tablets</i> to look at family photographs: reported by carers. • <i>MP3 player connected to a ‘pillow speaker’</i> to help deal with sleep interruptions, reported by carers (SoundAsleep 2015). • <i>Digital televisions/DVD players</i> to watch favourite films, reported by carers. 		



Moderate or severe dementia (2)			
Setting	Care home (or other formal care setting)		
Target user	Person with dementia	Carer	Paid carer/other professional
Tech function:			
Memory and support of self-care, daily living			
	Technology to support independence in daily tasks: <ul style="list-style-type: none">• <i>Technology-based verbal and pictorial cues</i> to support independence in daily tasks, tested in day centre (Lancioni et al. 2012) [sample of 3, feasibility study rather than evaluation].• <i>Orientation system using voice cues and light probes</i>, tested in day centre (Lancioni et al. 2013) [sample of 5, feasibility study]. Technology to support mobility: <ul style="list-style-type: none">• <i>Anti-collision power wheelchair</i> (Wang et al. 2011) [usability testing, very small study].		
Treatment/intervention delivery			
	'Therapeutic' robots: <ul style="list-style-type: none">• <i>Paro (robotic seal)</i> (Wada et al. 2005) [before & after, outcome: improvement measured with EEG] (Moyle et al. 2013) [randomised crossover study, small sample, found increased QoL, reduced anxiety, increased wandering].• <i>Sony Aibo</i> (Sony-AIBO 2015): Robot reacts to owner's voice and face. Management of challenging behaviour: <ul style="list-style-type: none">• <i>Simulated Presence Therapy (SPT)</i> using audio or videotape (Zettler 2008) [Meta-analysis: significant positive effect].		
Safety, security, monitoring, reassurance			
	Sensors: <ul style="list-style-type: none">• <i>Sensor mats, movement sensors</i> (Cheng and Zhuang 2011).		Sensors: <ul style="list-style-type: none">• <i>Sensor mats, movement sensors</i> possibility of aggregating data to analyse movement patterns (Cheng and Zhuang 2011).



Target user	Person with dementia	Carer	Paid carer/other professional
Tech function:			
Safety, security, monitoring, reassurance			
Sensors:			
			<ul style="list-style-type: none"> ● <i>Information Management System</i> to assess risk; the system allows staff to enter notifications which can be displayed on a screen (Riskman 2012).
Training			
		<ul style="list-style-type: none"> ● <i>Virtual dementia experience</i>: providing virtual experience of dementia for staff and carers (Alzheimer's Australia 2015) 	<ul style="list-style-type: none"> ● <i>Assistedliving app</i> (ALT) (Virtual College 2015) Information resource about what, how and who ICT can help. ● University of Salford (University of Salford, 2015): <i>Dementia Care and the Enabling Environment</i> (MSc, Pg Cert, Pg Dip): certificate and degree course. ● <i>Virtual dementia experience</i>: providing virtual experience of dementia for staff and carers (Alzheimer's Australia 2015).
Care delivery, management and support			
			<p>Support of person-centered care/care coordination/care recording:</p> <ul style="list-style-type: none"> ● <i>Micro-blogging mobile phone app: Carer</i> (adapted Yammer), used with mobile device in two care homes (Pitts et al. 2015) [Before & after, outcomes: including note taking, perhaps due to more flexibility of mobile device, also used to 'know to expect before a shift'.] ● <i>MyBrainBook</i> (MyBrainBook 2015): Helps carers deliver personalised care ● <i>re:Member app</i>: 'internal Facebook' app used to deliver person-centred care, accessible to families in an Alzheimer's health club (Memory & Company, 2015). <p>Communication tools:</p> <ul style="list-style-type: none"> ● <i>Talking mats</i> (Murphy et al. 2010) [cross over study, outcomes: in people with moderate dementia perform better than other types of conversation].



Target user	Person with dementia	Carer	Paid carer/other professional
Tech function:			
Care delivery, management and support			
			<p>Practical care tools:</p> <ul style="list-style-type: none"> • <i>Enuresis pad</i> (Tunstall Healthcare (UK) Ltd 2015a): Minimised night-time disturbance to service user: carers only came when alert sent, rather than come in each night to 'check'. Maintained dignity. • <i>Radio Frequency Identification buttons</i> (Tunstall Healthcare (UK) Ltd 2012c): Allows care home staff to identify owner of clothes. Protect dignity of service users by wearing their own clothes. • <i>CareAssist</i> (Tunstall Healthcare (UK) Ltd 2015b): Portable device; allows care home staff to receive alerts and to identify service user and specific sensor sending alert.
Social interaction/networking			
	<p>Tech. to enable communication with people outside care home:</p> <ul style="list-style-type: none"> • <i>Giraff</i>: Telepresence robot to enable communications with family members (Moyle et al. 2014) [feasibility study]. • <i>Videophones</i>: enable communication with family and encourage social interaction (Mickus & Lutz 2002) [feasibility study]. 	<p>Tech. to enable communication with relatives in care homes:</p> <ul style="list-style-type: none"> • <i>Giraff</i>: Telepresence robot to enable communications with family members (Moyle et al. 2014) [feasibility study]. 	
Other			
	<p>'Therapeutic' entertainment: games, music, films, photos:</p> <ul style="list-style-type: none"> • <i>Talking Photo Album</i> (Lifemax Ltd) (Living made easy 2015a): Helps service users reminisce about past events with photos and a descriptive recorded message. • <i>House of Memories (app)</i> (National Museums & Galleries on Merseyside, 2015): Allows service users to look at images that evoke good memories. Family members can help build 'memory box'. • <i>iPods (with earphones)</i>: use of specific music playlists (90 minutes) (Alzheimer's Disease International 2012). 		



Target user	Person with dementia	Carer	Paid carer/other professional
Tech function:			
Other			
	<p>‘Therapeutic’ entertainment: games, music, films, photos:</p> <ul style="list-style-type: none"> • <i>Entertainment robots:</i> such as Pepper, Palro, NAO, used to encourage interaction (AJDC Team, 2013; Khosla, R., 2015, Alzheimer’s Australia 2014, Inoue 2015). • <i>Interactive display of photos and text messages:</i> photos and messages are created on iPads by clients. Care manager also has access to internet embedded programme (reference provided by care manager; Upton et al. 2011). • <i>Nintendo Wii:</i> games to engage people with dementia (Padala 2008, Tobiasson 2010) [observational]. • <i>Flipcam:</i> short films with and about people with dementia, encouraging social engagement and re-developing cultural identity (Capstick 2011). • <i>Living the moment:</i> a number of computer games delivered on a large touch screen to stimulate active engagement (Alm et al. 2012) [research at the University of Dundee]. • <i>Picturegramophone:</i> personalised music can be combined with images. Lyrics of songs can be shown on screen (Topo et al. 2004). • <i>Sensory therapy</i> (Huntsman 2014): providing people with dementia with a virtual environment using video game technology. • <i>RemindMeCare</i> (RemindMeCare 2015): tablet-based tools to store and explore the personal history of a person with dementia, for use as a reminiscence tool for formal carers and families. 		



5. Views of people with dementia and carers

In this section, we report on views about technology of people living with dementia and carers. We have tried to gain an understanding of which technologies they use, how they use them, the positive and negative aspects they experience and, where possible, what they consider to be barriers to the use of technology.

As this is a short-term project, we have not been able to collect views directly from individuals for the purposes of this study, as we did not have enough time to obtain NHS ethics approval or to carry out fieldwork. We have instead adopted a pragmatic approach that we understand to be consistent with ethical guidelines.

With regards to people with dementia, we have relied on accounts of their use of technology that were publicly available in the internet. We have only used public-domain material from blogs. We also found discussions in online forums where people with dementia shared their views and experiences, but as we could not be sure that the people writing were fully aware of the public availability of the information they shared, we considered that we should not reproduce that material in a report.

For unpaid carers, we used a different approach. As this project was conducted in collaboration with the MODEM project (funded by ESRC/NIHR, 2014-18, led from the LSE and involving many of the authors of this report) – and which will be able to build on some of the research initiated in this short-term project – we used a meeting of the MODEM reference group of carers and people with dementia (for which we have ethical consent) to ask those present if they would like to share with us, via email, their experiences of using technology. Also, one carer who was recently interviewed in person for the MODEM project (with ethical approval) provided helpful information. In total we have information from seven carers. While we have not reproduced it here, as it is already on the Department of Health's website, there is also a well-known blog by a carer of someone with dementia and sight loss who lives alone (Spink 2013).

We also report on the use of technology at a very forward-thinking care facility in Canada, whose staff were happy to write to us about how they run their facility using technology.

Views and experiences of people with dementia

This section draws on three personal blogs. All three are written by people with early onset dementia who, given their ability to write and manage blogs and use social media, were probably already highly competent in the use of technology before developing dementia. The bloggers discuss both positive and negative aspects of technology.

Most of the technology they discuss is not dementia-specific, but they do report positive experiences about using items such as smartphones and computers to help them cope with some of their dementia-related symptoms. There are also examples of their views on the use of some technologies available for people with dementia, such as GPS tracking devices, even if they have not used them personally (Clasper 2015a), and also an interesting post where the blogger points out that a 'dementia-specific' app basically does the same as standard apps and questions the need for the 'dementia-specific' label:

While I understand the idea behind this app, and it is “FREE” to download, instead of choosing the songs they have on their app, there are tons of places to download free songs on your phone or tablet that can be tailored to your loved one's tastes (LeBlanc 2015c)



There is a description of a remarkable situation in which LeBlanc, when getting lost driving to somewhere that had been familiar to him (because it was familiar he did not know the address to look it up), accidentally turned on 'Siri' on his smartphone (an 'intelligent personal assistant with natural language user interface') that/who recognised the name of the place he wanted to reach and safely guided him there (LeBlanc 2015a). These various positive experiences of using technology are illustrated with excerpts from these blogs in the first box below.

Some of the negative examples discussed by these bloggers provide interesting suggestions for ways in which technologies could be made to work better for people with dementia. For example, smartphones, tablets or computers that rely on passwords can become very difficult to use for people with dementia, as described in the example below by Clasper (2015c). New smartphones and tablets with fingerprint recognition systems could be a much better alternative for people with memory impairments. Another negative example comes from a person finding that, as her dementia advances, the alarms that used to help her before are becoming confusing as she struggles to identify what they are for (Truthful Kindness, 2015). Clasper also finds that the use of mobile phones in public events can be very disruptive, as noise signals make it harder to follow what a speaker is saying, for example (Clasper 2015d). There is also a post that describes how the use of social media means that people with dementia may become upset when encountering people making distasteful jokes about dementia (LeBlanc 2015b). In the second box below we quote some illustrations extracted from these blogs of the various *negative* experiences of using technology.

Positive examples of the use of technology (excerpts from blogs)

a. The advantages of *global positioning system tracking devices* and the implications for loss of autonomy or freedom (Clasper 2015a)

'We are and should be allowed to enjoy going for walks etc., if we really want to, because we are more entitled to do so than those claiming to know all about us. We are living with this illness, and therefore know what it's like, and usually know our limits, although I confess we can get that wrong as I have found out before. But at the same time our carers have enough problems in life without watching over our every move, and they also have other things to sort out like shopping and also looking after themselves. ...

But if we really want to be honest, how many people these days use mobile phones social media etc? Yet each and every one of these devices can and are tracked by satellite, so why is it so wrong for joe public to be tracked on their mobile phones, yet it's wrong for people with dementia to use tracking schemes which are life savers. At the end of the day, it's a similar system through a SIM card within the tracker and all done through a mobile phone system.

Yes there are people out there who could misuse these schemes, but let's be very honest, you only need to look at the Governments who fiddle expenses, are they really are better or trust worthy, yet most of these people are well known and very well paid.

I personally think that those people who think the use of trackers is wrong, also think that those with dementia etc, should sit in a chair and not move. It's these people who do not understand the illness, yet they are trying to dictate to those living with it.'

b. Positive aspects of *social media* (Clasper 2015b)

'I think that if you can hang on to the computer, the world is your oyster, because you can keep in touch with others in the same boat. You can discuss your problems with others, and you soon realise that you



are not alone. The thought [of] having an online written conversation with someone in a far corner of the planet is amazing, yet it would have been thought impossible 10 years ago.

I personally find Facebook easier to follow, because you can look back to see what others have written, and follow it a lot easier than Twitter. On Facebook there are also different sections for people with various illnesses, just like self-contained chat rooms. Twitter is sometimes difficult to follow because, you are having to follow the topic from the beginning, and that to me is very hard at times.

I know for a fact that although some look at social media with disdain, it's certainly kept me going over the last few months when things have been stressful. So to me it has a very good role in supporting people these days.'

c. Using “personal assistants” in smartphones when getting lost while driving (LeBlanc 2015a)

'... Back to me sitting in the car in a complete blank state of mind. I don't how long I was there. I again went to my phone to try and look for the Google Maps app. I pushed the main button on the phone and I guess I held it for too long. I heard a sound and the words, “What Can I Help You With” appeared on the screen. It was my friend Siri.

Embarrassingly I started to cry, uncontrollably, you know the point in a movie where someone is stranded on a small, uninhabited island in the middle of the ocean and they see a ship headed their way to save them? THAT kind of uncontrollable crying!

Although I couldn't remember the name of the restaurant, I could remember Bang Bang Shrimp. So I asked Siri where to find Bang-Bang Shrimp. Bonefish Grill came up with directions.

SIRI SAVED ME!!!

(...)

Thank you **Siri**, and **Apple**. Making an app to be used as a personal assistant, in my opinion, was the best thing you've ever done. I sincerely hope people like me will use this feature instead of just asking: What is 0 divided by 0?'

d. Using a digital music player (Clasper 2015c)

'I have an Apple iPod touch where I store my music. This is very useful for me especially if I cannot sleep at night.'

e. Using the alarm function in smartphones (LeBlanc 2015d)

'For me, it would be very easy to just sleep the day (and night) away and let my Alzheimer's World just pass me by, not having to face things that normal-brained people don't even have to think about. For instance, I now have an alarm on my phone that goes off every morning, noon and night to eat. Yes ... to eat.

On a recent visit from my sister and brother-in-law, my sister noticed I had lost a good bit of weight. She asked about my eating habits and I told her, for the most part, I was eating very healthy. Shannon, my wife, said, “when he remembers to eat.” Hearing it said out loud, I came to the realization that I had been forgetting to eat on a regular basis. You would figure your empty stomach sends a message to your brain that says, “FEED ME!” My stomach probably does that but my brain forgets to tell me.

So in addition to the alarm telling me to eat, it also tells me when to take my medicine(s), when to get on my ALZ Assoc conference calls, when to read my emails, etc. Thank goodness for the alarm function on my iPhone.'



Negative examples of use of technology (excerpts from blogs)

a. The disruptive ‘overuse’ of mobile phones (Clasper 2015d)

“People doing presentations are always disrupted, by mobile phones going off, and when you have a memory problem or and neurological illness it really disrupts things. If you have dementia etc., it can get you to the point where you really do not know where you were. Even meetings can be disrupted when someone’s mobile phone rings.’

b. On alarms and how their appropriateness/usefulness changes with the progression of dementia (Truthful Loving Kindness 2015):

‘CRUMBLES !!

There goes another useless alarm of some type.

Tru here on July 30. This morning is driving me crazy. Since I have lost my auditory sense of direction, I can hear the sound but cannot tell what direction sound is coming from. And my memory is impaired so cannot remember what sounds the different appliances emit. I suspect the piercing chirps this morning were from smoke alarm somewhere. When I hear the other sounds I don’t know whether to check the toaster, stove, the convection oven, the landline phone, my cell phone, or look around for what I have forgotten elsewhere. Once in a while I figure out what is making the sound, but probably half the time I give up before figure it out. It is all just so very frustrating; an exercise for futility and patience. For many years alarms were wonderful tools to meet needs... but this year? ... I think I have progressed past their usefulness. grr-r-r !!’

c. On frustrations caused by passwords and software updates (Clasper 2015c)

‘Last week I had an update from Apple, and when it was downloaded, it wiped most of my music off the machine, and I found this to be horrifying. I confess that there was so much writing in the agreement, that I lost track and gave up, perhaps next time I will refuse to update things like this.

I tried to reload it, but got confused with all of the passwords, so I tried to reset it and made a complete mess of it. I even had new passwords sent through, but got them mixed up. So I gave up and left well alone.’

d. On negative aspects of social media: encountering stigma and ignorance about dementia, after encountering people joking about memory lapses using the #EarlyOnsetAlzheimers hashtag (LeBlanc 2015b)

‘... I also realized that newly diagnosed individuals use #EarlyOnsetAlzheimers to find out information that may help them cope, help them understand, help them get through to another day. They don’t go there to find people making jokes or pretending to have this disease.

So, for all those “Twitterers” out there who thinks it’s funny to use #EarlyOnsetAlzheimers to make jokes, I ask you to go to you a nearby care facility. Look at the faces of people with #Alzheimers. Look at the faces of their friends and family. Go to my Twitter account and look at my face. Take plenty of mental pictures so the next time you want use #EarlyOnsetAlzheimers to make a joke, use your brain to recall what you saw and realize that each day, those of with Alzheimer’s disease lose a little piece of our brain each and every day.’



Views and experiences of unpaid carers of people with dementia

Most of the carers from the MODEM reference group reported that they use technology that is not specific to caring or to dementia, such as tablets, baby monitors, smartphones, iPods, light sensors, ‘speaker pillows’, etc. None of the carers that we spoke to appeared to have been using technology obtained through statutory services. They have, instead, used a ‘DIY’ approach, using technologies that were easily available and probably already familiar to them.

We have summarised their accounts in table 2 below, where we have extracted the technologies used, the technologies that were mentioned explicitly as not being used, how the technology is (or was) used, the barriers encountered during use, what would help overcome those barriers, and what they perceive to be the benefits of technology.

Most carers mentioned using a tablet and/or a smartphone, both to support them in organising care and finding information, and to maintain relationships, particularly when moving as a result of the care situation.

The greatest barrier to technology seems to be difficulty obtaining flexible training and support. Access to flexible support managing day-to-day technology, perhaps through drop-in centres or specially trained home support staff is seen as the best way for carers to overcome their difficulties with the use of technology.

We also came across the blog by Spink (2015), who describes his own ‘DIY’ to remotely care for his father. While this may be not be a typical example, as he is a particularly technology-literate unpaid carer, it illustrates that individuals can access, in the open market, the components to create remarkably sophisticated systems:

“Before I knew it I had installed the following: talking motion sensors and personalised recorded messages that call Dad to the toilet, radio or front door; a cheap timer plug with a mains-powered talking motion sensor; and a personalised recorded message tells Dad to go back to bed if he tries to walk around during the night. I got them all on Amazon. Importantly, I bought different types to see what was the most efficient.

When Dad told me he was getting lost I realised that I could buy cameras that cover the downstairs living area. I bought four and can now keep an eye on him all day from my computer or my phone.”

**Table 2 Summary of views and experiences on the use of technology to support caring by unpaid carers of people with dementia**

Technology used	Technology not used (<i>where mentioned explicitly</i>)	How the technology is/was used	Barriers to use of technology	What would help	Perceived benefits of technology
Carer 1 Tablet Smartphone (in same way as tablet when tablet not to hand)	Telecare: explored but did not use it 'jointly' (purchased from Carers UK): not used because care home staff did not have the time, but carer thinks it would have been a useful tool if she had purchased it when he was still at home.	Tablet/smartphone: To share photos and videos of family members (<i>reminiscence, keeping up with family</i>) For music, films, etc (<i>reminiscence, entertainment</i>) To communicate (or attempt to) with far away relatives	In care homes: Staff did not have enough time		
Carer 2 Tablet Smartphone Television/ DVD/ Freeview box			<i>Lack of technology literacy</i> Others don't have time to help Difficulty coordinating drop-in centre's hours with caring schedule Drop-in centres can't help with non-portable devices Person with dementia interferes with technology Person with dementia used to deal with technology in the household, carer did not develop competence	Training so less reliant on others to use technology More support, at flexible times	Doing things online could save time
Carer 3 Speaking clock (but needs to remind X to use it)	Tablet (has one but has not really used it, after the meeting, considering using to show photos to X)				
Carer 4 iPod Shuffle Speaker pillow Light sensors in landing and bathroom		<i>Relaxation:</i> iPod Shuffle loaded with around 300 pieces of music, which she has attached to speaker pillow (a pillow with speakers inside). Used during the night to help X sleep. Light sensors come on if X gets up during the night to go to the toilet (<i>safety</i>)			Use of iPod/ speaker pillow : 'He sleeps better and goes back to sleep better if he wakes during the night'



Technology used	Technology not used (where mentioned explicitly)	How the technology is/was used	Barriers to use of technology	What would help	Perceived benefits of technology
Carer 5 Computer (used both by carer and person with dementia)	'Less interested in the use of robots '	Computer (use by carer): use 'in general'; professional use; researching the internet; communicating with friends & family; booking holidays; managing bank accounts; paying bills etc. Specific use related to caring for someone with dementia: writing a blog, sharing information with other carers, researching Frontotemporal Dementia. Computer use by person with dementia: write letters, manage photographic collection, play simple games		<i>Funding</i> for carers to purchase a PC/digital tablet <i>Support and train</i> them in basic ICT usage <i>Fund support workers</i> to make home visits to help them to manage their daily affairs and keep in touch with family/friends by email, Skype, etc.	Way of supporting carers from the 'relative peace of convenience of their own homes'
Carer 6 Wristlet alarm Baby monitor iPad	Pressure mat connected to an alarm to detect getting out of bed at night: used in the nursing home her mother lived in, but feels that, while useful in care home, not particularly useful at home.	Wristlet alarm connected to a home control box and L.A., if alarm sounds a voice asks if help is needed, or if no reply summons help. Feels that this can also be done with a mobile/cordless phone (completely unconscious). Got for own health reasons when realised that husband could no longer help Baby monitor: with two cameras, one in bedroom and one in sitting room, with portable monitor, so can keep an eye from anywhere in the house, bought to monitor if getting out of bed, now mostly to keep eye on choking risk. iPad was used in earlier stages to show slide shows of family photos.			
Carer 7 iPad	Big button phones/easy to use mobile phones , they needed to be set up and/or programmed. They were not used.	iPad was used, but can no longer be used independently. It can still be used to show pictures.	The ability of the person with dementia being able to use technological devices diminished very rapidly.		



Example from an innovative dementia care setting, managed with technology

Memory & Company is a 'health club' for people with dementia near Toronto, Canada. It offers day care for people with dementia, but with an emphasis on recreation and wellbeing. The aim is that people feel that they are going there to have a nice time, socialising and practicing their hobbies, rather than to be cared for. It is owned and run by two entrepreneurs who respectively have a background in technology and care.

The centre is managed using iPads, which are used by all the staff members. On the iPads they use a variety of off-the-shelf apps, both closed and open source. The iPads are used for a range of tasks including, but not limited to, security, access control notification, communication, and entertainment.

One app in particular has been created by the owners of the health club to manage the day-to-day operations. It handles scheduling, bookings, payroll, billing, and most importantly, "member management". They call it "re:Member", and describe it on their website (<http://memoryandcompany.com>). re:Member is similar to a private Facebook. Information is retrieved from their private server so that in the event an iPad were to be stolen, it would contain no private information. Each member has a profile and quick reference to important data such as emergency contacts, allergies, wander/fall risks, do not resuscitate orders, etc. But what re:Member is mostly used for is, in medical terms, 'charting' or in social media terms, a 'timeline.'

The staff members are encouraged to take social pictures, videos, and notes, throughout the day, of the members. This is considered a 'fun and light' activity, but the information can also be used to monitor people's condition. Although this is not 'live' yet, re:Member will allow family and health professionals to log in to view. If, for example, a family notices a change in their relative, then they or their doctor can peruse a full journal for indicators and symptoms.

The centre also finds the app helpful from a customer satisfaction standpoint, as they can show that the members are having a good time, even if the members cannot/do not communicate their experiences back to their families. Also, from a health and safety standpoint, they can document any accidents or injuries sustained and steps the steps taken to provide first-aid.

The app also contributes to a better business-flow, eliminating the need for staff members to sit at a desk at the end of the day, to do charting. Their system allows documentation to be done while still fresh in the staff member's mind, and allowing the recording to happen while still 'on the floor.' They have also designed their app to integrate the iPad's native Siri function, thus being able to speak-to-type. The owners feel that 'fresh-in-mind, on-the-floor, and speak-to-type all contribute to not only increased productivity, but quality productivity.'

From a business perspective, since they designed the app, they own it. This also means that, when polished, they can potentially licence it off as a revenue stream. They have had enquiries from the care industry about their system, but are not yet ready to licence it, as 'we are still beta-testing our own product'. In fact, not all the functions have been turned on yet or integrated.

Because of their technology-friendly approach, Memory & Company is also able to collaborate with research institutions. For example, they have partnered with Baycrest (a leading gerontology hospital and research facility) and the Art Gallery of Ontario, who have designed an app for art therapy. They have also partnered with the neurosciences department at York University (Canada), which has created an app that appears to slow down the progression of (and in some cases, improve) cognitive ability which Memory & Company are piloting.



Music and technology at Memory & Company

'As for the music area, we use iPads paired with Bluetooth headphones. We chose this method instead of wired headphones to minimize damage should a member get up to walk or dance. Every amplifier in our building, for that matter, has a bluetooth receiver.

We offer our members (and families) the free service to create personalized playlists of music of their choice, but we have found that no one has taken up the offer. Rather, we have found that our members prefer selecting genres instead of specific songs. So now, we simply loaded an internet radio app on the iPads which streams music, and can be classified by genres.

Our members' tech-savvy and abilities range. One gentleman carries and uses his own smartphone. He would be an example of someone who can use the iPad on their own once they have been familiarized with the internet radio app. Virtually all other members require assistance.

But you know what we find attracts our members the most? Our record player! They love selecting based on album cover, and loading the record themselves. And surprisingly, with all the different genres of music, when it comes to the record player, they will all gather around and dance, regardless of what music's being played. We're finding that it is more important for them to be social together, everyone listening and communicating about the same song, than it is to enjoy their own song alone on their own.'

(<http://memoryandcompany.com>)



6. Lifetime costs of dementia care and potential impact of technology

Scope and summary

To make an economic case for the use of technology to support people with dementia and their carers it is essential to show that technology can either reduce the substantial costs of care for dementia and/or improve the quality of life of the person with dementia or their (unpaid) carer. Moreover, the saving in costs of care or the value of the gain in quality of life needs to exceed the cost of the technology. It is usually considered sufficient to consider only the costs of formal care and support services, but much of the costs of care for dementia consist of the opportunity cost of unpaid care by family and friends. The analysis needs to consider wider societal costs and benefits. This is especially important given the recognition given in legislation to carers' needs, and also the pivotal role played by carers in allowing someone with dementia to continue to live in their own home.

We conduct our analysis in terms of lifetime costs of care for an individual person with dementia. The main reason for considering lifetime costs rather than annual costs per person is that some technologies involve purchase of equipment which may last for several years, in effect a form of capital expenditure. Since lifetime costs and benefits accrue over several years, we express them in both undiscounted form (as used in budgeting such as spending reviews) and discounted form (as used in economic appraisals).

We estimate that the lifetime costs of dementia care in old age are on average £200,000 per diagnosed person at 2015/16 prices. This relates to costs of all health care, formal social care and unpaid care by family and friends, from the point of diagnosis of dementia onward. Around half of this cost relates to formal health and social services (including privately funded services) and half to the opportunity cost of unpaid care. After discounting at 3.5% per year, the present value of this cost is £187,000.

We examine the impact of technology on the lifetime costs of care through three scenarios. We planned to examine the impacts of the scenarios over different time spans: short (three years), medium (five years) and longer-term (10 or more years). At the individual level the time span of the impacts is discussed under each scenario. At the collective level, however, we have not found any evidence to assess quantitatively the likely speed of uptake of current and emerging technologies.

Method

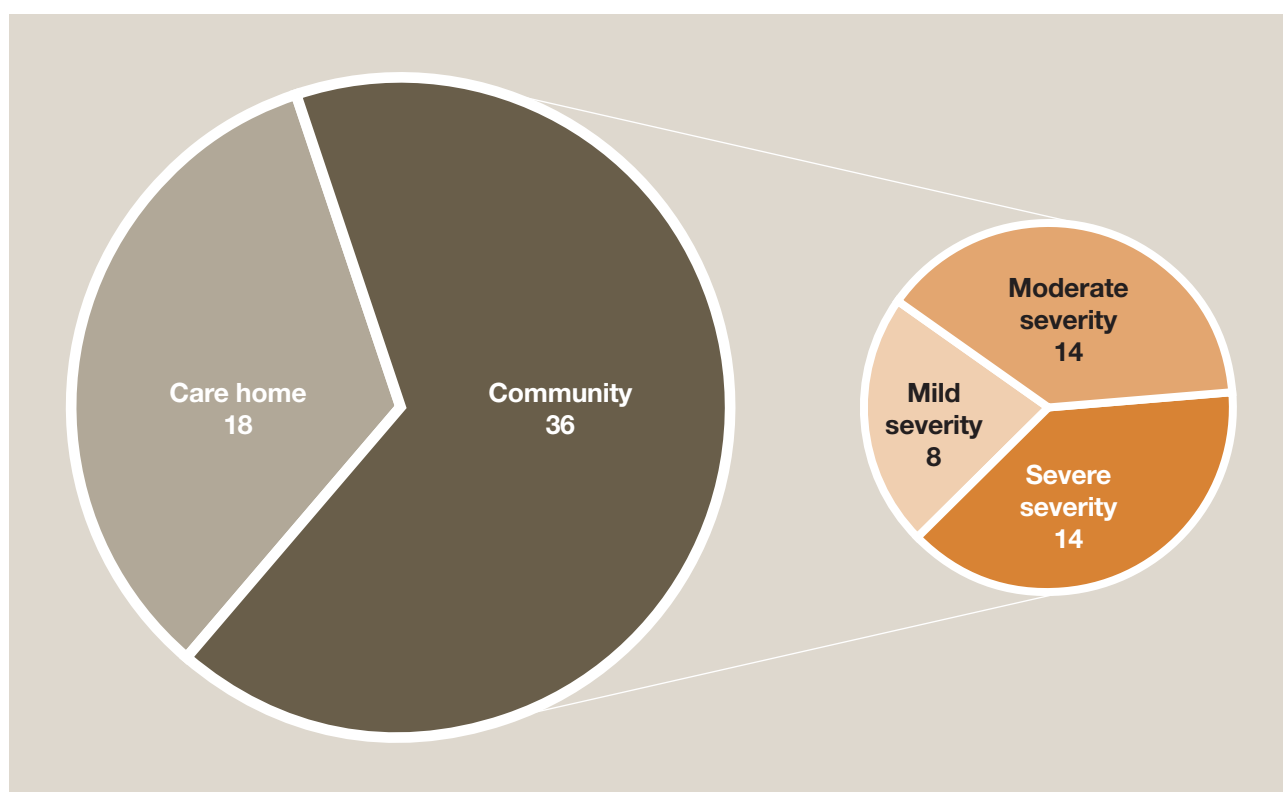
Our cost estimate relates to a person whose survival with dementia is 4.5 years from onset to end of life. We use a figure of 4.5 years since Xie et al. (2008) found a population-based median survival for incident dementia of 4.5 years, with an inter quartile range of 2.8 to 7.0 years. It should be noted that our estimate relates to the period from onset of dementia and not from diagnosis, which may be a considerable time after onset.

We divide this median duration of 4.5 years first between home-based care and residential care, and then between periods of mild, moderate and severe cognitive impairment. The Cognitive Function and Ageing Study (CFAS) found that around 30% of older people with dementia are resident in a care home and that around 70% of care home residents have dementia (Matthews et al. 2013). This suggests that, typically, 1.5 years with dementia are spent in a care home and 3.0 years in the community.



Since the great majority of people with mild cognitive impairment do not have dementia, we assume that only 15% of the 4.5 years is with mild cognitive impairment. In the absence of data we assume that the rest of the 3.0 years in the community are divided equally between moderate and severe cognitive impairment. This produces a breakdown of eight months mild cognitive impairment, 14 months moderate cognitive impairment, 14 months severe cognitive impairment in the community, and 18 months in a care home (as illustrated by figure 1). Our cost estimate is not especially sensitive to the exact breakdown between severity groups of the period of three years in the community; i.e. changes to that assumption do not much alter the cost calculations.

Figure 1 Estimated median survival with dementia by care location and severity of cognitive impairment in months (at baseline)



We apply to each month of care an appropriate monthly per capita cost. The costs of residential and nursing home care are derived from official statistics (Health and Social Care Information Centre 2014). A diagnosis was assumed to cost £700, a community care assessment £525 and care management £1,400 per year (Knapp et al. 2014; estimates uprated to 2014/15 prices).

The costs of care of home-based care and unpaid care, for each severity level, are derived from our analyses of service use data from a number of trials, as described in Knapp et al. (2014). We were able to collect, from a dozen studies in which we had previously participated, detailed information on about 1,400 people with dementia and on more than 200 carers. From the trials we use (retrospective) baseline data only (for both intervention and control groups). Services and support data for individual people with dementia were recorded in those trials, in all but one case using adapted versions



of the Client Service Receipt Inventory (CSRI) completed by a family or professional carer (Beecham and Knapp 2001). Coverage in those studies was comprehensive across all services, including (but not confined to) inpatient stays, outpatient attendances, day hospital treatment, visits to social clubs, meals at lunch clubs, day care visits, hours spent in contact with community-based professionals such as community teams for older people, community psychologists, community psychiatrists, general practitioners, nurses (either practice, district or community psychiatric), social workers, occupational therapists, paid home help or care workers, and physiotherapists.

In all studies, information was collected on unpaid support provided by family and friends. Data on hours of unpaid care provided by carers are available for co-resident and non-co-resident carers, and these are totalled. In some studies, co-resident carers had been asked to estimate the percentage of time they could spend away from the person with dementia (e.g. 0–25%, 25%–50%), and we take mid-points of these ranges and convert them into hours (assuming a waking day of 16 hours). The method used to value the hours of unpaid care has been described in detail in our chapter in Prince et al. (2014 p76). It distinguishes between the estimated caring time spent providing ‘hands-on’ assistance with personal care tasks (activities of daily living) which is valued at replacement cost, and other care activities, which are valued using an opportunity costs approach.

The service use data collected in the individual studies noted above are converted to cost estimates. The studies from which data were drawn had used unit costs that reflect reasonably well long-run marginal opportunity costs, and generally came from sources in the public domain – mainly from the PSSRU volume (Curtis 2013) and the National Health Service Schedule of Reference Costs (for inpatient and outpatient costs). All costs are inflated to 2015/16 prices.

The costs are those of the total care and support used, not just those that can be directly attributed to dementia. It is not possible with the data available for this study to separate costs associated with treatment and care of dementia from those associated with treatment and care linked to *other* health or social care needs. Indeed, in a clinical context it would often be extremely difficult to separate the reasons for particular treatments and care arrangements.

We have summed the costs for each month for each severity of cognitive impairment and care setting for all 54 months, and added the cost of diagnosis and community care assessment. This produced our estimate of around £200,000 for the lifetime cost of dementia, comprising around £30,000 for health care, £70,000 for social care and £95,000 for unpaid care, all before discounting. It should be noted that there are also other costs of dementia, such as special housing costs, policing, etc., which are not taken into account and that are likely to be low relative to the costs of care.

Healthcare costs are assumed to be met entirely by the NHS. Social care costs would be met on average around half by local authorities and half by people with dementia themselves, through self-funding their care or through user charges; but for any individual the proportion met by their local authority depends on their savings and income. The costs of unpaid care fall to the carers, although they may receive social security benefits (especially Carers Allowance) and/or social services support in recognition of their caring role. Carer costs are generally not out-of-pocket payments but the opportunity costs of time spent providing unpaid care and support. Savings in carer costs are therefore mostly not ‘cashable’, but nevertheless represent important societal contributions to the lives of people with dementia.



Potential impact of technology

We examine the impact of technology on the lifetime costs of care through three scenarios which consider the impact on unpaid carers. This is because we have found some evidence that technology can have a positive impact on carers, for example reducing the burden of caring. We have not found robust evidence on whether technology has a direct impact on the quality of life of people with dementia using scales which we could adapt for scenarios. This does not mean that technology does not benefit people with dementia themselves, as well as their carers; it is simply that extant evidence has not been generated using any measures which we were able to turn into monetary magnitudes (either as cost savings or outcome valuations).

In fact, in the literature review carried out for this study (see section 2 above), we have found several examples of technologies that benefit both members of the ‘care dyad.’ For example, an evaluation of a GPS and mobile communication device was found to reduce worry in carers and at the same time provide people with dementia with an increased ability to go outside on their own and greater independence (from their carer) (Pot et al. 2012). Another example is an MP3 player loaded with a personalised music list which was found to reduce carer stress significantly, as well as providing ‘valued respite’ (Lewis et al. 2015).

There are other technologies that have been shown to have a positive effect on the person with dementia. For example, evaluations of the Paro seal, a therapeutic robot, by Wada et al. (2005) and Moyle et al. (2013) report some positive outcomes for people with dementia in care homes. Unfortunately, we have not found studies that report the type of evidence of benefits to people with dementia on which we could base scenarios for our analyses.

There are also many examples of technology being used to deliver interventions to improve the health and wellbeing of carers, resulting in positive outcomes for carers in terms of their competence (Van Mierlo et al. 2012), self-efficacy (Marziali and Garcia 2011), burden and depression (Nichols et al. 2011) or stress (Kajiyama et al. 2013, Gallagher-Thompson et al. 2010). However, those studies do not evaluate technologies *as such*; rather they look at interventions that involve substantial non-technological therapeutic inputs, which means that the outcomes reported cannot – on the basis of the evidence reported – be attributed to the technologies used.

Ideally, we would have modelled the impact of using technology on the observed costs and outcomes reported in economic evaluations. However, most of the evaluations of the impact of technology we have found, as discussed in sections 2 and 4, are very small and tend to focus more on the uptake, usage and usability of technologies, rather than on the outcomes for the person with dementia and/or the carer. Most of the studies that do report outcomes, with the exception of a few small randomised controlled trials, are before-and-after studies.

Scenario 1: Postponement of care home admission

It has been argued that technology can allow people to stay in their own home for longer and delay admission to a care home. While in our literature review we have not found any articles that provide robust evidence of delays to institutionalisation, we have found a small Finnish study where, in the professional opinion of care managers, the use of assistive and safety technologies would delay care home admission by eight months on average for the people in the sample (Riikonen et al. 2010).



Based on that study, we model a scenario where assistive and safety technologies are assumed to postpone care home admission by eight months, which in our analysis reduces the period in a care home from an average of 18 to an average of 10 months.

Under this scenario the cost of formal health and social care over the period of 4.5 years is reduced by around £13,000 (present value of £11,750 after discounting at 3.5% per year). This means that, from the health and social care perspective (i.e. excluding carer costs), the technology intervention would be cost-effective provided that its cost plus the cost of the assessment and care services that may need to accompany it was less than £13,000 (present value of £11,750) over 4.5 years.

However, under this scenario the *overall* cost of care over 4.5 years is increased by £8,000, before considering the cost of the intervention, due to an increase in the cost of unpaid care of some £21,000 (present value of £19,000 after discounting), assuming that the daily number of hours of unpaid care remains the same. This means that, from a societal perspective, the technology intervention would not be cost-effective if its only effect was to postpone care home admission. To be cost-effective the intervention would need not only to postpone care home admission by eight months but also reduce by almost 20% the carer's weekly hours of caring, to reduce the unpaid care cost by £21,000.

Figure 2 Cost distributions (health and social care verses unpaid care) for our baseline and first scenario

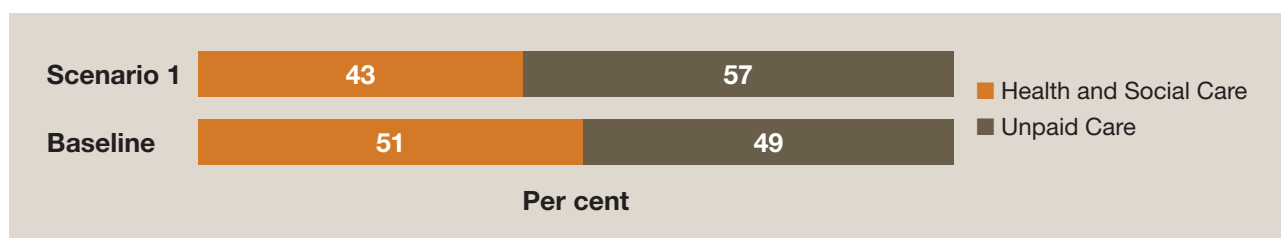
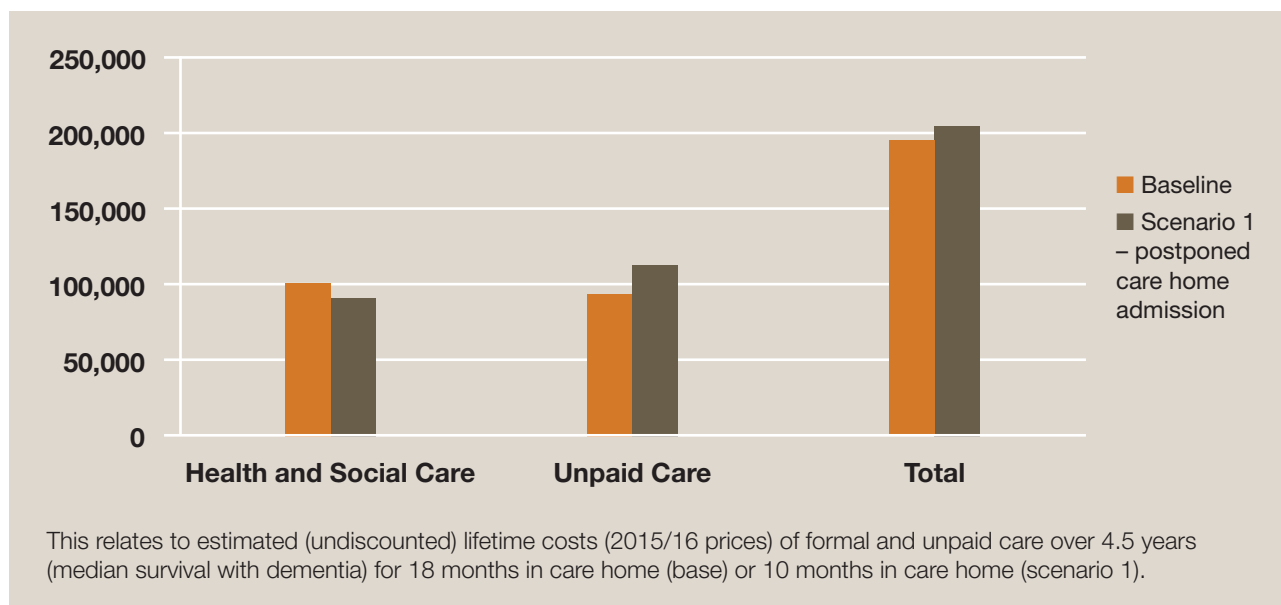


Figure 3 Estimated lifetime costs of care (£) per person, with and without postponement of care home admission





Scenario 2: Reduction in carer stress

Another way in which the economic impact of technology can be evaluated is by considering its impact in terms of gains (or losses) of quality-adjusted life years (QALYs). Many technology interventions aim to decrease the stress and carer burden experienced by unpaid carers and to improve their quality of life. Therefore, effectiveness evaluations that measure the impact of technology on outcomes such as quality of life or carer burden can be used for economic modelling. Empirical analyses which we have conducted using data collected in the START trial (described in Knapp et al. 2013 and Livingston et al. 2013, 2014) but reanalysed for the purposes of this study confirm that, for example, reported decreases in carer burden measured with the Zarit scale are associated with improvements in quality of life on the EQ-5D scale, which can be used to calculate gains in QALYs.

We now consider a second scenario where technology is assumed to reduce carer stress and increase the carer's quality of life by 0.05 on the EQ-5D tariff. The increase in quality of life is assumed to last for three years, that is, while the person with dementia lives in the community. This scenario is informed by the findings of a study by Torkamani et al. (2014) which found that carers of people with dementia using the technology intervention (in this case a computerised platform designed to minimise carer burden and distress) reported significantly lower burden of care at six months, as well as an improvement in quality of life of 5%, compared to the control group.

If a QALY is valued at between £20,000 and £30,000 (which is the cost-effectiveness threshold range employed by NICE, which some health economists have used to value QALY gains), the value of the carer's quality of life gain under this scenario would be £3,000 to £4,500 (slightly less after discounting). This means that from a societal perspective, the technology intervention would be cost-effective so long as its cost, plus the cost of the assessment and care services that may need to accompany it, was less than £3,000 or £4,500 over 4.5 years.

However, there would be no reduction in the cost of formal services and no cash-releasing saving under this scenario. To achieve cost-effectiveness from both a health and social care and a societal perspective, the quality of life improvement would need to be combined with a delay in care home admission and a reduction in the number of hours of unpaid care. An example would be a technology intervention costing less than £13,000 over 4.5 years which produced a quality of life gain for the carer of 0.05 QALY per year, postponed care home admission by eight months and reduced the carer's weekly hours of caring by around 15%.

Scenario 3: How much benefit, relative to costs, should technology produce to be cost-effective?

Finally we consider a scenario where the technology intervention and accompanying assessment and services costs £5,000 over 4.5 years, or more specifically over the period during which the person with dementia lives in the community if the technology ceases to be of value after care home admission. This intervention would be cost-effective from a health and social care perspective if it postponed care home admission by around three months or more. To be cost-effective from a societal perspective it would also need to reduce the carer's hours of care by around 8% or increase the carer's quality of life by some 0.06 to 0.08 QALYs per year or some combination of these two positive effects.



Summary of scenarios

Table 3 summarises the necessary conditions for cost-effectiveness – from both health and social care and societal perspectives – for the three scenarios.

Table 3 Summary of necessary conditions for cost-effectiveness for three scenarios

Requirements for cost-effectiveness	Delay in care home admission	Reduction in unpaid care hours/costs	Carer QoL gain	Total cost of the intervention
Scenario 1 Eight-month postponement in care home admission	8 months (fixed)	20%	N/A	< £13,000
Scenario 2 0.05 QALY gain for carers	8+ months	15%	0.05 (fixed)	< £13,000
Scenario 3 Total intervention cost of £5,000	3+ months	8%	0.06-0.08	£5,000 (fixed)



7. Investment and state action

The final aim of our study was ‘to get an understanding of the type of investment required to develop technologies in this field, and for what types of technology. This would include examination of the role that state investment could play, and whether it could act as an effective accelerator to development of the technology and delivery of subsequent economic benefits.’

By its very nature, therefore, this section is pulling together some of the evidence described earlier in this report, including lessons from the literature review, the views of a wide range of individuals with an interest in this area, and our economic modelling. Many of our interviewees were asked questions directly linked to this aim. We describe their responses in this section, and also draw on other evidence, organising our findings around what we call the barriers to the use of digital and other technologies in care of people with dementia. We then pull out implications for policy and state investment.

We were able to get some information from 24 people with experience or expertise in the area: academic researchers (n=7), providers of remote care services based in the UK (3) and in Spain (1), local authority commissioners of adult care services (including one specialising in dementia services) (6), an independent telecare service commissioner (1), an independent home care provider (1), and health practitioners (2). We also held discussions with people from third sector organisations, including one person each from a leading dementia charity, an independent government agency for technology innovation, and an independent think tank for ICT solutions for care. In addition, we were able to draw on material from interviews with, and reports by, people with dementia and unpaid carers on their experiences of using technology and (in particular for this aim) the perceived barriers to its use, and how those barriers might be overcome.

It will probably not be a surprise, given what we have reported already, that we interpret ‘investment’ quite broadly in this section: what could be the role of the state in order to encourage the appropriate, economically justified use of technology in supporting people with dementia and their carers?

Demand for technology

There are numerous different sources of demand for technology in the context of dementia care, and it is perhaps helpful to distinguish the different stages of dementia, mindful of the considerable inter-individual differences that are experienced across the population. Needs and potentially also preferences change over time, and so the services that individuals want and from which they might benefit – both telecare and others – should therefore change too.

Technology can potentially support *dementia risk-reduction* by changing behaviours and improving health from quite early in life right through into old age. This has not been our focus in this study, but it was alluded to during our interviews, and might include diet and exercise reminders and aids (apps, for example), perhaps also brain games, if their effectiveness has been established.

With *MCI and in the early stages of dementia*, when people will typically not be eligible for local authority (LA) support, many will already be in touch with memory clinics in the health sector, and there might be benefits derived from use of digital and other technology at this stage of their illness. This view came through quite strongly from the interviews. If there was any formal public sector encouragement, advice or



support for using technology at this stage, it would presumably be easiest to arrange through the NHS, although local authorities might see longer-term cost advantages in encouraging wider use of technologies by people with dementia or their carers, provided those technologies can be shown to be effective. At this stage of dementia, any technology that is used will most likely have been purchased privately – by the person with dementia or their family (one interviewee referred to ‘tech-savvy’ children and grandchildren purchasing apps for their older relatives) – from third or private sector care providers or direct from technology providers.

There are often differences between the supply of telecare services in the statutory and private-pay markets. One remote-care provider noted that many suppliers of private-pay services offer simple pendant alarm services; very few supply more advanced monitoring systems to self-funders. However, the interviewee expected that private service providers will soon offer a wider range of telecare as they are beginning to realise the potential of this market. Whether the complexity of the needs of many recipients has been factored into this projection is unclear. There may also be differences in the response mechanism, although increasingly it appears that, when an alert is raised, a call centre will arrange the appropriate response from a designated relative, neighbour or friend, whether the remote-care service is provided by a statutory body or is self-funded. Several of our expert interviewees referred to what they saw as (in the words of one person) the ‘obvious social and economic benefits’ of telecare services for people with MCI or mild/moderate dementia. At that stage of their illness, it was thought that people are able to understand and to learn new techniques for managing their activities of daily living, whereas they would be less able to cope with ‘new ways of doing things’ in the more severe stages.

At the *moderate and severe stages of dementia*, and if someone with dementia is still living at home, their level of need is likely to mean they will be eligible for local authority support, even if they have to pay for services themselves. There is therefore potential for them to be offered telecare services as part of a funded or organised care package (perhaps taking advantage of a publicly brokered block contract or negotiated price), or to purchase such services from a personal budget or direct payment. Continuing assessments will be required as individual needs, circumstances and preferences change. Current budgetary pressures on adult care services, coupled with growth in the number of older people with needs for care and support (and particularly the rapid growth in the number with dementia), are shifting the eligibility threshold and hence the boundary between publicly supported and self-funded care.

The suggestion was also made that ‘frugal technologies (simple, low-cost mainstreamed technologies)’ would be best, being more acceptable to people with dementia, especially if they can be used for general purposes in their daily routine (see our discussion of design and related issues later). Direct payments or the individual’s own income resources could be used to purchase such low-cost devices.

As we found from our literature review, growing attention is being paid to the use of technology to deliver interventions to support *carers*, thereby reducing anxiety, stress or burden.

If someone with more severe dementia needs to move into a care home, then technology might be used as part of the support provided in that setting, typically to support paid care staff, but it could also allow family members to keep in touch or to monitor the care that is provided. This raises questions about staff training and attitudes, something to which we will return later in this section.



The potential purchasers of technology – including the ‘brokers’ who could interact between those purchasers and the suppliers – can be identified as including at least the following:

- individuals who do not have dementia but who might purchase and use technology as a preventive strategy;
- people with MCI or dementia;
- unpaid carers of people with MCI or dementia;
- other relatives or friends who may not necessarily be very active as regular carers but have concerns that prompt them to purchase technology to monitor or support;
- community bodies such as third sector organisations (e.g. Age UK, Alzheimer’s Society) that might make some services available in their day care and other facilities;
- local authorities purchasing on behalf of people who are eligible for public support because of their social care needs and economic means;
- NHS bodies; and
- providers of care services (e.g. care homes), most of whom will be in the private sector.

As described earlier, there are many technologies that could potentially support people with dementia in their own home or in a care home, or support their unpaid carers. They include safety devices to reduce the risk of adverse events, monitoring devices to collect data on vital signs or check for falls, assistive technologies to aid mobility or control the environment, information and communication technology to provide customised advice or support self-care, and medication or other reminders to help people live independently. These technologies vary in complexity and cost. What then are the barriers to the use of these technologies in the care of people with dementia? In the subsections that follow we discuss a number of (inter-connected) barriers and what they might imply for ‘state investment’, interpreting that latter term broadly.

Under-developed technologies

One barrier to the use of digital and other technologies could be that what is currently available is not appropriate or effective for people with dementia and/or their carers, and more work is needed to develop new, better technologies that work outside of the controlled environments in which some are tested, and/or when delivered at scale.

Remote-care providers, service commissioners, and an interviewee from a think tank for ICT solutions for care all argued that the main delivery route for technology for dementia care is likely to be through statutory health and social care services in the form of telecare (alarm and monitoring) and telehealth (vital signs monitoring) devices and services. Service commissioners explained that most common telecare service deployed by local authorities consist of simple pendant alarms, even though these might be completely ineffective for most people with moderate/severe dementia and many people with mild dementia would not qualify for local authority help. (Of course, simple technologies have been available for quite some time in municipal sheltered housing, so it is actually possible to access telecare in some places without having to go through either adult social care or a private provider.) These commissioners also commented that more recently they have been deploying a greater number of more sophisticated monitoring services (such as bed sensors and door exit alarms) and GPS localisation services to people with dementia.

The supply chain for digital and other technologies used by people with dementia and carers is complex, involving a number of stakeholder groups from private,



public and third sector organisations. Even within the statutory sector system – as commissioners and remote-care providers explained – alert signals generated by pendant alarms and monitoring devices, for example, are transmitted to call centres which, although often initially run by individual local authorities, are now quite likely to have been consolidated into a smaller number of larger centres spanning several local authority areas and often out-sourced to charities and private sector companies.

Several of the experts we interviewed referred to the small, but growing, consumer market for mainstream ICT devices (e.g. smartphone, tablet computers, laptops) and apps which are used to support the needs of people with dementia and their carers. The suppliers of the ICT devices are the large technology companies such as (but not exclusively) Apple, Lenovo, Samsung and Sony. The suppliers of the apps designed to support people with dementia and their carers are often small or medium-sized enterprises, although an interviewee from a large remote-care provider indicated that they too will soon be entering the market with a range of apps for care. In fact, the technology available to people with dementia and carers in the UK originates from a variety of suppliers from both within and outside the UK, some of which are operating in much larger markets than the UK. They could reasonably be expected to be sources of continuous innovation, not just linked to the ‘dementia care market’ (if we can use that term) but to the rapidly growing wider market for assistive devices and, more generally, for digital and robotic technologies for all manner of purposes across the national and global economy.

No single technology or technology-enhanced service provided by any vendor has been found to be the ‘silver bullet’ that addresses all or even most of the needs of people with dementia and their carers. The emphasis should be on making existing technologies ‘fit for purpose’ rather than developing new systems. It is not uncommon for manufacturers to ‘invent’ a new device and then afterwards give consideration to how it should be used and to whom it should be marketed. But the close involvement of people with dementia and their carers is needed in designing and testing new devices that could work for them, providing feedback about needs that could have a technological solution.

We see no major ‘market failures’ on the supply side, but there are many difficulties – barriers as we are referring to them here – on the demand side. Developing strategies to foster the development of needed skills could play an important role in upgrading the appropriate, ethical, sustainable use of technology in commissioned services. But even when initial findings are encouraging, these positives often seem to evaporate when technologies are scaled up, perhaps because of loss of skill at the assessment stage. Indeed, for those people with dementia who receive care and support through local authorities, our review of evidence on this matter – which is admittedly not very plentiful – suggests that only a few local authorities have developed models for providing appropriate technology-enhanced services.

As will become clear as we consider the range of barriers below, we have avoided recommending any strategies that might lead to picking any one particular technology, partly out of a concern that it would quickly be surpassed by newer technologies, but mainly because the focus should be on improving the match between technology, need and expressed preference through careful and ongoing assessment; i.e. the focus needs to be on the human factors in engaging with the technology rather than the functionality of gadgets.



Evidence barriers

We have already summarised the available evidence on the use of digital, robotic and other technology in the care of people with dementia. The evidence base includes a number of positive studies and testimonials, but overall there is not a great deal of evidence, and some of it is quite weak methodologically.

However, as we have already noted, what came through quite clearly from a number of our interviews was that carers often derive considerable benefit from off-the-shelf technologies (tablets, smartphones, baby alarms and MP3 players). More sophisticated, dementia-focused technologies could prove to be even more useful: remote-care providers whom we interviewed suggested that some technology services, such as alarms and monitoring systems designed to support people with dementia to live independently at home, are also effective in abating some of the anxieties felt by family carers. An interviewee from a specialist think tank suggested that by incorporating technology earlier on in the progression of dementia it offers greater potential for building up the ‘resilience’ of the informal care network by, for example, spreading responsibilities across several carers, and that this network might then become a resource for support as the needs of the person with dementia change over time. Using ICT platforms, different forms of community support network for unpaid carers might be created. Another interviewee, from an independent government agency for technology innovation, agreed that introducing early technical interventions for people with dementia could help reduce carer stress, and added that early intervention could also enable some carers to maintain their participation in the paid workforce, thereby contributing to national productivity. ICT services and applications can facilitate communication, information and support between carers (and with care professionals).

As discussed in the literature review, technology is already used, particularly in the U.S., as a means to deliver effective interventions to improve the unpaid carers’ health and wellbeing through the delivery of psychotherapeutic support groups, telecoaching, cognitive behavioural therapy or stress management. It is also well known from other research that the availability of supportive unpaid care can have a major bearing on the quality of life of people with dementia living in the community, and also have an impact on costs, for example by reducing the likelihood of nursing home admission (e.g. Hébert et al. 2001, Knapp et al. 2015, Luppá et al. 2010, Woolham 2006, Yaffe et al. 2002). Yet until recently, relatively little attention has been paid in research as to how technologies might support carers in their day-to-day activities.

Statutory guidance to section 2 of the Care Act makes clear that councils’ responsibilities on prevention relate to carers as well as people with disabilities, and that they are not limited to people with current eligible care needs for care packages. It specifically mentions assistive technology to help carers (paragraph 2.16), and reminds councils that they may not charge for aids and adaptations costing less than £1000, which presumably applies to IT hardware, although in any case councils have not usually charged for carer support. There is also perhaps a need to consider whether there are any ethical issues here: the provision of telecare specifically to support carers could be seen to shift the purpose of the intervention from using technology to try to compensate for disabilities directly caused by dementia to using it to offer reassurance to carers and to reduce carer burden and stress. However, if the way in which telecare is deployed in order to manage behaviours by someone with dementia that carers found troublesome, and thereby disempowering the person with dementia, this might make its use less acceptable. We think that these kinds



of ethical issues would need to be considered carefully in each case and carefully calibrated judgements made accordingly. This raises further questions about who would be required to make these kinds of judgements, and the determination of the circumstances in which they are necessary.

An important barrier, therefore, is simply the absence of good evaluative data on what are the demonstrably best tools and services in specific circumstances, whether targeted on people with dementia or their carers. (It should be noted, however, that even when evidence is available, it might get ignored; we discuss this later.) The absence of good evaluations in dementia care feeds into the narratives of both health and social care professionals, and also of people with dementia and carers who are not inclined to consider technological solutions. It also has an influence on commissioners faced with difficult decisions about how to spend their tightening budgets. Research in this area is not easy to conduct. One reason is the rapidity with which existing technologies can become obsolete. Another is that – as we have noted earlier and will reinforce below – technologies should be responsive to the needs, circumstances and preferences of individuals if they are to be effective, and this means that evaluations also need to be able to work within and indeed examine the consequences of such heterogeneity. This could rule out, for example, the standard randomised controlled trial. A third challenge is the co-mingling of technology tools with other services, which makes it harder to disentangle the separate effects of the various components. (See Barlow and Knapp 2013 for more discussion of these and other evaluation issues.)

Price barriers

There is potentially a substantial market for technology in dementia care: there are already 800,000 people with dementia in the UK, and it is expected that the number will more than double by 2051 (Prince et al. 2014). It is also estimated that there are 670,000 unpaid carers of people with dementia in the UK today (Alzheimer's Society 2015c) – a number that will also grow to represent what could be another substantial source of demand. Although potentially considerable, estimating *actual* demand – both now and in the future – is more challenging (Barlow et al. 2012). As the WSD trial found, the costs of telehealth and telecare are decreasing with technological advances, and there were considerable economies of scale still to be exploited, especially in monitoring and response-management and in the initial set-up costs of remote care infrastructure. These all influence the potential cost-effectiveness of such services (Henderson et al. 2014, Hendy et al. 2012). Although future costs might be expected to be lower than current costs⁵, the challenge is still to get from here to there.

The currently wide difference between potential and actual demand (from public and private, corporate and individual sources) was commented upon by many people to whom we spoke. Indeed, one expert representing a large home care services provider to local authorities explained that, despite procuring telecare services (pendant alarms and monitoring systems), the service provider does not actively promote the use of telecare due to the low demand by local authorities. An independent telecare commissioner opined that the greatest economic benefits would be achieved by deploying telecare services to people with dementia who had low-to-moderate care needs, characterised by this interviewee as generally needing three short visits by home care staff per day. This interviewee suggested that the use of telecare could cut those daily visits from three to two, with an associated cost saving. We will return below to the question of replacing face-to-face contacts with remote care.

⁵ Some historical numbers – taken from Damant and Knapp (2015), which gives original sources – illustrate the cost-reducing potential of technical development and economies of scale. The first mobile phone call in the UK was made in January 1985 with the Transportable Vodafone V1: it weighed 5kg, cost approximately £5,000 at today's prices, and only 12,000 were in circulation by the end of that year. Today, the weight of a mobile phone averages 110g, cost averages £180 for a smartphone, and 93% of the UK population own or use one. Huge mainframe computers in 1955 took up several large rooms and were available to businesses for around £500,000 at today's prices. By the mid-1980s computers could easily fit into an average sized room, cost around \$3,000 USD at the time, and over 30 million had been sold. Today computers are of course available in many different forms and prices vary, but are considerably lower.



Other interviewees made similar comments about the private consumer market. Telecare providers and two independent market observers (one from a technology innovation agency and the other from a think tank for ICT in care) agreed that the increasingly influential ‘Silver Market’ has led to expansion of the consumer market for ICT devices, services and applications, including those which target people with cognitive impairment. A number of interviewees also often referred to the growing number of applications aimed at family carers, such as information and support apps, as well as carer networking management apps (see the table in section 4). We got a different view from three interviewees from a leading remote-care provider, who felt that the private market remains ‘very small’.

One argument we heard from a number of people is that the current procurement model has not reached its cost-minimising scale. According to a remote-care provider, the currently small scale of the statutory market creates a ‘chicken-and-egg situation’: in addition to there being only a small number of people aware of available technology-based services, potential service users who perceive themselves to be relatively ‘fit, healthy and independent’ are less likely to seek a technical solution through the health and care system. These reasons slow the demand in the consumer market, making it harder for providers (even those which have a considerable share of the remote-care market) to grow beyond the ‘business-to-business’ phase of market development. The *potential* demand implied that economies of scale would be achievable, but only by engaging in a ‘business-to-consumer’ model in the private market, engaging with the relatively untapped market of people with early stage dementia who are not eligible for statutory care. The range of potential technology solutions suitable for such people is likely to be wider (including active as well as passive devices), and ethical issues are less prominent as there will be more capacity to consent (see section 3 and below). On the other hand, it creates a further tier in terms of access based on wealth rather than need, because people with dementia and their families who have low incomes may not be able to afford private purchases (Mason et al. 2012), and it raises questions about the quality of information provided, and who provides it – an issue to which we return below.

Even for those with a reasonable income, perceived price could be a barrier (Damant and Knapp 2015). It has been suggested that many older people perceive ICT more as a luxury good than a tool for improving life quality (Weaver et al. 2010). An Independent Age report (2010) noted that many older people express concerns about the ongoing or increasing costs of maintaining, updating, and replacing hardware, software and security packages. There are certainly differences by income group, but perceptions of affordability have been found to be important determinants of e-inclusion (Hill et al. 2008, Independent Age 2010, Ofcom 2012). One possible model could be for privately purchased telecare users (and those who sell this equipment) to piggy-back onto existing, council-managed or – funded call centres – or indeed to piggy-back onto council-negotiated contracts with providers which come with price reductions – but if so, on what basis and with what implications? Statutory bodies could even purchase and then lend or rent out equipment to individuals not eligible for state-funded support.

There is another cost issue to consider here. One interpretation of findings from the WSD telecare trial was that there may well have been higher use of health and/or social care services as a result of closer, more regular, more intensive monitoring. The links created through telecare may have uncovered previously unrecognised or unmet needs: the short-term consequence could be increased service utilisation and cost, but with the expectation that utilisation and costs would fall below pre-baseline levels in the longer term (other things being equal). The WSD trial was too short (12 months) to observe any such trends.



It may therefore be the case that good technologies have been developed but they are not affordable – or perceived to be affordable – by a sufficient number of purchasers (public or private) to reap economies of scale. One role for state action might be to provide assurances that demand will be sufficiently large, stable or predictable to encourage suppliers to invest in the capacity to deliver at scale. This is reminiscent of discussions around block contracts for some social and healthcare services, which of course have their downsides as well as advantages, and also similar to volume and price negotiations between the NHS and pharmaceutical companies and equipment manufacturers. However, whether such an approach would be consistent with person-centred responses to needs is a moot point.

Design barriers

One argument that came through from some interviews and from other sources was that available technology was not designed in a way that makes it easily usable by people with dementia. These design barriers, as we might term them, include broadband and 4G coverage, technological literacy, sensory and physical abilities, and cognition. The continuing age-related and dementia-linked changes in abilities and cognition experienced by many people complicate things further. Interviewees and commentators in the literature sometimes also referred to what we might call the hegemony of the youth market. There is also a possible issue with stigma.

A basic infrastructure requirement for many technologies is internet access. While this is improving nationwide, there are still groups in the population – especially those who are old, poor or live in rural areas – with limited access. As Damant and Knapp (2015) describe from published Ofcom data, in the nine authorities across England with the poorest levels of internet speed, between 14% (Suffolk County) and 18% (Herefordshire) of the local population are affected by poor access; and eight of these nine authorities (the exception is Milton Keynes) have an older population that is above the English national average. The government's market-led 'Next Generation Access' roll-out of broadband thus disadvantages areas with large older populations: in areas with poor infrastructure, residents have only basic internet functions and unreliable connections (Mason et al. 2012).

A second issue is technological literacy. A message coming through from numerous sources is that many older people – including people with dementia and their carers – do not use technologies (even the generally available technologies) because they do not have the requisite skills. It has been estimated that 9.5 million adults in Britain do not have the basic skills needed to use the internet, including 4.8 million people aged 65 and over (Go ON UK 2014, Office for National Statistics 2014). There is a strong negative association between age and ICT-related abilities (Wagner 2010), perhaps because of poorer operational skills such as scrolling and clicking (Mason et al. 2012; Olson et al. 2011) or just because older people have less experience with operating systems and software (Olson et al. 2011), with many having left employment before ICT became commonplace in the workplace. (There may be a cohort effect here, with future cohorts of older people having acquired technological literacy before the stage in their lives when they may need care, but this could be an over-simplistic assumption; we discuss this again below.) Nevertheless, it may well be that a lot can be done with technologies that are already available and used for other purposes. Giving people with dementia and carers ideas and advice – improving their technological literacy – could be beneficial. Partnerships with third sector organisations such as AgeUK and the Alzheimer's Society could help in this regard.



There would certainly appear to be support for the supposition that negative attitudes towards ICT demonstrated by some older people (as shown in many surveys and other studies) – particularly the lack of perceived benefits – stem from a view that ICT is primarily aimed at and designed for a younger generation. Introducing people to technology earlier in their lives, and certainly before dementia might emerge, when they are better able to understand and to learn new techniques for managing their activities of daily living (for example), might help – a point made by a number of our interviewees.

Older people, and especially those living with dementia, have characteristics that may complicate their engagement with certain technologies, either because of deterioration in manual dexterity or visual acuity, or because of cognitive decline. Technologies need to be designed in more sympathetic fashion, taking account of individual capabilities. We recently reviewed international evidence in this area for an SSCR-supported study (Damant et al. 2015) and found evidence describing:

- specific ‘physical’ challenges faced by older people when using peripheral equipment (mouse, keyboard);
- difficulties with gripping and pressing mobile phone keys or remote control buttons;
- poor accessibility for people with arthritis, tremors or ‘achy hands’;
- deteriorating eyesight making it hard to operate mobile phones;
- difficulties caused by fonts, colours and layouts of web-based applications;
- pendant alarms found to be too bulky, cumbersome and awkward to wear by some older people;
- interactive remote health consultation systems found to be hard to use;
- some home monitoring and community alarm services having inadequate reach, confining older adults with mobility difficulties to restricted areas within their own homes;
- confusion caused by some telecare services;
- people with hearing impairment having difficulty with poor sound quality of audio equipment (videophone, emergency call phone);
- touchscreen devices are more ‘age-friendly’ due to their intuitive application-based interfaces and improved manipulability compared to mice and keyboards, leading to fewer mistakes for older adults with hand tremors, but not everyone finds tablet computer interfaces easy to comprehend, and one study found that tablet computers were not effective for people with cognitive impairment (Alvseike and Brønnick 2012).

We have listed here the difficulties that can arise for some people because of age-related changes in abilities. Our earlier summary of evidence obviously gives a fuller account, and we need to emphasise that the situation is certainly not entirely negative. The point to stress here is that changes in abilities, and particularly those that might be accelerated by dementia, can erect barriers to effective use of technology for some people.

Cognitive changes, already noted, are obviously a particular challenge for people with dementia, and previous research has pointed to age-related decline in ‘mechanical cognition’ and memory loss, which can affect ability to navigate and retrieve information from the internet (again see Damant and Knapp 2015 and Damant et al. 2015 for reviews). Some monitoring and alarm equipment may lack memory-aid features, which can be especially problematic if services do not adapt as individuals’ needs change over time (Botsis and Hartvigsen 2008, Brignell et al. 2007, Lauriks et al. 2007, Milligan et al. 2011).



Remote-care providers whom we interviewed also noted that many telecare devices and services are poorly designed for the range of needs of people at different stages of dementia. Falls-monitoring systems could actually cause confusion, and some services users were said by one interviewee to 'throw the devices away' or refuse to use them. However, technology developers discussed how companies are looking to make their devices and services more relevant and accessible. One large remote-care provider explained how they are investing in developing more apps for remote care. A small remote-care provider described how they adapted their mobile phone (used as the interface of their telecare services) in response to feedback from their customers with dementia: the original phone had too many buttons and functions, the settings were too easy to change inadvertently, the display screen was too small, and the two-way communication system too intrusive and stigmatising. (Users did not like walking around with a voice giving them instructions.) A new phone was developed to include fewer buttons and limited functions (panic button, and voice buttons) which were less easily changed unintentionally.

As noted already, part of the challenge could be that many older adults do not perceive mainstream ICT to be relevant to their needs (Roberts 2009), seeing it as 'not for people of my age' (Dutton and Blank 2013; see also Age UK 2010a, Ofcom 2011). Whether these perceptions are based on informed judgements, or reflect underlying anxieties, low skills or financial concerns is unclear (Berry 2011, Ofcom 2012), but it makes it harder to encourage older people to gain familiarity with generic technology as preparation for using it for care purposes. There is no doubt that there is an industry-wide focus on younger people, and this has led to widespread neglect of the needs, preferences and capabilities of older people. Indeed, an Independent Age (2010) report argued that if there was a clear business case for age-friendly ICT products, why had it not been pursued already?

Our conversations with people with dementia, carers, and other experts revealed that in many cases people will turn first to off-the-shelf technologies that are not dementia-specific. Examples include baby monitors used instead of various sensors, GPS locators built into smartphones, and tablets and smartphones for music and video entertainment. For all of these devices the need to be user-friendly in order to remain competitive in the market is congruent with the demands of people with dementia and carers for devices that are dementia-friendly. We have already referred to these as 'frugal technologies' which, some of our interviewees argued, could be more acceptable to people with dementia, especially if they can be used for general purposes in daily life (on-line banking, shopping and so on), although they still need to be aesthetically appealing.

It could be argued that the ingenuity of the market should help drive the acceptance and utilization of these *general-purpose devices*, especially for self-funders, but for these devices to reach the full spectrum of people who could potentially benefit from them there must be better internet access, improved technological literacy and a change in perception. This has been argued to be simply a cohort effect, so that – as current generations age – ICT literacy among older people will no longer be an issue and internet access will (should) eventually be ubiquitous. It is also quite possible, however, that technological advances will be so rapid that they will always run ahead of the experiences and capabilities of older people, leaving them still lagging behind younger generations, which could of course be especially challenging for individuals with symptoms of dementia (and especially those with fewer economic, family or other resources).



What we see today is clearly some distance from a dementia-friendly technological world. Such a situation would probably need to incorporate two related strands of thinking. First, any technology under consideration for use by and with people with dementia must be needed by those individuals, *wanted* by them, and/or *appropriate* for their unique and changing situations, in turn therefore requiring ongoing assessment and associated adjustment. This line of argument runs through the Alzheimer's Society *Dementia Friendly Technology Charter*, for example. The second strand is tied more broadly to the principles of universal (or inclusive) design, a term used more in the US than the UK; it is defined in the U.S *Assistive Technology Act* as 'a concept or philosophy for designing and delivering products and services that are usable by people with the widest possible range of functional capabilities...' (Section 3(19), amended 2004). This suggests the need for technology developers and manufacturers to consider the reality of the lives of people with dementia and carers to ensure that their products continue to evolve so as to be appropriate. Involving people with dementia in technological development – particularly as technology becomes more complicated, as it is very likely to – is imperative. A simple example of the universal design principle would be to design devices like smart phones with fingerprint or facial recognition technology instead of requiring passwords for access. An initiative that government could take would be to require that devices purchased with public funds (through local authority or NHS commissioning, most likely) should meet some kind of universal design standards, such as simplicity of use or not requiring active user input at all. This would create an important financial incentive for technology vendors, and would encourage additional competition from vendors in countries where these requirements are further developed.

It is also imperative that social and health care staff are trained to support people with dementia and carers who choose to use technology for care-related needs. An expert from a think tank for ICT solutions in care whom we interviewed suggested that self-funders often received too little support or training on how to use current telecare services: they were just told 'simply push the button when you are in trouble.' But even this kind of task could put too much responsibility onto people with dementia, and passive rather than active technologies might be more suitable. Other interviewees argued that the level and quality of telecare provision and support by local authorities varied greatly across the country, which meant that poor support was not unique to the private-pay sector.

A number of third sector organisations are active in raising awareness of the benefits of e-inclusion, providing information about devices and services, facilitating public access to computers and the internet, and developing the skills of people who are digitally excluded; examples include Digital Unite, Citizens' Online, Digital Outreach and Convey, Tinder Foundation, UK Online Centres and Age UK (again see Damant and Knapp 2015 for more details, and Agnew and Ripper 2011 for evidence of positive impacts on confidence and attitudes towards the internet).

Finally, in our discussion of design barriers (broadly interpreted) is the potential stigmatising effect of ICT-based care services, such as monitoring services and wearable devices, especially if these are signalling to older users that they are becoming increasingly frail and dependent (e.g. Age UK 2010a, Roberts 2009, Sanders et al. 2012, Sixsmith and Sixsmith 2008).



Trust barriers and preferences

We have already mentioned technological literacy. One commissioner of social care services suggested that a lack of understanding of the potential of technology to meet daily needs could be related to the fact that many people with dementia are of the generation which is less comfortable with technology, and therefore not inclined to seek out technological solutions to meet their needs. A common thread across several of the interviews was the notion of ‘normalising’ technology in the daily lives of people with dementia. One remote-care provider commented on what they saw as the flawed logic of the current remote-care model: ‘The majority of the population don’t have it in their heads that [using telecare] is something they ought to do. Just as there isn’t a notion that at a certain age, one should consider using remote-care technology.’ The interviewee was implying that technology should be presented as multi-purpose tools useful for routine daily tasks, which would help maintain independence. An expert from a technology innovation agency similarly argued that in order to ‘normalise’ technology for this group of people, it is necessary to engage different sectors of society - such as banking, retail, and supermarkets - in the supply chain of care in order to promote technology as both a positive and normal aspect of daily life. Two telecare commissioners gave similar suggestions about using mainstream marketing channels to inform the public about remote care services. For instance, the commissioners (separately) suggested incorporating the use of telecare into the story lines of popular TV soaps. Whether this line of argument is sufficiently person-centred is a moot point.

Older people certainly appear to be deeply ambivalent about ICT (Helsper 2008). Several studies note that older people use ICT for only limited purposes (Olson et al. 2011; Wagner et al. 2010, Age UK 2010a, Dutton and Blank 2013), and only when it does not interfere with their daily lives. Dutton and Blank (2011) found that 30% of retired respondents did not use – or had ceased to use – the internet because they perceived it to be ‘too time consuming’ (p.57), suggesting that ICT was a distraction from other activities.

Indeed, it is not only a case of not finding ICT useful, but many older people appear quite suspicious of it. They are distrustful of online services, fearing (and not without good cause) identity theft, other fraud, abuse of personal information, perceived health risks such as radiation, computer viruses and financial exploitation (Dutton and Blank 2013; Hill et al. 2008; Independent Age 2010, Mason et al. 2012, Wright and Wadhwa 2010). Many also worry about privacy and personal security (Leppel and McCloskey 2011; Mason et al. 2012; Wright and Wadhwa 2010). An expert from a leading remote-care provider explained that often when ‘new boxes’ appear in service users’ homes, they are met with suspicion.

Some older people decline to accept telecare services because of the loss of social contact that results. As Sanders et al. (2012) describe from the WSD study: ‘Comments regarding current services indicated that respondents were reluctant to disrupt services that were currently working well and that they often valued highly. Much of this satisfaction seemed to be associated with stable relationships that had been developed with specific service providers and there were concerns about what changes the equipment might bring to those relationships.’ Contacts with health and social care professionals are valued highly by some older people, particularly when this may be the only human contact they have on some days.



Linked to this reluctance to lose current services is what an expert from a technology innovation agency noted as a tendency for many people with dementia (and older people more generally) to feel a *sense of entitlement* to receive care from the state after having ‘paid into the system for many years’, often accompanied by clear expectations of what care services should be like. These service users are perhaps less likely to seek information about alternative technology services, devices or applications from the consumer market.

This hesitation about technology could therefore be seen as a perfectly rational, carefully thought-out expression of preferences. It has parallels with the issue of non-adherence with medications: the decision to decline a service or medication cannot simply be dismissed as irrational; rather there is a need to understand the reasons for refusal, non- or variable use after installation.

Awareness barriers

Although not especially plentiful or robust, there is nevertheless some evidence that the use of digital, robotic and other technology in the care of people with dementia can be effective. There is not, however, very wide appreciation of what is (or is not) likely to be effective, and in what circumstances. This lack of understanding applies to people with dementia and carers who might potentially be in the private-pay market or holding a direct payment, local authority and NHS commissioners, and individual social and health care staff. The problem could be that the evidence is perceived to be too weak or uncertain to persuade potential purchasers to commit resources to buy things that might not work, or it could simply be that information on what works is not getting through to the people who matter.

We will discuss commissioning and staff awareness later. For people with dementia, their carers and indeed the general public there are a number of options. These include local ‘signposting’ by statutory services, more structured local brokerage through publicly funded or other services, and wider (i.e. national or international) information resources.

Currently, few people with dementia have access to, and use, state-funded remote-care services. Our interviewees were asked to comment on how people with dementia who are ineligible for state-funded support become aware of, and gain access to technologies. One interviewee from a leading remote-care provider described various channels, explaining that their company is most likely to reach its private-paying customers through social services’ departments. Another important channel was through Age UK, which provides online information and advice about different technologies and assistive devices, and which runs a telecare monitoring service for private-paying service users. The same interviewee also suggested that word of mouth is important: ‘Our users are our best promoters of [our telecare services]’. Awareness about telecare services for people with dementia among the general public is low, partly – it was suggested – because the distribution of telecare systems has rested predominantly within the statutory care system, so that few people learn about the various remote-care services.

In addition to information about what is available, people with dementia and carers will also need access to ongoing support as they use their selected telecare tools. While in some cases this might be available from specific technology vendors, many self-funders and personal budget-holders may choose to use technologies that are not specific to dementia, and so partnerships with libraries, older people’s organisations



and day services may be needed. However, whether it is for initial acquisition or ongoing support, accurate and unbiased information about technology tools and options is generally not readily available.

It is unlikely that many 85-year olds who have just been diagnosed with dementia will want to browse a telecare catalogue or even the very informative AT Dementia online resource (see below) like a mail-order shopper. Information needs to be mediated and presented by someone who can provide some continuity over subsequent processes. This is clearly one function of an ongoing assessment process, but could take a number of forms. Any such signposting or brokerage would certainly need to be locally delivered. A number of interviewees mentioned local authority 'signposting services' as an important channel for private-paying users to learn about telecare and other technology solutions. One local authority commissioner described their local dementia care advisory service, a joint initiative between the council, CCGs and a leading dementia charity. The service provides information and advice to anyone with a clinical diagnosis of dementia, regardless of whether they meet eligibility criteria for local authority, and part of its remit is to guide people to alternative resources for care and support, including telecare services (which, in this council, are commissioned by an independent firm that provides services to both those eligible for state-funded care and self-funders).

A social care commissioner from another council told a similar story about signposting. Their council no longer provides telecare services itself; individuals fund their own ICT-based care from their personal budgets or own finances. The council pays for installation and support services for those eligible for state-funded care, and has developed an internal information and advice service about the different technology options for care. This advice service includes an interactive website that signposts service users to different care resources according to their needs. There was no mention of whether quality assurance mechanisms or adult safeguarding procedures are employed.

Despite these examples of what might be seen as good brokerage practice in two county councils, a number of interviewees felt that, overall, local signposting services were ineffective in helping people with dementia get the support they need. (This must be, of course, the proof of the pudding: is the service to which someone is directed actually effective in meeting needs or improving wellbeing.) One of the concerns raised by an interviewee was that only those individuals who contacted health (e.g. for a GP diagnosis) or social care services (e.g. for a needs assessment) were actively signposted to the range of service options, leaving many other people with dementia and their carers ignorant about the potential for using technology to meet their needs. Another interviewee – from a think tank for ICT solutions for care – also questioned the overall quality of signposting across the country, suggesting that some local authorities offer a signposting service simply to fulfil the requirements of the Care Act, but provide little or no guidance or personalised support for people with dementia about how to identify or adopt the appropriate technologies for their needs. In this person's view, there is a general lack of sufficient appraisals of, or information about, the wider array of equipment, devices and interfaces that are 'dementia-friendly.' An independent service commissioner and two interviewees from a remote-care provider made similar points: signposting efforts, particularly for technology services, are inconsistent across the country.

Section 3 of the statutory guidance to the Care Act 2014 explains councils' statutory duty under the Act to provide information and advice on care and support. It does not specifically refer to information and advice on technology, but there is specific



reference to information and advice on aids and adaptations and a statement that ‘care and support’ should not be interpreted narrowly. There would be advantage in national rather than purely local efforts, either to establish a coordinated national strategy for providing information and advice (especially about consumer market products), or at least to support a national resource. For example, the *Putting People First Concordat* from 2007 suggested a coordinated approach to providing information and advice (in general, not specifically on technology). That would increase the likelihood that appropriate technology will reach the people who need and want it, and in a timely fashion. Partnering with third sector organizations and professional associations that can be encouraged to develop accurate and unbiased information that is made publicly available would also help people with dementia and carers, particularly the growing number of self-funders.

There are some such resources already available. A number of third sector organisations already have resources, either to support individual purchasers or to provide training materials for professional care staff, although the quality varies somewhat. One effort that is seen by many people as providing independent, accurate, and easy to understand information is AT Dementia (www.atdementia.org.uk), managed by Trent Dementia Services Development Centre (a registered charity) and funded by the Department of Health ‘to develop an online information resource on assistive technologies for use by people with dementia, carers and professionals’. The Alzheimer’s Society publishes a factsheet on assistive devices. The TeleSCoPE project (Telehealth Services Code of Practice for Europe www.telehealthcode.eu), funded by the EC, is developing a code of practice for telehealth services to ‘improve confidence in and acceptance of telemedicine’ and to collect ‘good practice on deployment of telemedicine services.’

The NHS has explored the idea of identifying apps that can be recommended by health and care professionals. One first step was to make publicly available an online library of ‘safe’ health apps, three of which were dementia apps. This was only a temporary exercise and the library ceased to be publicly available in October 2015. This particular initiative was criticised because the apps had only been reviewed for safety, not for effectiveness (Leigh et al. 2015, National Elf Service 2015). At the moment the National Information Board has a work stream aimed at ‘providing citizens with access to an assessed set of NHS and social care “apps”’ (www.gov.uk/government/uploads/system/uploads/attachment_data/file/467065/Work_stream_1.2_with_TCs.pdf). As part of this work, which is expected to be concluded by December 2015, there is an intention to design an evaluation system for apps that would start to be tested from April 2016.

There is also a need for ‘start-up information’ about telecare and other technologies – simply to raise general awareness – where older people (in particular) are most likely to see it: post offices, GP surgeries, libraries, cafes, bus stations and traditional media such as newspapers, magazines, radio and television.

Individualisation barriers

Assistive technologies will be more effective if they are tailored to individual circumstances, needs and preferences. The interviews and the literature point to the failure to assess individual circumstances, characteristics, preferences and so on, so that technological ‘solutions’ offered to people are simply inappropriate for them. We have given a number of examples already.



This point is of course consistent with the broader trends towards ‘personalisation’ in health and social care policy and practice in the UK over recent decades, and the growth of interest in ‘precision medicine’ (formerly ‘personalised medicine’) internationally. There is also a market-driven desire to individualise remote care, because to do so should make it easier to persuade hesitant individuals to accept this new approach to their treatment, care and support. Such individualisation requires at least four things: (a) the existence of a range of (if necessary, inter-operable) technologies and/or the ability to adapt a single technology to different circumstances; (b) their commissioning by public purchasers; (c) their careful deployment in cognisance of the needs and preferences of potential users; and (d) some minimum level of continuing support to address users’ technology challenges, incorporating periodic assessments of the fit between technology and users’ needs and preferences. Many people with dementia might need to be able to trust and depend on others in many areas of their lives, as we noted earlier in the report, while being independent in others.

A common and strong thread running through our interviews – as we have already discussed in section 3 – was practitioner skill and the ability to identify needs and potential technology solutions for individual people with dementia. Better assessment and matching is fundamental to the success of technologies in dementia care, yet we were told of care staff who are often unclear about how telecare devices could help service users achieve their care outcomes, even though they have been installed.

One independent commissioner to whom we spoke noted that local commissioners often enter into several different contracts with several local remote-care providers in order to meet the specific needs of small groups of service users, which makes sense from the point of view of person-centred assessment and deployment, but is in tension with advantages of a mass market which achieves economies of scale. Previous research has rarely investigated the benefits of individually tailored responses, although the small-sample MonAMI study (of older people *without* dementia) found that telecare that was more individualised was associated with better short-term outcomes (Damant et al. 2013).

Commissioning barriers

We have already discussed the (actual or perceived) price barriers faced by private purchasers, and we have referred quite a lot to public sector commissioning when considering other barriers to the use of technology in dementia care. It is clear that there are wide variations – a postcode lottery perhaps – in access to publicly funded technologies.

Many of our interviewees from the technology sector, including those from remote-care providers, as well as some local commissioners, were firmly of the view that there were substantial economic benefits to be derived by local authorities from telecare (such as alerts, monitoring services, and localisation services). These benefits included the reduced need for unnecessary ‘checking-in’ visits by home care staff, improved service user safety at home, delayed admission into costly residential care, and a decrease in family carer breakdown. Some saw these social and economic benefits as ‘obvious’, especially for people with MCI or mild/moderate dementia, although our earlier summary of the findings from our extensive searching did not provide especially strong support such a view.



Commissioners, on the other hand, presumably find the cost too high or the evidence too weak, particularly with care budgets already under considerable pressure. There may also be a perverse incentive at play: the main savings from community-installed telecare might come from reduced need for inpatient admissions, or shorter stays, but such savings – which might not even be cashable – will flow to the NHS rather than local authorities. One interviewee from a technology innovation agency referred to the ‘silo’ behaviour of the health and social care sectors in terms of the commissioning, procurement, and deployment of remote-care services, although some social care commissioner interviewees referred to a few good examples of partnerships between local authorities and CCGs.

There is also very limited take-up of technologies by service providers. For example, care homes are not major users of technology, and few offer wifi access to residents (around 20% according to carehomes.co.uk 2014), presumably on the grounds of affordability and lack of perceived benefits in a sector which has generally low profit margins. On the other hand, some housing associations employ services such as community alarms and 24-hour monitoring services (Aragon Housing Association 2014; Technology Services Association 2013).

If the effectiveness and cost-effectiveness evidence is strong enough, then there may be a need for a better commissioning model, one that is outcomes-focused rather than input-driven, and one that addresses the need for ‘diagonal accounting’: investment from one budget generates benefits to another budget and in a later financial year. Neither of these is going to happen overnight. There is obviously enormous emphasis on better coordination between health, social care, housing and other systems; whether the need for technology in dementia care will make much difference to the wider picture is unclear, but it is certainly an area which encapsulates well the nature of the challenge.

Societal attitudinal barriers

Negative attitudes about dementia, as well as poor awareness and ignorance about what it means to live with the condition, have a number of adverse consequences, and the 2009 *National Dementia Strategy* and both editions of *The Prime Minister’s Challenge on Dementia* have emphasised the need to achieve change. There have been substantial investments in raising awareness and changing public attitudes to dementia in recent years, with some degree of success (Knapp et al. 2014b ch.5). Improvements in this domain could in principle mean that technology providers (special and generic) are better aware of the needs and preferences of people with dementia and their carers, and it could reduce the reluctance of people with dementia and carers to make approaches for help (from specific or generic services).

An interviewee from a technology innovation agency discussed the lack of information about the availability of the various technological solutions for dementia care in the wider consumer market. In this expert’s view, this information gap is partly attributable to a reluctance of large mainstream remote care providers to associate their products with the ‘silver market.’ A related issue was mentioned by another interviewee, this time from a large remote-care provider: their engagement with mainstream providers has often revealed that the latter have limited understanding of the market and especially of the needs of people with dementia. Seeing technology as a progressive and affirmative part of daily life could help to counter the attitudes and ignorance in many sectors.



Staff skills, awareness and attitude barriers

A frequently mentioned barrier to the wider and better use of technology in the support of people with dementia and their carers is that health and social care staff (commissioners and providers) do not have the necessary skills or the right attitudes. Some of our interviewees described what they saw as a general lack of knowledge and understanding about technological solutions for dementia care. An interviewee from a think tank for ICT solutions for care mentioned that occupational therapists (for example) are not trained in technological equipment for people with dementia, are often not confident with it, and are therefore not interested in recommending it to service users. An independent telecare commissioner implied that policies which promoted the procurement - and deployment - of bespoke telecare systems failed to ensure that local authorities also had the appropriate skill-set to appraise the equipment and to match services to service users' needs, capabilities and lifestyles. These same concerns have been expressed by people with dementia and carers (see above).

There are many dimensions to this 'barrier'. It might be, for example, that a GP is unaware of possible telecare solutions and thus neglects to inform patients of these options. This interpretation was suggested by at least two of our interviewees (one from a remote-care provider, and the other from a think tank). But it could also be that the GP is on top of the available evidence, and has inferred from, for example, the large, independently conducted WSD trials that telehealth and telecare do not generate good outcomes, or remains unconvinced by other technologies that have not been as rigorously evaluated as, say, medications and most medical devices.

Another factor could be that (say) social care staff fear threats to their professional culture, or worry that any technology might come at the cost of their jobs. But they might equally be alert to concerns expressed by many older people with social care needs, especially those who are socially isolated, that they will lose some of the face-to-face contacts that mean a great deal to them. One of our expert interviewees felt that part of the problem was that there is no pre-existing professional group that might be expected to 'adopt' technology: its use requires the skills of many professionals, including GPs, community psychiatric nurses, occupational therapists, social workers, other social care staff, and housing staff.

In addition, several interviewees argued that current policies put a heavy emphasis on deploying equipment and very little on how the equipment could help achieve service users' personal goals and care outcomes. To do this would require incorporation of the technological dimension into the broader assessment rather than having it as a standalone activity undertaken by people skilled in technology but not knowledgeable about broader health and social care issues for people with dementia.

It is clearly important that professional staff are sufficiently skilled not only in assessing the needs of people living with dementia, but also sufficiently familiar with technological as well as other ways to meet those needs. They need to be able to raise awareness among the people they support and also provide reassurance. The 'technology charter' endorsed by the Alzheimer's Society (2014), which seeks to identify the 'components of a good quality technology service', might be a useful approach, provided that all relevant stakeholders have the knowledge, skills and incentives necessary to implement it. More generally, training and continuing professional education curricula (across all relevant professions) will increasingly need to be upgraded to include electronic assistive technologies. The emphasis should not be on specific products or devices (and certainly not just the occasional half-day



workshop run by a telecare company), but rather on guiding principles, the research evidence and case examples, and ethical issues appropriate to the specific field. Ultimately, this will require changes in graduation requirements for the appropriate degrees and credentials. The key group to reach with training and on-going professional development and support should be those who assess people with dementia for telecare (and ideally within the context of wider assessment); in other words, the responsibility sits squarely within local authority social care departments.

It would also help considerably if those authorities could develop more research-friendly records related to telecare used by people with dementia and carers, because in this way it would be possible to build the possibility for directly helpful evidence. A starting point would be to give service users and carers an opportunity to consent to their contact details to be made available to legitimate researchers, or to encourage them to contact Join Dementia Research.

A slightly different approach was described by an independent service commissioner to whom we spoke. One local authority has adopted a brokerage model to commission telecare services. As part of the general needs assessment of an individual, care staff will consider the suitability of a range of care services, including telecare. The independent commissioner then receives all referrals (regardless of eligibility status) of individuals assessed as being suitable for telecare. Those individuals who agree to adopt telecare are re-assessed by a specialist telecare installation company which determines the precise equipment and services that would best meet the needs of the individual service user. Telecare equipment and services are procured from an array of suppliers, allowing the commissioner to install the devices and services which best meet the needs of the service user, thus facilitating a more individualised approach. The independent commissioner provides this service to private-paying customers, having direct contracts with them (rather than with the council). This has the potential to overcome skill limitations among social care staff and to achieve a more personalised response, but is also open to the danger that technology is seen as separate from other ways to meet needs. It also has the advantage of not being tied to a specific technology provider, giving commissioners more flexibility in the range of services they can offer to the people they support. In turn this could encourage innovation through competition within the technology-for-care industry by breaking down some of the barriers to market entry for smaller technology developers.

Implications for state investment

The potential demand for technology linked to the needs of people living with dementia is considerable, especially if looked at across the lifespan. But to date, digital and other technology has not played a very large role in this sector. There are no doubts about the ingenuity or ability of the technology industry to develop products that, in the right circumstances, could have the potential to improve lives, although the evidence base that has accumulated to date is disappointing in both quantity and quality. What is in doubt, however, is whether those technologies that are currently available are deployed appropriately, and that led us to focus in this section on what we called the barriers to the use of digital and other technologies in the care and support of people with dementia and their carers.

What do these barriers imply for state action? In the bullet points below we have identified a number of things that governments – or indeed other collective bodies – might do to address the barriers that we have identified from our evidence reviews and interviews.



-
- As far as we can see, there are no major market failures on the supply side, although that situation may need to be monitored. When considering the very wide range of uses across the full life-span, there is an enormous and highly profitable market for new digital, robotic and other technologies. Technologies that could support people with dementia or their carers ought to be relatively straightforward spin-offs of that wider market-driven technological development. The barrier is not the lack of technology, but the failure to convert that potential into an effective reality for people with dementia-related needs. One implication for state action is to encourage digital, robotic and other technology industries to see the 'dementia market' as an attractive current and future prospect, and thereby to continue to explore technologies that meet people's needs. There are relatively few companies active in this market currently, which may also suggest that government could help to reduce barriers to entry faced by (or perceived by) new technology providers. This would be helped by addressing the various barriers that we identified.
 - Our evidence review did not uncover a vast volume of material on whether technologies are effective in dementia care, but there is some. There is a need to develop an evidence base quite quickly, and in a way that matches the speed of development of technology (a topic to which we will return in section 8).
 - As evidence on effectiveness accumulates, it is also important that individuals and organisations who are contemplating purchasing technology have easy access to understandable, trusted summaries of it. There have been some moves in that direction in the dementia field, as in other fields, and these need to be supported further. It could be argued that manufacturers of technologies of the kind discussed here, which are obviously not restricted by any rules about direct-to-consumer advertising, could be making more such information available themselves, but there would still be a need for some intermediary or brokerage role for a collective body (state or third sector) to quality-assure it.
 - Commissioner awareness of research evidence is potentially another barrier, which would imply a need for investment locally or centrally in processes that can improve access to reliable information on both potential advantages and pitfalls. Co-ordinated action across health, social care, housing and perhaps other sectors could be sensible, given the multifarious needs of people with dementia and their carers, implying a potential need for what is sometimes called 'diagonal accounting', addressing the issue that spending from one budget generates its greatest economic benefits in other budgets and in later years.
 - Relatively little of the evidence that we found addressed the needs of carers of people with dementia, yet these people are potentially the main users of new technologies. Using provisions under the Care Act, for example, public bodies could encourage much greater attention to be paid to carers in this sphere, with potentially significant benefits not only for the wellbeing of carers, but also the wellbeing of the people they support and (in so far as those benefits make it possible for people with dementia to live in their own homes for longer, should they wish to do so) also economic benefits for the public bodies or individuals paying for residential care.
 - For many self-funders as well as for public purchasers, technologies are seen to be expensive: there is a perceived price or cost barrier. For individual older people, and particularly those who have not engaged much throughout their lives with digital technology, purchasing a computer or smart phone is not an insignificant step, particularly if they are worried about ongoing costs and other risks (see below). For many public bodies, given the evidence that the use of telecare has



not significantly reduced the use of other services, their purchases have been held back by concerns about lack of cost-effectiveness (i.e. that spending money on technologies does not offer better value than spending it in other ways) and affordability (i.e. the initial investment costs are too high). A role for the state is to find ways to encourage the market to reach a size where economies of scale can be realised – economies in production, deployment, response to calls etc. Suppliers need reassurance that demand will be sufficient and stable, which means that purchasers need encouragement and support to take that plunge, which in turn means they need the evidence that these technologies will work. Such action on the part of the state might be seen to be inconsistent with the strong policy push towards personalisation of health and social care, but in fact need not close off choice options for individual people.

- We identified a number of ‘design barriers’ - difficulties experienced by people with dementia and their carers in engaging with technology. Internet access is variable across the country, and improvements in that regard would presumably be a government responsibility given that is a public good. Technological literacy among older people, particularly those with dementia or their carers, is a barrier that may or may not be simply a cohort effect that will soon disappear, although we tend to the view that the technology-related abilities of older people will always lag behind those of younger age groups, as technologies will develop with the much bigger, ‘younger’ market in mind. State encouragement and support for older people to gain sufficient technological literacy to make good use of life-enhancing technology would be beneficial. Industry probably should not need specific reminders to design technologies that can be used by people who have dexterity, sensory or cognitive difficulties, but they may perhaps help. Involving people with dementia and carers in the development of technology is a fundamental requirement of course, as is the need to ensure that technologies that work well in laboratory environments will transfer well into real-world settings. One line of argument would be that the state could espouse the principles of universal or inclusive design in the way that has happened in the US, or that there should be the requirement that technologies purchased by public sector bodies should meet certain universal design or other standards.
- As noted a number of times, many older people express disquiet about technologies that are unfamiliar to them, fearing identity theft, fraud, and other abuses. Improving technological literacy could provide reassurance, but there is also simply a need for greater protection for vulnerable people from cyber-crime.
- A major barrier found in some studies is that many older people, particularly those who have mobility problems or who live alone, fear that telecare and similar technologies will mean reduction in the face-to-face contacts that often mean a great deal to them. The daily visit of the home care worker, even if only for 15 or 30 minutes, may be the most meaningful social contact that they have. Replacing some of those visits with remote monitoring risks further isolating those individuals. It is also the case that many carers of people with dementia feel ‘imprisoned’ by their caring responsibilities, so again the replacement of face-to-face support with remote technology might be quite a loss. If, therefore, the economic case for digital, robotic or other technologies rests substantially on the ability to reduce the amount of (relatively expensive) staff time required to deliver social or healthcare services, then one role for the state should be to find other ways to address the challenges of social isolation and loneliness, both of which can have significant deleterious consequences for health and wellbeing. If, on the other hand, the economic case rests more on using technology to delay or remove the need for someone with dementia to go into residential care or hospital, then this issue does not arise in the same way.



-
- Personalising technologies in response to the needs, circumstances and preferences of individuals is fundamental, not just because it is consistent with a broader health and care policy thrust of recent years and for the foreseeable future, but primarily to improve the chances that people living with dementia will engage with and then benefit from technologies.
 - Continued commitment by the state to raise awareness of dementia and thereby and in other ways to change social attitudes would help to tackle another barrier to the use of technology.
 - Health and social care professionals in regular direct contact with people with dementia and their carers appear not to be as aware as they might be of the available evidence on technologies. This is perhaps not surprising given the many pressures on those care professionals, particularly in a rapidly developing field, but it nevertheless emphasises the need for training and continuing professional education to include the potential technological solutions to the changing needs of people with dementia. Those professionals need to be skilled in assessment (and ongoing re-assessment as dementia progresses), the ability to match technologies to needs and circumstances (or to advise on the range of possibilities), and to provide reassurance for those people living with dementia. If, however, there is a concern among care staff that technology threatens their jobs, then investments in training and professional development will need to be managed carefully.



8. Conclusions

The context in which this small study was conducted is the expected worldwide growth over the coming decades in the number of people living with dementia. One particular aim for policy and practice has been to improve care and support so as to improve the lives of people affected by dementia, but in ways that are affordable. Our examination of the roles that digital and other technologies might play in health and social care started with a rapid review of the available international evidence on effectiveness and cost-effectiveness, included consideration of the conditions needed for successful adoption of technology (and especially appropriate matching through assessment of needs, circumstances and preferences), and liaison with a wide range of people from industry, government, academic, third sector and other sectors, and with people with dementia and carers. We conducted economic modelling to examine the economic case, using the UK as context. We then looked at the roles that state investment or action could play, perhaps to accelerate development of the technology and to ensure delivery of both wellbeing and economic benefits.

We now offer some brief concluding comments.

Evidence review

Our rapid literature review used a systematic approach to identify studies that evaluated technological interventions in the care and support of people with dementia and their (unpaid) carers. We also looked for evidence on interventions used by paid care staff and other professionals working in dementia care and treatment. We found only 47 papers that met our inclusion criteria (eight of them literature reviews). The quality of the evidence was mixed, but generally not strong or easily generalisable.

Only a few of these studies reported outcomes for people with dementia as a result of using a particular technology, but some reported evidence of increased independence. Most studies reported outcomes for carers, often reporting reduced carer distress, burden or mental health morbidity, or better quality of life.

There are in fact a number of evaluation challenges that need to be overcome, including the potential speed of development of new technologies, the need to tailor technologies to individual circumstances, thereby complicating some forms of research, and the tendency for technologies to be used alongside other services, making it hard to separate the marginal effects.

Matching technology to needs and preferences

We also reviewed evidence on how well technologies are matched to the needs, circumstances and preferences of individuals. We considered the necessary conditions for successful adoption of technology. Our conclusion would be that those necessary conditions include at least the following:

- sufficient focus on using devices sensibly and appropriately (matching the technology to need, although we do not have a view from the evidence on who should lead on assessment in this context);
- recognition that many people with dementia will not be able to act autonomously in all areas of their lives, but will be dependent on others;
- better and up-to-date information about products and services (independent of manufacturers, and easily accessed and understood) to inform decisions (by all parties) about what technology to purchase or deploy;



-
- awareness of the potential ethical issues raised by use of technology in support of people whose dementia has progressed to a point where they may have limited capacity to consent;
 - assessments that are user-focused rather than technology-based, integrated within wider (usual) assessment processes;
 - earlier introductions to technology-based possibilities and in particular before an individual reaches the current eligibility threshold for local authority support;
 - carers included in those assessments as they could benefit from the technology, and often play a key role in ensuring that devices work and are used properly;
 - and clear guidance available to relatives who are contemplating the use of telecare technologies independently, to help them select and use these tools sensibly and to be aware of any ethical considerations.

Current state of development of technologies

We interviewed a number of experts from industry, government, academic and third sectors, as well as obtaining information via various channels from people with dementia and carers. We asked them about many things including the current state of development of technologies. We linked technologies to different stages of dementia, based on the functions served, who might benefit or use them, and in which care settings.

During the MCI and early dementia stages, much of the relevant technology is focussed on supporting individuals to live independently (such as GPS and communication devices), helping them address memory problems, improving safety and encouraging self-management of health. Technology might also be used to deliver care and has a role in helping reduce worry for relatives. People with MCI or dementia and carers are increasingly using social media and the internet to obtain information about their needs, to share experiences, and to obtain support.

During the moderate and severe stages of dementia, and when people with the condition are living at home, technology could continue to play a role in supporting independence and maintaining skills. Assistive and safety technology therefore continues to be relevant. We also saw growing 'therapeutic use' of technology, for example with devices such as tablets or digital music players, to help people with dementia reminisce and enjoy their favourite music or films, and to look at photographs.

Carers often carry huge responsibilities at this stage. Technology can be helpful in delivering interventions to improve their health and wellbeing, as well as providing some 'respite' and reassurance. It could be a means to coordinate care and support, either between different unpaid carers, or between those carers and professional health and care staff, or to facilitate social interaction and networking more generally. Technology might also be used to deliver training to carers and professional staff.

For people with moderate/severe dementia who are in congregate care settings such as nursing homes or day centres, technology could perhaps help them retain some independence. It can be used for therapeutic effects as with pet robots, or therapeutic 'entertainment and reminiscence' technology such as photo albums, music, games, films, and karaoke-style apps. Technology is also used to link with a resident's relatives, and perhaps to help relatives be more involved and understand better the care of their family members. Some care homes and day centres are using mobile technology to facilitate person-centred care and to take notes 'on the spot', carry out risk assessments and coordinate with other professionals involved in the care of an individual outside the care setting.



New areas of research and development include:

- analytics technologies, which include ‘stratified medicine’ and diagnostic tools designed to identify people at risk of dementia or in its early stages;
- integration of ‘digitalised care pathways’ of long-term conditions, including dementia, into mainstream care systems, designed to join-up information from different care agencies;
- gaming technologies: products such as Xbox, WiiFit, brain teasers and other apps used increasingly to support management of long-term needs and to maintain health, and also being developed as tools to elicit behaviour change, such as in relation to taking medications;
- memory and augmented reality technologies, designed to help carers understand, in a virtual world, the experiences and needs of people with dementia.

Views of people with dementia and carers

There was insufficient time to obtain ethical approval for a study involving interviews of people with dementia, and we relied on publicly available sources such as internet blogs. These bloggers are, by definition, ‘technology-friendly’ people with dementia (and hence not representative of all people with dementia). They mostly described using technologies that are not dementia-specific (e.g. smartphones and computers). Most of the reported experiences from using technology were positive, such as making it easier to get peer-support and information, and using Siri to get home), but some were negative, such as the challenge of remembering passwords or what specific alarms were for.

We also benefited from discussions with a group of carers involved in a related project, who mostly reported using technology that is not specific to caring or to dementia (including tablets, baby monitors, smartphones, light sensors, and ‘speaker pillows’). None of these carers appeared to have used technology obtained through statutory services, but we make no claims about representativeness. These individuals have tended to use ‘DIY’ approaches, using readily-to-hand and familiar technologies. The greatest barrier to technology use reported by these carers was difficulty obtaining advice and support.

Economic modelling

We estimated that the lifetime costs of dementia care in old age in England average £200,000 per diagnosed person, including all health care, formal social care (including self-funded) and unpaid care by family and friends, and measured from the point of diagnosis of dementia onward. The opportunity cost of unpaid care accounts for about half this total. We examined the impact of technology on lifetime costs through three scenarios, each considering the impact on carers. Our ability to model the economic consequences was heavily constrained by the availability of evidence.

Scenario 1, based on findings from a Finnish study, modelled a situation where assistive and safety technologies postponed care home admission by 8 months. The cost of formal health and social care over 4.5 years was reduced by £13,000, so that a technological intervention (plus the cost of assessment and any care services accompanying the technology) that cost less than £13,000 over the same period would be cost-saving from a health and social care perspective. But there would be higher costs of unpaid carer time (£21,000, assuming that daily hours of unpaid care remain the same), so that the intervention would not be cost-saving from a societal perspective. If



the effect of the intervention was not only to postpone care home admission but also to improve quality of life, then even if costs do not fall it could still prove to be cost-effective if the outcomes are seen to justify any incremental cost increase.

Scenario 2 was based on results from an evaluation of a computerised platform designed to minimise carer burden and stress. We converted the study findings to specific assumptions about improvements in carer quality of life, and attached a value to those improvements linked to the NICE thresholds for cost-effectiveness. From a societal perspective, the technology would be cost-effective if its cost (plus assessment and any accompanying care services) was less than £3,000 or £4,500 over 4.5 years. However, there would be no reduction in the cost of formal services and no cash-releasing saving under this scenario. To achieve cost-effectiveness from both health and social care and societal perspectives, the quality of life improvement would need to be combined with delay in care home admission and reduction in hours of unpaid care.

Scenario 3 took a different approach, and examined how much benefit, relative to costs, a technology would need to generate to be cost-effective if it cost (along with the accompanying assessment and services) £5,000 over 4.5 years. This intervention would be cost-effective from a health and social care perspective if it postponed care home admission by 3 months or more. It would be cost-effective from a societal perspective if it reduced carer hours of care by about 8% or improved carer quality of life by 0.06 to 0.08 QALYs per year (or some combination of the two).

Barriers to wider use of technology

We summarised the latent demand for digital and other technologies to support people with dementia or their carers, and then – using the material described earlier in the report – considered the barriers to the use of these technologies, and what they might imply for state action.

The main barriers identified were:

- under-developed technologies
- poor evidence
- price or cost
- design
- trust and preferences
- limited awareness of people with dementia and carer
- the need for individualisation
- commissioning
- societal attitudes
- staff skills, awareness and attitudes

Each has implications for a number of things, including action by public sector bodies.

State action

Although digital and other technologies have not played major roles in dementia care and support, there is considerable potential. We did not see evidence of ‘market failure’ on the supply side; rather the barriers just noted are stopping conversion of the potential of these technologies into ‘effective reality’ for people with dementia and carers.



Action by the state could therefore take many possible forms:

- to encourage digital, robotic and other technology industries to see the 'dementia market' as an attractive prospect;
- to pay attention to the possibility that barriers to market entry might develop, limiting the choices open to purchasers;
- to support the generation of reliable evidence, matching the speed with which technologies can develop;
- to support ways to make information on that evidence widely available and in a form that is understandable to all potential purchasers, including individuals with dementia and their carers;
- to encourage commissioners to have sufficient awareness of what technologies can achieve in the dementia area;
- to encourage commissioners across different systems to work together to overcome boundary-related disincentives;
- to use provisions under the Care Act to encourage greater attention to carers, given the potential benefits both to them and the people they support;
- to find ways to help the market to reach a size where economies of scale can be realised, this bringing down the price of technologies to public and private purchasers;
- to improve broadband coverage across the country, especially in areas with low penetration currently;
- to encourage and support older people to gain sufficient technological literacy to be able to use technology;
- to encourage the involvement of people with dementia and carers in the development of new technologies;
- to require that technologies purchased by public sector bodies should meet certain standards of (say) universal design;
- to take actions that could allay fears held by many older people about identity theft, fraud and other cyber-crime;
- to address head-on the question of how to balance the pursuit of cost savings from deploying technology in the community without requiring people with dementia or their carers to lose face-to-face service contacts that they value, especially for people who have mobility problems, are socially isolated or lonely;
- to ensure that assessments are person-centred and integrated rather than technology-dominated and separate;
- to encourage development of personalised technologies, responding to the needs, circumstances and preferences of individuals;
- to continue to raise awareness of dementia and so change attitudes that could be a barrier to the use of technology;
- to improve the awareness, attitudes and skills of key health and social care professionals as regards digital and other technologies, for example through qualification requirements and continuing professional education.



References

- Aanesen M, Lotherington AT, Olsen F (2011) Smarter elder care? A cost-effectiveness analysis of implementing technology in elder care. *Health Informatics J*, 17, 161-72.
- ABC News (2010) *New technique to comfort dementia patients* – ABC News (Australian Broadcasting Corporation) [online] Available at: www.abc.net.au/news/2010-11-23/new-technique-to-comfort-dementia-patients/2348692 (accessed 28 September 2015).
- Aboujaoude E, Salame W, Naim L (2015) Telemental health: A status update. *World Psychiatry*, 14, 223-230.
- ADASS (Association of Directors of Adult Social Services) (2014) Better Care Technology Survey 2014 Report. ADASS.
- Age UK (2010a) Technology and older people: evidence review. London: Age UK.
- Age UK (2010b) The Golden Economy. London: Age UK.
- Age UK (2015) *Computers and technology* [online]. Available at: www.ageuk.org.uk/professional-resources-home/services-and-practice/computers-and-technology/what-we-do (accessed 28 September 2015).
- Agnew I, Ripper L (2011) Using embedded outreach to bridge the digital divide. *Working with Older People*, 15, 3, 127-134.
- AJDC Team (2013) *Robots in Dementia Care: Australian Journal of Dementia Care* [online]. Available at: <http://journalofdementiacare.com/robots-in-dementia-care> (accessed 1 October 2015).
- AKTIVE Consortium (2013) The role of telecare in meeting the care needs of older people – Themes, debates and perspectives in the literature on ageing and technology. *AKTIVE Research Report Vol.1*.
- Alm N, Astell A, Gowans G (2012) Living in the moment, University of Dundee. Available at: [www.dundee.ac.uk/media/dundeewebsite/djcad2/documents/Living in the Moment - click here to download PDF description.pdf](http://www.dundee.ac.uk/media/dundeewebsite/djcad2/documents/Living%20in%20the%20Moment%20-%20click%20here%20to%20download%20PDF%20description.pdf).
- Alaszewski A, Cappello R (2006) Piloting Telecare in Kent County Council: the key lessons. Final report. Canterbury: University of Kent Centre for Health Services Studies.
- Alvseike H, Brønnick K (2012) Feasibility of the iPad as a hub for smart house technology in the elderly; effects of cognition, self-efficacy, and technology experience. *J Multidiscip Healthc*, 5, 299-306.
- Alzheimer's Australia (2014) *Testing robots: Professor Rajiv Koshla | Alzheimer's Australia Dementia Research Foundation (AADRF)* [online] Available at: <http://dementiaresearchfoundation.org.au/news/testing-robots-professor-rajiv-khosla> (accessed 1 October 2015).
- Alzheimer's Australia (2015) *Alzheimer's Australia | Virtual Dementia Experience* [online]. Available at: <https://vic.fightdementia.org.au/vic/events/virtual-dementia-experience-0> (accessed 1 October 2015).
- Alzheimer's Disease International (2012) *Alive Inside! The power of music comes to people with dementia via iPods* [online]. Available at: www.alz.co.uk/icaniwill/library/alive-inside-power-music-comes-to-people-with-dementia-via-ipods (accessed 1 October 2015).
- Alzheimer's Society (2013) Research into online cognitive behavioural therapy for carers of people with dementia, *Living with Dementia*, March. Alzheimer's Society [online]. Available at: www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2140&pageNumber=6 (accessed 1 October 2015).



- Alzheimer's Society (2014) *Dementia-friendly technology – A charter that helps every person with dementia benefit from technology that meets their needs* London: Alzheimer's Society.
- Alzheimer's Society (2015a) *Talking Point app*. Alzheimer's Society [online]. Available at: www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2206, (accessed September 23, 2015).
- Alzheimer's Society (2015b) *Urinary tract infections (UTIs) and dementia*. Alzheimer's Society [online]. Available at: www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1777 (accessed 1 October 2015).
- Alzheimer's Society (2015c). Available at: www.alzheimers.org.uk/statistics (accessed 30 September 2015).
- Anderson G and J Oderkirk (eds) (2015) *Dementia Research and Care: Can Big Data Help?*, OECD Publishing, Paris. Available at: www.oecd-ilibrary.org/social-issues-migration-health/dementia-research-and-care_9789264228429-en
- AppCrawlr (2015) *AppCrawlr – The App Discovery Engine* [online]. Available at: <http://appcrawlr.com> (accessed 28 September 2015).
- Aragon Housing Association (2014) No Title. Available at: www.aragon-housing.co.uk (accessed 26 September 2014).
- Archer N, Keshavjee K, Demers C, Lee, R (2014) Online self-management interventions for chronically ill patients: cognitive impairment and technology issues. *Int J Med Inform*, 83, 264-72.
- Arntzen C, Holthe T (2014) Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers, *Dementia*.
- Association of Directors of Adult Social Services (ADASS) (2014) *Better Care Technology Survey 2014 Report*.
- AskSara (2015) *AskSara – Guided advice about daily living* [online]. Available at: <http://asksara.dlf.org.uk> (accessed 28 September 2015).
- Assistiveware (2015) *A voice for those who cannot speak – Proloquo2Go* [online]. Available at: www.assistiveware.com/product/proloquo2go (accessed 28 September 2015).
- Astell A, Malone B, Williams G, Hwang F, Ellis M (2014) Leveraging everyday technology for people living with dementia: a case study. *J Assist Technol*, 8, 164–76.
- AT Dementia (2015) *at dementia – information on assistive technology for people with dementia* [online]. Available at: www.atdementia.org.uk (accessed 28 September 2015).
- Barlow J, Knapp M (2014) *Evaluating telehealth and telecare: note for the Medical Research Council*. London: Imperial College Business School and LSE.
- Barlow J, Curry R, Chrysanthaki T, Hendy J, Taher N (2012) *Remote Care plc – Developing the capacity of the remote care industry to supply Britain's future needs* London: Health and Care Infrastructure Research and Innovation Centre.
- Barnes M (2011). Abandoning care? A critical perspective on personalisation from an ethic of care. *Ethics and Social Welfare*, 5, 2, 153–67.
- BBC Health (2014) *Health apps – are they all good news?* [online]. BBC. Available at: www.bbc.co.uk/news/health-27141119 (accessed 28 September 2015).
- Beauchamp N, Irvine AB, Seeley J, Johnson B (2005) Worksite-based internet multimedia program for family caregivers of persons with dementia. *Gerontologist*, 45, 793-801.



- Beecham J and Knapp M (2001) Costing psychiatric interventions, in G Thornicroft (ed.) *Measuring Health Needs*, 2nd ed., 204-224. London: Gaskell.
- Bemelmans R, Gelderblom GJ, Jonker P, De Witte L (2012) Socially assistive robots in elderly care: A systematic review into effects and effectiveness. *Journal of the American Medical Directors Association*, 13, 114-120.e1.
- Bemelmans R, Gelderblom GJ, Jonker P, De Witte L (2015) Effectiveness of Robot Paro in intramural psychogeriatric care: a multicenter quasi-experimental study. *J Am Med Dir Assoc*.
- Beresford P (2008) Time to get real about personalisation. *Journal of Integrated Care*, 16, 2, 2-4.
- Beresford P (2009a) Social care, personalisation and service users: addressing the Ambiguities. *Research, Policy and Planning*, 27, 2, 73-84.
- Beresford P (2009b) Whose Personalisation? *Compass: Direction for the Democratic Left Think Pieces* 47, 1-5.
- Beresford P (2011) Are personal budgets necessarily empowering for service users? If not, what's it all about? *Research, Policy and Planning*, 29, 1, 37-43.
- Berry R (2011) Older people and the internet: Towards a "system map" of digital exclusion. London: International Longevity Centre UK.
- Bharucha AJ, Anand V, Forlizzi J, Dew MA, Reynolds CF, Stevens S, Wactlar H (2009) Intelligent assistive technology applications to dementia care: current capabilities, limitations, and future challenges. *The American Journal of Geriatric Psychiatry*, 17, 88-104.
- Bjoreby S, Topo P, Holthe T (1999) *Technology Ethics and Dementia: a guidebook on how to apply technology in dementia care*, The Norwegian Centre for Dementia Research SEM Norway.
- Board N I (2014) Personalised Health and Care 2020 – Using Data and Technology to Transform Outcomes for Patients and Citizens – A Framework for Action. London: HM Government.
- Boletsis C, McCallum S, Landmark B (2015) The Use of Smartwatches for Health Monitoring in Home-Based Dementia Care. In: Zhou J, Salvendy G (eds) *Human Aspects of IT for the Aged Population. Design for Everyday Life*. Springer International Publishing.
- Boot WR, Champion M, Blakely DP, Wright T, Souders DJ, Charness N (2013) Video games as a means to reduce age-related cognitive decline: attitudes, compliance, and effectiveness. *Front Psychol*, 4, 31.
- Botsis T, Hartvigsen G (2008) Current status and future perspectives in telecare for elderly people suffering from chronic diseases. *J Telemed Telecare*, 14, 195-203.
- Bowes A, Dawson A, Greasley-Adams C (2013) Literature review: the cost effectiveness of assistive technology in supporting people with dementia. The Atlantic Philanthropies: Dementia Services Development Centre, University of Stirling.
- Boyle D (2013) The Barriers to Choice Review: how are people using choice in public services? London, Ipsos Mori.
- Brignell M, Wootton R, Gray L (2007) The application of telemedicine to geriatric medicine. *Age and Ageing*, 36, 4, 369-374.
- Brittain H, Corner L, Robinson L, Bond J (2010) Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Social Health Illn*, 32, 272-87.



- Buckle P (2014) Human factors that influence the performance of the telecare system. *The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes – Working Papers from the ACTIVE project 2011-2014*. University of Leeds: CIRCLE.
- buddi (2014) *buddi – a go anywhere, anytime personal emergency response service* [online]. Available at: www.buddi.co.uk (accessed 23 September 2015).
- Buettner LL, Yu F, Burgener SC (2010) Evidence supporting technology-based interventions for people with early-stage Alzheimer's disease. *Journal of Gerontological Nursing*, 36, 15-19.
- Burrow S, Brooks D (2012) ATDementia: an information resource on assistive technologies that help support the independence of people with dementia. *Dementia*, 11, 553-7.
- Canary (2015) Canary [online]. Available at: www.canarycare.co.uk (accessed 28 September 2015).
- Capstick A (2011) Travels with a Flipcam: bringing the community to people with dementia in a day care setting through visual technology. *Visual Studies*, 26, 2, 142-147.
- Carehome.co.uk (2014) Care homes/nursing homes with internet access in the UK [online]. Available at: www.carehome.co.uk/care_search_results.cfm/searchcountry/uk/searchchtype/internet-access (accessed 22 July 2014).
- Carers UK (2014a) *E-learning for carers – Carers UK* [online]. Available at: www.carersuk.org/help-and-advice/equipment-and-technology/our-products-for-carers/about-me-e-learning (accessed 23 September 2015).
- Carers UK (2014b) *Jointly App – Carers UK* [online]. Available at: www.carersuk.org/search/jointly-app (accessed 23 September 2015).
- Carers UK (2014c) *Our products* [online]. Available at: www.carersuk.org/help-and-advice/equipment-and-technology/our-products-for-carers (accessed 28 September 2015).
- Carretero S (2015) Mapping of effective technology-based services for independent living for older people at home. Seville: Joint Research Center, Institute for Prospective Technological Studies, JRC Scientific and Technical Reports Series.
- Cartwright M, Hirani S, Rixon L, Beynon M, Doll H, Bower P, Bardsley M, Steventon A, Knapp M, Henderson C, Rogers A, Sanders C, Fitzpatrick R, Barlow J, Newman S, (2013) Effect of telehealth on quality of life and psychological outcomes over 12 months (Whole Systems Demonstrator telehealth questionnaire study: nested, pragmatic, cluster randomised controlled trial. *British Medical Journal* 246 f653 doi: 10.1136/bmj.f653.
- Cheng HT, Zhuang W (2011) Bluetooth-enabled in-home patient monitoring system: early detection of Alzheimer's disease, *Wireless Communications, IEEE*, 17, 1, 74-79.
- Chiatti C, Rimland JM, Bonfranceschi F, Masera F, Bustacchini S, Cassetta L, Lattanzio F (2015) The UP-TECH project, an intervention to support caregivers of Alzheimer's disease patients in Italy: preliminary findings on recruitment and caregiving burden in the baseline population. *Aging & Mental Health*, 19, 517-525.
- Chiu T, Marziali E, Colantonio A, Carswell A, Gruneir M, Tang M, Eysenbach G (2009) Internet-based caregiver support for Chinese Canadians taking care of a family member with alzheimer disease and related dementia, *Can J Aging*, 28, 4, 323-36.
- Chiu TML (2010) *Usage and non-usage behaviour of ehealth services among Chinese Canadians caring for a family member with dementia*. 71, ProQuest Information & Learning.



- Chou HK, Yan SH, Lin IC, Tsai MT, Chen CC, Woung LC (2012) A pilot study of the telecare medical support system as an intervention in dementia care: the views and experiences of primary caregivers, *J Nurs Res*, 20, 3, 169-80.
- Clarke J (2007) Unsettled Connections: Citizens, Consumers and the Reform of Public Services. *Journal of Consumer Culture*, 7, 2, 159-78.
- Clarke J, Smith N, Vidler E (2006) The indeterminacy of choice: political, policy and organisational implications. *Social Policy and Society*, 5, 3, 327-36.
- Clarke J, Newman J, Westmarland L (2008). The Antagonisms of Choice: New Labour and the Reform of Public Services. *Social Policy and Society*, 7, 2, 245-53.
- Clasper K (2015a) Keeping people safe after the diagnosis of be dementia or memory problems Pt1. *MCI and memory problems* [Internet blog]. 3 August 2015. Available at: <http://ken2clasper.blogspot.co.uk/2015/08/keeping-people-safe-after-diagnosis-of.html?spref=fb> (accessed 28 September 2015).
- Clasper K (2015b) The role of social media when you are living with neurological problems. *MCI and memory problems* [internet blog]. 24 August 2015. Available at: <http://ken2clasper.blogspot.co.uk/2015/08/the-role-of-social-media-when-you-are.html> (accessed 28 September 2015).
- Clasper K (2015c) Back on track again. *MCI and memory problems* [Internet blog]. 14 July 2015. Available at: <http://ken2clasper.blogspot.co.uk/2015/07/back-on-track-again.html> (accessed 28 September 2015).
- Clasper K (2015d) Mobile technology. *MCI and memory problems* [Internet blog]. 30 June 2015. Available at: <http://ken2clasper.blogspot.co.uk/2015/06/mobile-technology.html?spref=fb> (accessed 28 September 2015).
- Comans TA, Martin-Khan M, Gray LC, Scuffham P A (2013) A break-even analysis of delivering a memory clinic by videoconferencing. *Journal of Telemedicine and Telecare*, 19, 393-396.
- Curtis L (2013) *Unit Costs of Health and Social Care 2013*, Canterbury: PSSRU, University of Kent.
- Daly G (2012) Citizenship, choice and care: an examination of the promotion of choice in the provision of adult social care, *Research, Policy and Planning*, 29, 3, 179-90.
- Damant J, Knapp M (2015) What are the Likely Changes in Society and Technology which will Impact upon the Ability of Older Adults to Maintain Social (Extra-Familial) Networks of Support now, in 2025 and in 2040?, Future of ageing: working paper. London: Foresight, Government Office for Science.
- Damant J, Knapp M, Buescher A, Kung A, Ellis M (2011) Mainstreaming on Ambient Intelligence. London: London School of Economics and Political Science.
- Damant J, Knapp M, Watters S, Freddolino P, Ellis M, King D (2013) The impact of ICT services on the perceptions of quality of life of older people. *Journal of Assistive Technology*, 7, 5-21.
- Dang S (2008) Care coordination assisted by technology for multiethnic caregivers of persons with dementia: a pilot clinical demonstration project on caregiver burden and depression. *Journal of Telemedicine and Telecare*, 14, 8, 443-7.
- Davies A, Rixon L, Newman S (2013) Systematic review of the effects of telecare provided for a person with social care needs on outcomes for their informal carers. *Health Soc Care Community*, 21, 582-697.
- De Leonibus V, Bartosova R, Lewis E (2013) ALT market in the UK. AKTIV Consortium.



Dementia Circle (2015) *dementia circle | Doro Remote Control* [online] Available at: www.dementiacircle.co.uk/dementia-circle-%E2%94%82-doro-remote-control.html (accessed 1 October 2015).

Department of Health (2005a) *Building Telecare in England*. London, Department of Health.

Department of Health (2005b) *Independence, Well-being and Choice*. London: The Stationary Office.

Department of Health (2005c) *Strategic Business Case Models for Telecare and further guidance*. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4115665.pdf (accessed 1 October 2015)
Available at: <http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Telecare/AdviceonTelecare/TelecareImplementationGuide>.

Department of Health (2010) *A Vision for Adult Social Care: Capable Communities and Active Citizens*. Gateway ref. 14847. Department of Health, London.

Digital Health Stoke-on-Trent, (2015) '*Simple Telehealth is the NHS inspired and owned Telehealth solution; quick and easy to use it is massively scalable and cost effective*' [online]. NHS. Available at: www.digitalhealthsot.nhs.uk (accessed 28 September 2015).

Disabled LivingFoundation (2015) *Loan library* [online]. Disabled Living Foundation. Available at: www.dlf.org.uk/library (accessed 28 September 2015).

Down K (2005) *Assistive Technology, and education, a career, a partnership*, London, Foundation for Assistive Technology.

Duff P, Dolphin C (2007) Cost-benefit analysis of assistive technology to support independence for people with dementia – part 2. Results from employing the ENABLE cost-benefit model in practice. *Technol Disabil*, 19, 79–90.

Duffy S (2008) Personalisation in Social Care. *Consumer Policy Review*, 18, 5, 132–36

Dunn S, Hicks B, Miller L (2012) *Using ICT in activities for people with dementia: A short guide for social care providers*. London: Social Care Institute for Excellence.

Dutton WH, Blank G (2011) *Next Generation Users: The Internet in Britain: the Oxford Internet Survey 2011 Report*. Oxford.

Dutton WH, Blank G (2013) *Cultures of the internet: the internet in Britain: Oxford Internet Survey 2013 Report*. Oxford.

Dyer EA, Kansagara D, McInnes DK, Freeman M, Woods S (2012) VA Evidence-based Synthesis Program Reports. *Mobile Applications and Internet-based Approaches for Supporting Non-professional Caregivers: A Systematic Review*. Washington (DC): Department of Veterans Affairs.

EasylinkUK (2015) *Easylink UK – Making Independent Living a Reality* [online]. Available at: www.easylinkuk.co.uk (accessed 28 September 2015).

Ekeland AG, Bowes A, Flottorp S (2010) Effectiveness of telemedicine: A systematic review of reviews. *International Journal of Medical Informatics*, 79, 736–771.

Enabled by Design (2014) *enabled by design – People passionate about Design for All* [online]. Available at: <http://enabledbydesign.org> (accessed 28 September 2015).



England N (2014) *Health and social care leaders set out plans to transform people's health and improve services using technology* [online]. NHS England. Available at: www.england.nhs.uk/2014/11/13/leaders-transform (accessed 28 September 2015).

Feltoe E and Orellana K (2013) *Making Managed Personal Budgets Work for Older People. What Older People Want, What Works and How to Achieve the Best Outcomes*. London: Age UK.

Ferguson I (2007) Increasing user choice or privatizing risk? The antinomies of personalization. *British Journal of Social Work*, 37, 3, 387-403.

Fine M, Glendinning C, (2005) Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing and Society*, 25, 601-621, doi: 10.1017/S0144686X05003600.

Finerday (2015) *Welcome to finerday* [online]. Available at: www.finerday.com (accessed 23 September 2015).

Finkel S, Czaja SJ, Schulz R, Martinovich Z, Harris C, Pezzuto D (2007) E-care: A telecommunications technology intervention for family caregivers of dementia patients. *The American Journal of Geriatric Psychiatry*, 15, 443-448.

Fleming R, Sum S (2014) Empirical studies on the effectiveness of assistive technology in the care of people with dementia: a systematic review. *J Assist Technol*, 8, 14-34.

FAST (Foundation for Assistive Technology) (2005) *Assistive technology: an Education, a Career, a Partnership*. London, Foundation for Assistive Technology. Available at: www.fastuk.org/fastdocuments/ATEducationv5.doc.

Franco GC, Gallay F, Berenguer M, Mourrain C, Couturier P (2008) Non-invasive monitoring of the activities of daily living of elderly people at home – a pilot study of the usage of domestic appliances. *J Telemed Telecare*, 14, 5, 231-5.

Fry G (2014) Coping with Change: frail bodies and daily activities in later life. *The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes – Working Papers from the AKTIVE project 2011-2014*. Leeds: Centre for International Research on Care, Labour and Equalities.

Gallagher-Thompson D, Wang, P-C, Liu W, Cheung V, Peng R, China D, Thompson LW (2010) Effectiveness of a psychoeducational skill training DVD program to reduce stress in Chinese American dementia caregivers: Results of a preliminary study. *Aging & Mental Health*, 14, 263-273.

Gardener D (2015) *Box of trix final draft in order* [online] Available at: www.youtube.com/watch?v=RsB-Uhkmg0&feature=youtu.be (accessed 23 September 2015).

Gibson G, Dickinson C, Brittain K, Robinson L (2015) The everyday use of assistive technology by people with dementia and their family carers: a qualitative study. *BMC Geriatr*, 15, 89.

Gibson G, Newton L, Pritchard G, Finch T, Brittain K, Robinson L (2014) The provision of assistive technology products and services for people with dementia in the United Kingdom. *Dementia*.

Glaser B (1965) The Constant Comparative method of qualitative analysis. *Soc Probl*, 12, 436-45.

Glendinning C, Challis D, Fernández, J-L, Jacobs S, Jones K, Knapp M, Manthorpe J, Moran N, Netten A, Stevens M, Wilberforce M (2008). *IBSEN: Evaluation of the Individual Budgets Pilot Programme: Final Report*. York: Social Policy Research Unit University of York.



- Godwin B (2012) The ethical evaluation of assistive technology for practitioners: a checklist arising from a participatory study with people with dementia, family and professionals. *J Assist Technol*, 6, 123–35.
- Go ON UK (2014) Go ON UK: the UK's digital skills alliance [online] Available at: www.go-on.co.uk (accessed 22 September 2014).
- Graybill EM, McMeekin P, Wildman J (2014) Can aging in place be cost effective? A systematic review. *PLoS ONE* 9(7): e102705. doi:10.1371/journal.pone.0102705
- Greenhalgh T, Procter R, Wherton J, Sugarhood P, Shaw S (2012) The organising vision for telehealth and telecare: discourse analysis. *BMJ Open*, 2, e001574.
- Greenhalgh T, Wherton J, Sugarhood P, Hinder S, Procter R, Stones R (2013) What matters to older people with assisted living needs? A phenomenological analysis of the use and non-use of telehealth and telecare. *Social Science & Medicine*, 93, 86–94.
- Hagen I, Holthe T, Gilliard J, Topo P, Cahill S, Begley E, Jones K, Duff P, Macijauskiene J, Budraitiene A, Bjørneby S, Engedal K (2004) Development of a protocol for the assessment of assistive aids for people with dementia. *Dementia*, 3, 281–296.
- Hagen I, Alwin J, Krevers B, Johansson U, Josephsson S, Haraldson U, Bostroem C, Rosshagen A, Persson J (2007) Health economic and process evaluation of AT interventions for persons with dementia and their relatives – a suggested assessment model. *Technology & Disability*, 19, 61–71.
- Hamblin K (2014) Lifestyles in Later Life: identity, choice and stigma. *The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes*. Leeds: Centre for International Research on Care, Labour and Equalities, University of Leeds
- Hamblin K (2014b) Risk, Freedom and Control in Older People's Lives: the relevance of telecare. *The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes – Working Papers from the AKTIVE project 2011–2014*. University of Leeds: CIRCLE.
- Health and Social Care Information Centre (2014) Personal Social Services: Expenditure and Unit Costs, England: 2013–14 Final release, 9 December 2014
- Hébert R, Dubois MF, Wolfson C, Chambers L, Cohen C (2001) Factors associated with long-term institutionalization of older people with dementia: data from the Canadian Study of Health and Aging. *Journal of Gerontology Series A: Medical Sciences*, 56, M693–M99.
- Helsper E (2008) Digital Inclusion: an analysis of social disadvantage and the Information Society. London: Department for Communities and Local Government.
- Henderson C, Beecham J, Knapp M (2013) The costs of telecare and telehealth. In Curtis L (ed.) *Unit Costs of Health and Social Care 2013*. Canterbury: PSSRU, University of Kent.
- Henderson C, Knapp M, Fernandez J-L, Beecham J, Hirani SP, Beynon M, Barlow J (2014) Cost-effectiveness of telecare for older people with social care needs: The Whole Systems Demonstrator cluster randomised trial. *Age and Ageing*, 43, 6, 794–800.
- Hendy J, Chrysanthaki T, Barlow J, Knapp M, Rogers A, Sanders C, Bower P, Bowen R, Fitzpatrick R, Bardsley M, Newman S (2012) An organizational analysis of the implementation of telecare and telehealth: the Whole Systems Demonstrator, *BMC Health Services Research*, 12, 1, 403.
- Hft (2015) *hft Virtual Smart House* [online]. Available at: www.hftsmarthouse.org.uk/#prettyPhoto (accessed 28 September 2015).



- Hicks B, Miller L (2012) Research to inform development of a guide to online activities for people with dementia. Brighton: Institute for Employment Studies.
- Hill R, Beyon-Davies P, Williams MD (2008) Older people and internet engagement. *Information Technology and People*, 21(3), 244-266.
- HM Government (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*. HM Government, London.
- HM Government (2009) *Shaping the Future of Care Together. Green Paper*. Cm 7673, Gateway ref. 11774. The Stationery Office, Norwich.
- Hughes R (2009) Safer walking? Issues and ethics in the use of electronic surveillance of people with dementia. *J Assist Technol*, 2, 45-8.
- Huntsman M (2014) *How a Virtual Reality Forest Helps Alzheimer's Patients* [online]. Available at: www.alzheimers.net/2014-04-03/how-a-virtual-reality-forest-helps-alzheimers-patients (accessed 1 October 2015).
- Huttin CC (2015) Perspectives of biologists, epidemiologists and geneticists' controversies in sciences and health system reforms. *Technol Health Care*, 23, 103-8.
- Independent Age (2010) Older people, technology and community. London: Calouste Gulbenkian Foundation.
- Independent for Longer (2015) *Independent for longer – Showcasing Real Examples of Technology Enabled Care Services in Action* [online]. Available at: www.independentforlonger.com/our-community (accessed 28 September 2015).
- Inoue T (2014) Communication Robot for Persons with Dementia-Based on Field-based Innovation. Presentation at the Global Dementia Legacy event in Japan, November 2014. Available at: www.ncgg.go.jp/topics/dementia/documents/Topic3-5TakenobuInoue.pdf (accessed 6 October 2015).
- Inventya Ltd. (2015) The evolving UK market for telecare [online]. Available at: www.aktive.org.uk/downloads/Evolving_UK_market_for_telecare.pdf (accessed 28 September 2015).
- Japan Times (2015) Contest for humanoid robot Pepper won by team with app to help dementia patients. 22 February 2015. Available at: www.japantimes.co.jp/news/2015/02/22/business/corporate-business/contest-humanoid-robot-pepper-won-team-app-help-dementia-patients/#.VhOcDZcsCeA (accessed 6th October 2015).
- Just Checking (2015) *Helping people to stay at home* [online] Available at: www.justchecking.co.uk/#simple2 (accessed September 22, 2015).
- Kajiyama B, Thompson LW, Eto-Iwase T, Yamashita M, Di Mario J, Marian Tzuang Y, Gallagher-Thompson D (2013) Exploring the effectiveness of an internet-based program for reducing caregiver distress using the iCare Stress Management e-Training Program. *Aging Ment Health*, 17, 544-54.
- Khosla R (2015) *Emotionally intelligent robots for social innovation, Research, La Trobe University*, [online]. Available at: www.latrobe.edu.au/research/research-impacts/researchers/videos/emotionally-intelligent-social-robots-for-social-innovation (accessed 1 October 2015).
- Khosravi P, Ghapanachi AH (2015) Investigating the effectiveness of technologies applied to assist seniors: A systematic literature review. *Int J Med Inform*.
- Kikhia B, Hallberg J, Bengtsson JE, Sävenstedt S, Synnes K (2010) Building digital life stories for memory support *Int. J. Computers in Healthcare*, 1(2), 161-176.



King's Fund, The (2013) *The future of health and social care timeline* [online]. Available at: www.kingsfund.org.uk/time-to-think-differently/timeline (accessed 28 September 2015).

Knapp M, Chua K-C, Broadbent M, Chang C-K, Fernandez J-L, Milea D, Romeo R, Lovestone S, Spencer M, Thompson G, Stewart R, Hayes R (2015) Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register. Under review.

Knapp M, Lemmi V, Romeo R (2013) Dementia care costs and outcomes: a systematic review. *International Journal of Geriatric Psychiatry*, 28, 6, 551-561.

Knapp M, Comas-Herrera A, Wittenberg R, Hu B, King D, Rehill A, Adelaja B (2014) *Scenarios of Dementia Care: What are the Impacts on Cost and Quality of Life?* London: Personal Social Services Research Unit, London School of Economics and Political Science.

Knapp M, King D, Romeo R, Schehl B, Barber J, Griffin M, Rapaport P, Livingston D, Mummery C, Walker Z, Hoe J, Sampson EL, Cooper C, Livingston G (2013) The START study (STrategies for RelaTives): Cost-effectiveness of a manual-based coping strategy programme in promoting the mental health of family carers of people with dementia: a pragmatic randomised controlled trial. *British Medical Journal*, 347: f6342.

Knapp M, Wittenberg R, Hu B (2014a) The economic consequences of a disease-modifying treatment for dementia: a modelling study for the Office for Life Sciences. London: PSSRU, London School of Economics and Political Science. (This report is not in the public domain.)

Knapp M, Black N, Dixon J, Damant J, Rehill A, Tan S (2014b) Independent Assessment of Improvements in Dementia Care and Support since 2009. Policy Innovation Research Unit, LSE and LSHTM.

Koivunen, E-R (2014) Telecare and older people's social relations. *The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes*. Leeds: Centre for International Research on Care, Labour and Equalities.

Kubitschke L, Cullen K (2010) ICT & Ageing – European Study on Users, Markets and Technologies. European Union.

Lakey L and Saunders T 2011. *Getting Personal? Making Personal Budgets Work for People with Dementia*. Alzheimer's Society, London.

Lancioni GE, Perilli V, Sing NN, O'Reilly MF, Sigafoos J, Cassano G, Pinto K, Minervini MG, Oliva D (2012) Technology-aided pictorial cues to support the performance of daily activities by persons with moderate Alzheimer's disease. *Res Dev Disabil*, 33, 265-73.

Lancioni GE, Perilli V, O'Reilly MF, Singh NN, Sigafoos J, Bosco A, Caffo AO, Picucci L, Cassano G, Groeneweg J (2013) Technology-based orientation programs to support indoor travel by persons with moderate Alzheimer's disease: impact assessment and social validation. *Res Dev Disabil*, 34, 286-93.

Landau R, Werner S (2012) Ethical aspects of using GPS for tracking people with dementia: recommendations for practice. *Int Psychogeriatr*, 24, 358-66.

Lauriks S, Reinersmann A, Van Der Roest HG, Meiland FJ, Davies RJ, Moelaert F, Mulvenna MD, Nugent CD, Droes RM (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Res Rev*, 6, 223-46.

Leadbeater C (2004) *Personalisation through Participation: A New Script for Public Services*. Demos, London.



- LeBlanc B (2015a) Saved by Siri. *Alzheimer's The Journey... A peek inside* [Internet blog] 4 July 2015. Available at: <http://abitofbriansbrilliance.com/2015/07/04/saved-by-siri> (accessed 28 September 2015).
- LeBlanc B (2015b) Attack of the mean tweets. *Alzheimer's The Journey... A peek inside* [Internet blog] 7 August 2015. Available at: <http://abitofbriansbrilliance.com/2015/08/07/attack-of-the-mean-tweets> (accessed 28 September 2015).
- LeBlanc B (2015c) Eat THESE! Take THAT! Look at THIS... Fact or Fiction? *Alzheimer's The Journey... A peek inside*. [Internet blog] 7 August 2015. Available at: <http://abitofbriansbrilliance.com/2015/04/22/eat-these-take-that-look-at-this-fact-or-fiction> (accessed 28 September 2015).
- LeBlanc B (2015d) There is a reason it's called: taking the easy way *Alzheimer's The Journey... A peek inside*. [Internet blog] 30 September 2015. Available at: <http://abitofbriansbrilliance.com/2015/09/30/theres-a-reason-its-called-taking-the-easy-way/#like-518> (accessed 30 September 2015).
- Lee E (2015) Do Technology-Based Support Groups Reduce Care Burden Among Dementia Caregivers? A Review. *J Evid Inf Soc Work*, 1-14.
- Leigh S, Flatt S (2015) App-based psychological interventions: friend or foe? *Evidence Based Mental Health*, doi:10.1136/eb-2015-102203.
- Leroi I, Woolham J, Gathercole R, Howard R, Dunk B, Fox C, O'Brien J, Bateman A, Poland F, Bentham P, Burns A, Davies A, Forsyth K, Gray R, Knapp K, Newman S, McShane R, Ritchie C (2013) Does telecare prolong community living in dementia? A study protocol for a pragmatic, randomised controlled trial. *Trials*, 14, 349, 1-9.
- Leuty V, Boger J, Young L, Hoey J, Mihailidis A (2013) Engaging older adults with dementia in creative occupations using artificially intelligent assistive technology. *Assist Technol*, 25, 72-9.
- Lewis J and West A (2014) Re-Shaping Social Care Services for Older People in England: Policy Development and the Problem of Achieving 'Good Care'. *Journal of Social Policy*, 43, 1, 1-18.
- Lewis V, Bauer M, Winbolt M, Chenco C, Hanley F (2015) A study of the effectiveness of MP3 players to support family carers of people living with dementia at home. *International Psychogeriatrics*, 27, 471-479.
- Licea S (2015) *Reminder, Calendar, Alarm and Voice Reminders – Aida Reminder Lite (Remind Me App)* [online]. iTunes Preview. Available at: <https://itunes.apple.com/us/app/aida-reminder-lite-voice-reminders/id469454389?mt=8> (accessed 28 September 2015).
- Living made easy (2015a) *Talking Photo Album* [online]. Available at: www.livingmadeeasy.org.uk/loan_library/memory-prompts-p/talking-photo-album-0044375-3854-information.htm (accessed 23 September 2015).
- Living made easy (2015b) *Voice Cue* [online]. Available at: www.livingmadeeasy.org.uk/loan_library/memory-prompts-p/voice-cue-0045853-3854-information.htm (accessed 23 September 2015).
- Living made easy (2015c) Disabled Living Foundation [online]. Available at: www.livingmadeeasy.org.uk (accessed 28 September 2015).
- Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, King D, Livingston D, Mummery C, Walker Z, Hoe J, Sampson EL, Cooper C (2013) Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial, *British Medical Journal*, 347, f6276.



Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, King D, Romeo R, Livingston D, Mummery C, Walker Z, Hoe J, Cooper C (2014) Long-term clinical and cost-effectiveness of START (STrategies for RelaTives) psychological intervention for family carers and the effects on cost of care for people with dementia: a randomised controlled trial. *Lancet Psychiatry*, 1, 7, 537-548.

Lloyd L (2010) The Individual in Social Care: The Ethics of Care and the "Personalisation Agenda" in Services for Older People in England. *Ethics and Social Welfare*, 4, 2, 188-200.

Loc8tor healthcare (2014) *Loc8tor for Healthcare UK – World's Best Trackers & Finders* [online] Available at: www.loc8tor.com/uk/healthcare (accessed 22 September 2015).

Lundberg S (2014) The results from a two-year case study of an information and communication technology support system for family caregivers. *Disabil Rehabil Assist Technol*, 9, 353-8.

Luppa M, Luck T, Weyerer S, König HH, Brähler E (2010) Prediction of institutionalization in the elderly: a systematic review. *Age & Ageing*, 39, 31-8.

Mason M, Sinclair D, Berry, C (2012) *Nudge or Compel? Can behavioural economics tackle the digital exclusion of older people?* London: International Longevity Centre – UK.

Mahoney DF, Tarlow BJ, Jones RN (2003) Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. *Gerontologist*, 43, 556-67.

Matthews FE, Arthur A, Barnes LE et al. (2013) A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function & Ageing Study I and II, *Lancet*, 382, 1405-12.

Matthews F, Brayne C, Medical Research Council Cognitive Function and Ageing Study Investigators (2005) The incidence of dementia in England and Wales: findings from the five identical sites of the MRC CFA study. *PLoS Medicine* 2, 8, e193.

Marshall M (2000) *ASTRID: A social and technological response to meeting the needs of Individuals with Dementia and their carers*. London: Hawker Publications.

Marziali E, Donahue P (2006) Caring for others: Internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *Gerontologist*, 46, 398-403.

Marziali E, Garcia LJ (2011) Dementia caregivers' responses to 2 internet-based intervention programs. *American Journal of Alzheimer's Disease and Other Dementias*, 26, 36-43.

McNicoll A (2012) *Social care and social work: is there an app for that?* [online]. Community Care – Inspiring excellence in social care. Available at: www.communitycare.co.uk/blogs/mental-health/2012/06/social-care-and-social-work-is (accessed 28 September 2015).

McShane R, Skelt, L (2009) GPS tracking for people with dementia. *Working with Older People*, 13, 3, 34-37.

Memory & Company (2015) Re:member [online] <http://memoryandcompany.com> (accessed 6 October 2015).

MI (2013) *I do it Mi way – more independent* [online]. Available at: www.moreindependent.co.uk/news/what-is-telecure (accessed 28 September 2015).

Mickus M, Luz C (2002) Televisits: sustaining long distance family relationships among institutionalised elders through technology, *Ageing and Mental Health*, 6, 387-396.



- Mihailidis A, Boger JN, Craig T, Hoey J (2008) The COACH prompting system to assist older adults with dementia through handwashing: an efficacy study. *BMC Geriatrics*, 8, 28-28.
- Milligan C, Roberts C, Mort M (2011) Telecare and older people: who cares where? *Soc Sci Med*, 72, 347-54.
- Milne A, Sullivan M, Tanner P, Richards S, Ray M, Lloyd L, Beech C, Phillips J (2014). Social work with older people: a vision for the future. The College of Social Work. Available online at: http://cdn.basw.co.uk/upload/basw_103616-1.pdf (accessed 8 June 2015).
- Miskelly F (2001) Assistive technology in elderly care, *Age Ageing*, 30, 6, 455-458.
- Miskelly F (2004) A novel system of electronic tagging in patients with dementia and wandering, *Age Ageing* 33,3, 304-306.
- Mitchell R (1996, unpublished) Mobile Emergency Care Dementia Project, Falkirk SSD.
- Morris M, Ozanne E, Miller K, Santamaria N, Pearce A, Said C, Adair B (2012) Smart technologies for older people – a systematic literature review of smart technologies that promote health and wellbeing of older people living at home. Melbourne: Institute for a Broadband-Enabled Society, The University of Melbourne.
- Moyle W, Cooke M, Beattie E, Jones C, Klein B, Cook G, Gray C (2013) Exploring the effect of companion robots on emotional expression in older adults with dementia: a pilot randomized controlled trial. *Journal of Gerontological Nursing*, 39, 46-53.
- Moyle W, Jones C, Cooke M, O'Dwyer S, Sung B, Drummond S (2014) Connecting the person with dementia and family: a feasibility study of a telepresence robot. *BMC Geriatr*, 14, 7.
- Murphy H (2014) *Social care: Is there an app for that?* [online]. Joseph Rowntree Foundation. Available at: www.jrf.org.uk/blog/social-care-there-app (accessed 28 September 2015).
- Murphy J, Gray CM, Van Achterberg T, Wyke S, Cox S (2010) The effectiveness of the Talking Mats framework in helping people with dementia to express their views on well-being. *Dementia: The International Journal of Social Research and Practice*, 9, 454-472.
- MyBrainBook (2015) *MyBrainBook – MyBrainBook* [online] Available at: <http://mybrainbook.com/login> (accessed 23 September 2015).
- National Elf Service (2015) No proof that 85% of mental health apps accredited by the NHS actually work [online] Available at: www.nationalelfservice.net/mental-health/depression/no-proof-that-85-of-mental-health-apps-accredited-by-the-nhs-actually-work (accessed 14 October 2015).
- National Institute for Health and Care Excellence (2015) Home care: delivering personal care and practical support to older people living in their own homes. NICE.
- National Museums & Galleries on Merseyside (2015) My House of Memories. Android App [online]. Available at: <https://play.google.com/store/apps/details?id=com.nlm.myhouseofmemories> (accessed 23 September 2015).
- Newton A, Shepherd D, Thompson E (2008) An evaluation of Lincolnshire's telecare service. *Journal of Assistive Technologies*, 2, 2, 48-51.
- NHS choices health apps library (2013) *NHS Health and Symptom Checkers – Health Apps Library* [online] Available at: <http://apps.nhs.uk/app/nhs-health-and-symptom-checkers> (accessed 23 September 2015).



- NHS (2015) *NHS choices health apps library* [online]. Available at: <http://apps.nhs.uk> (accessed 28 September 2015).
- NHS (2014) *Digital inclusion* [online]. Available at: www.nhs.uk/NHSEngland/digital-inclusion/Pages/importance-of-digital-inclusion.aspx (accessed 28 September 2015).
- NHS (2015) *Technology Enabled Care Services (TECS) – Launch of Technology Enabled Care Services (TECS) Resource for Commissioners* [online]. Available at: www.england.nhs.uk/ourwork/qual-clin-lead/tecs (accessed 28 September 2015).
- Nichols LO, Martindale-Adams J, Burns R, Graney MJ, Zuber J (2011) Translation of a dementia caregiver support program in a health care system – REACH VA. *Arch Intern Med*, 171, 353-9.
- Nijhof N, van Gemert-Pijnen JEW, Burns CM, Seydel ER (2013a) A personal assistant for dementia to stay at home safe at reduced cost. *Gerontechnology*, 11, 469-479.
- Nijhof N, van Gemert-Pijnen JEW, Woolrych R, Sixsmith A (2013b) An evaluation of preventive sensor technology for dementia care. *Journal of Telemedicine and Telecare*, 19, 95-100.
- Nygard L (2008) The meaning of everyday technology for people with dementia who live alone. *Dementia*, 7, 481–502.
- O’Connell ME, Crossley M, Cammer A, Morgan D, Allingham W, Cheavins B, Dalziel D, Lemire M, Mitchell S, Morgan E (2014) Development and evaluation of a telehealth videoconferenced support group for rural spouses of individuals diagnosed with atypical early-onset dementias. *Dementia: The International Journal of Social Research and Practice*, 13, 382-395.
- Ofcom (2011) Communications Market Report: UK. London: Ofcom.
- Ofcom (2012) Communications Market Report 2012. London: Ofcom.
- Office for National Statistics (2013) National Population Projections, 2012-based Statistical Bulletin, available at www.ons.gov.uk/ons/dcp171778_334975.pdf.
- Office for National Statistics (2014) Internet access: households and individuals 2014. Retrieved 13 September 2014, from www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-322080.
- Olson KE, O’Brien MA, Rogers WA, Charness N (2011) Diffusion of technology: frequency of use for younger and older adults. *Ageing International*, 36, 1, 123-145.
- Orellana K (2010) *Personalisation in Practice: Lessons from Experience. Making Personal Budgets, Support Planning and Brokerage Work for People in Later Life*. Age UK, London.
- Oysta Technology (2012) *Creative Safety Solutions* [online]. Available at: www.oysta-technology.com (accessed 28 September 2015).
- Padala KP (2008) *Wii-Fit for Improving Activity, Gait and Balance in Alzheimer’s Dementia* | National Institute on Aging [online] Available at: www.nia.nih.gov/espanol/alzheimers/clinical-trials/wii-fit-improving-activity-gait-and-balance-alzheimers-dementia (accessed 1 October 2015).
- Pawson R, Boaz A, Grayson L, Long A, Barnes C (2003) Types and quality of knowledge in social care. London: Social Care Institute for Excellence.
- Pilotto A, D’Onofrio G, Benelli E, Zanzetto A, Cabello A, Margeli MC, Wanchoo-Politis S, Seferis K, Sancarlo D, Kiliadis D (2011) Information and communication technology systems to improve quality of life and safety of Alzheimer’s disease patients: a multicenter international survey. *Journal of Alzheimer’s Disease*, 23, 131-141.



- Pitts K, Pudney K, Zachos K, Maiden N, Krogstie B, Jones S, Rose M, Macmanus J, Turner I (2015) Using mobile devices and apps to support reflective learning about older people with dementia. *Behaviour & Information Technology*, 34, 613-631.
- Pot AM, Willemse BM, Horjus S (2012) A pilot study on the use of tracking technology: Feasibility, acceptability, and benefits for people in early stages of dementia and their informal caregivers. *Aging & Mental Health*, 16, 127-134.
- Prince M, Prina M, Guerchet M (2013) *World Alzheimer Report 2013*, Alzheimer's Disease International, London.
- Prince M, Knapp M, Guerchet M, McCrone P, Prina M, Comas-Herrera A, Wittenberg R, Adelaja B, Hu B, King D, Rehill A, Salimkumar D (2014) *Dementia UK: Second Edition*. London: Alzheimer's Society.
- Procter R, Greenhalgh T, Wherton J, Sugarhood P, Rouncefield M, Hinder S (2014) The day-to-day co-production of ageing in place. *Computer Supported Cooperative Work (CSCW)*, 23, 245-267.
- Pursell S (2015) *Digital skills boost the power of community* [online]. Gov.uk. Available at: <https://socialcare.blog.gov.uk/2015/09/16/digital-skills-boost-the-power-of-community>.
- Pym H (2015) *Is this cuddly robot coming to a care home near you?* [online]. BBC. Available at: www.bbc.co.uk/news/health-34271927 (accessed 28 September 2015).
- Rainey C, Woolham J, Stevens M (2015) Research Capacity, Knowledge, Skills and Use in Councils with Adult Social Care Responsibilities. London: SSRG/PSSRU, SCEiP.
- Rally Round (2015) *Rally Round – start an account to organise care for someone who needs help* [online] Available at: www.rallyroundme.com/welcome (accessed 23 September 2015).
- Ray M, Milne A, Beech C, Phillips J, Richards S, Sullivan M, Tanner D, Lloyd L (2014) Gerontological social work: reflections on its role, purpose and value. *British Journal of Social Work*.
- RED Embedded Systems (2014) *RED Embedded Systems: visual care systems* [online] Available at: www.redembedded.com/systems (accessed 22 September 2015).
- RemindMeCare (2015) RemindMeCare Improving life for those affected by dementia [online] Available at: www.remindmecare.com (accessed 28 September 2015).
- Richard F, Shima S (2014) Empirical studies on the effectiveness of assistive technology in the care of people with dementia: a systematic review. *Journal of Assistive Technologies*, 8, 14-34.
- Riikonen M, Maekelae K, Peraelae S (2010) Safety and monitoring technologies for the homes of people with dementia. *Gerontechnology*, 9, 32-45.
- Riskman (2012) *Riskman – RiskMan.Net* [online]. Available at: www.riskman.net.au/Services/RiskMan-Net (accessed 28 September 2015).
- Roberts S (2009). The fictions, facts and future of older people and technology. London: International Longevity Centre UK.
- Roberts C (2015) Next-Generation Social Care – The Role of E-Marketplaces in Empowering Care Users and Transforming Services. London: Institute for Public Policy Research.
- Robinson H, MacDonald B, Kerse N, Broadbent E (2013) The psychosocial effects of a companion robot: a randomized controlled trial. *J Am Med Dir Assoc*, 14, 661-7.



Robinson L, Brittain K, Stephen L, Jackson D, Olivier P (2009). Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. *Int Psychogeriatr*, 21, 494-502.

Robinson L, Hutchings D, Corner L, Beyer F, Dickinson H, Vanoli A, Finch T, Hughes J, Ballard C, May C, Bond J (2006) A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use. *Health Technol Assess*, 10, iii, ix-108.

Rosenberg L, Kottorp A, Nygard L (2012) Readiness for technology use with people with dementia: the perspectives of significant others. *J Appl Gerontol*, 31, 510-30.

Rosenberg L, Nygard L (2012) Persons with dementia become users of assistive technology: a study of the process. *Dementia*, 11, 135-54.

Rowe MA, Kairalla JA, McCrae CS (2010) Sleep in dementia caregivers and the effect of a nighttime monitoring system. *J Nurs Scholarsh*, 42, 338-47.

Sanders C, Rogers A, Bowen R, Bower P, Hirani S, Cartwright M, Newman SP (2012). Exploring barriers to participation and adoption of telehealth and telecare within the Whole Systems Demonstrator trial: a qualitative study. *BMC Health Services Research*, 12, 220-231. doi:10.1186/1472-6963-12-220.

Salecl R (2010) *Choice*. London: Profile Books.

Saleh AO, Ric F, Rod L (2012) Impact and economic assessment of assistive technology in care homes in Norfolk, UK. *Journal of Assistive Technologies*, 6, 192-201.

Schwartz B (2005) *The Paradox of Choice: why more is less*. New York: Harper.

Scott JL, Dawkins S, Quinn MG, Sanderson K, Elliott KE, Stirling C, Schuz B, Robinson, A (2015) Caring for the carer: a systematic review of pure technology-based cognitive behavioral therapy (TB-CBT) interventions for dementia carers. *Aging Ment Health*, 1-11.

SeNCit (2013) *Multi function TeleCare Monitor with SMS Text Message Alerts* [online] Available at www..co.uk/SeN-Cit/index.shtml (accessed September 22, 2015).

Sixsmith A, Sixsmith J (2008) Ageing in place in the United Kingdom. *Ageing International*, 32, 3, 219-235. Retrieved from <http://link.springer.com/10.1007/s12126-008-9019-y>.

Skills for Care (2015) *Assisted living technology* [online]. skillsforcare. Available at: www.skillsforcare.org.uk/Skills/Assisted-Living-Technologies/Assisted-living-technology.aspx (accessed 28 September 2015).

Slasberg C, Beresford P, Schofield P (2012). How self directed support is failing to deliver personal budgets and personalisation. *Research, Policy and Planning*, 29, 3, 161-77.

Solihull Metropolitan Borough Council (2014) *Top 10 Social Care & Health Apps* [online]. Available at: www.solihull.gov.uk/Portals/0/SocialServicesAndHealth/Telecare/Top_10_Social_Care_-_Health_Apps.pdf (accessed 28 September 2015).

Solihull Metropolitan Borough Council (2014) *Using Apps to Support Health and Well-being – What are ‘Apps’ and why should I use them?* [online]. Available at: www.solihull.gov.uk/Portals/0/SocialServicesAndHealth/Telecare/Apps_Guidance.pdf (accessed 28 September 2015).

Sony-AIBO (2015) *Sony Aibo website for all models of Sony Aibo ERS-7, ERS-210, ERS-220, ERS-11x, ERS31x* [online]. Available at: www.sony-aibo.co.uk (accessed 23 September 2015).



SoundAsleep (2015) *Home – SoundAsleep* [online]. Available at: www.soundasleeppillow.co.uk (accessed 1 October 2015).

Spink K (2015) Technology can make a difference. *Social Care Blog*, Department of Health, England, 10 June 2015. [internet blog] Available at: <https://socialcare.blog.gov.uk/2015/06/10/technology-can-make-a-difference-2> (accessed 1 October 2015).

Staffordshire Cares (2015) *Me, Myself and I* [online]. Available at: www.memyselfandigame.co.uk (accessed 28 September 2015).

Staffordshire Cares (2013) *Staffordshire Care – Here to help you every step of the way* [online]. Available at: www.staffordshirecares.info/Homepage.aspx (accessed 28 September 2015).

Stephen C, Sultan H, Frew E (2014) Valuing telecare using willingness to pay from the perspective of carers for people with dementia: a pilot study from the West Midlands. *Journal of Telemedicine and Telecare*, 20, 141-146.

Steventon A, Bardsley M, Billings J, Dixon J, Doll H, Hirani S, Cartwright M, Rixon L, Knapp M, Henderson C, Rogers A, Fitzpatrick R, Hendy J, Newman S (2012) Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial. *British Medical Journal*, 12 e3874 doi: 10.1136/bmj.e3874.

Steventon A, Bardsley M, Billings J, Dixon J, Doll H, Beynon M, Hirani S, Cartwright M, Rixon L, Knapp M, Henderson C, Rogers A, Hendy J, Fitzpatrick R, Newman S. (2013) Effect of telecare on use of health and social care services: findings from the Whole Systems Demonstrator cluster randomised trial. *Age and Ageing*, 42, 4, 501-8.

Sugarhood P, Wherton J, Procter R, Hinder S, Greenhalgh T (2014) Technology as system innovation: a key informant interview study of the application of the diffusion of innovation model to telecare. *Disability & Rehabilitation: Assistive Technology*, 9, 79-87.

Technology platform for the assisted living of people with dementia and their carers. *Journal of Alzheimer's Disease*, 41, 515-523.

Technology Services Association (2013) Telecare and telehealth [online]. Available at: www.telecare.org.uk/consumer-services/telecare-and-telehealth (accessed 10 September 2014).

Tedim Cruz V, Pais J, Alves I, Ruano L, Mateus C, Barreto R, Bento V, Colunas M, Rocha N, Countinho P (2014) Web-based cognitive training: patient adherence and intensity of treatment in an outpatient memory clinic. *Journal of Medical Internet Research*, 16, e122-e122.

Telecare services association (2013) *What is mCare?* [online]. Available at: www.telecare.org.uk/consumer-services/what-is-mcare (accessed 28 September 2015).

Tobiasson H (2010) *Game over or play it again and again ... participatory design approach within special housing*. Student thesis, Linköping University, Department of Management and Engineering. Available at: www.diva-portal.org/smash/record.jsf?pid=diva2%3A291681&dswid=6268.

Topo P, Mäki O, 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*, 3, 3, 331-350.

Torkamani M, McDonald L, Saez Aguayo I, Kanios C, Katsanou MN, Madeley L, Limousin PD, Lees AJ, Haritou M, Jahanshahi M (2014) A randomized controlled pilot study to evaluate a technology platform for the assisted living of people with dementia and their carers, *J Alzheimers Dis*, 41, 2, 515-523.



Truthful Loving Kindness (2015) Sound DisOrientation as Dementia Symptom. *Truthful Loving Kindness, Patient with dementia symptoms* [Internet blog], 11 August 2015. Available at: <http://truthfulkindness.com/2015/08/11/sound-disorientation-dementia-symptom> (accessed 28 September 2015).

Tunstall Healthcare (UK) Ltd (2012a) MyAmie pendant. [online]. Available at: www.tunstall.co.uk/Uploads/Documents/MyAmie_datasheet_0414.pdf (accessed 23 September 2015).

Tunstall Healthcare (UK) Ltd (2012b) *Sensory impairment solutions* [online]. Available at: www.tunstall.co.uk/Uploads/Documents/Sensory_impairment_solution_sheet.pdf (accessed 23 September 2015)

Tunstall Healthcare (UK) Ltd (2012c) *Telehealthcare solutions: key information for health and social care professionals and carers – Dementia Care* [online]. Available at: [www.tunstall.co.uk/Uploads/Documents/Telehealthcare Solutions - Dementia Care.pdf](http://www.tunstall.co.uk/Uploads/Documents/Telehealthcare_Solutions_-_Dementia_Care.pdf) (accessed 22 September 2015).

Tunstall Healthcare (UK) Ltd (2015a) *Enuresis Sensor* [online]. Available at: www.tunstallhealthcare.com.au/solutions/enuresis-sensor (accessed 28 September 2015).

Tunstall Healthcare (UK) Ltd (2015b) *CareAssist* [online]. Available at: www.tunstall.co.uk/solutions/care-assist (accessed 28 September 2015).

Tynetec (2015) *Day clock – A simple dementia support tool that can tell someone what time of the day it is* [online]. Available at: www.tynetec.co.uk/dementia-solutions/day-clock (accessed September 22, 2015).

University of Salford (2015) *Dementia: Care and the Enabling Environment MSc/ PgDip/ PgCert – Postgraduate Taught Courses – University of Salford, Manchester* [online]. Available at: www.salford.ac.uk/pgt-courses/dementia-care-and-the-enabling-environment (accessed September 23, 2015).

Upton D, Upton P, Jones T, Jutlla K, Brooker D (2011) Evaluation of the impact of touch screen technology on people with dementia and their carers within care home settings Worcester: University of Worcester.

Van Mierlo LD, Meiland FJ, Droes RM (2012) Dementelcoach: effect of telephone coaching on carers of community-dwelling people with dementia. *Int Psychogeriatr*, 24, 212-22.

Van Mierlo LD, Meiland FJ, Van De Ven PM, Van Hout HP, Droes RM (2015) Evaluation of DEM-DISC, customized e-advice on health and social support services for informal carers and case managers of people with dementia; a cluster randomized trial. *Int Psychogeriatr*, 1-14.

Virtual College (2015) *Assisted Living on the App Store* [online] Available at: <https://itunes.apple.com/gb/app/assisted-living/id687336068?mt=8> (accessed 23 September 2015).

Wada K, Shibata T, Musha T, Kimura S (2005) Effects of robot therapy for demented patients evaluated by EEG. *Intelligent Robots and Systems, 2005. 2005 IEEE/RSJ International Conference*, 2-6 August 2005, 1552-1557. doi:10.1109/IROS.2005.1545304

Wagner N, Hassanein K, Head M (2010) Computer use by older adults: a multi-disciplinary review. *Computers in Human Behavior*, 26, 870-882.

Walker A, Craig J, Neary D (2013) *innovAge*. Sheffield: the University of Sheffield. [www.innovage.group.shef.ac.uk/assets/files/Innovage - About the project.pdf](http://www.innovage.group.shef.ac.uk/assets/files/Innovage_-_About_the_project.pdf)



- Wang RH, Gorski SM, Holliday PJ, Fernie GR (2011) Evaluation of a contact sensor skirt for an anti-collision power wheelchair for older adult nursing home residents with dementia: safety and mobility. *Assistive Technology*, 23, 117-134.
- Ward L, Barnes M (2015) Transforming practice with older people through an ethic of care. *British Journal of Social Work*, advanced access published 7 April 2015, 1-17.
- Weaver CK, Zorn T, Richardson M (2010). Goods not wanted. *Information, Communication & Society*, 13, 5, 696-721.
- Weiner MF, Rossetti HC, Harrah, K (2011) Videoconference diagnosis and management of Choctaw Indian dementia patients. *Alzheimers Dement*, 7, 562-6.
- Wey S (2005) One size does not fit all: person-centred approaches to the use of assistive technology. In Marshall M (ed.) *Perspectives on Rehabilitation and Dementia: Think Rehab*. London: Jessica Kingsley Publishers.
- Wey S (2006) Working 'in the zone': a social-ecological framework for dementia rehabilitation. In Woolham J (ed.) *Assistive Technology and Dementia Care: developing the role of technology in the care and rehabilitation of people with dementia: current trends and perspectives*. London: Hawker Publications.
- Wherton J, Sugarhood P, Procter R, Rouncefield M, Ddwsbury G, Hinder S, Greenhalgh T (2012) Designing assisted living technologies 'in the wild': preliminary experiences with cultural probe methodology. *BMC Medical Research Methodology*, 12, 188-188.
- White EB, Montgomery P, McShane R (2010) Electronic tracking for people with dementia who get lost outside the home: a study of the experience of familial carers. *British Journal of Occupational Therapy*, 73, 4, 152-159.
- Whitten PS, Mair FS, Haycox A, May CR, Williams TL, Hellmich S (2002) Systematic review of cost effectiveness studies of telemedicine interventions. *BMJ*, 324, 1434-1437.
- Willison A (2014) Assistive Technology (AT) in Buckinghamshire. Buckinghamshire: Buckinghamshire County Council.
- WIN (2015) *WIN Open Network – 26 November 2014* [online]. Available at: <https://wmhin.org/open-network-26-november-2014> (accessed 28 September 2015).
- Woolham J, (2005) *Assistive Technology in Dementia Care: developing the role of technology in the care and rehabilitation of people with dementia – current trends and perspectives*. London: Hawker Publications.
- Woolham J, Frisby B, (2002) Building a local Infrastructure that supports the use of AT in the care of people with dementia. *Research Policy and Planning* 20, 1, 11-24.
- Woolham J (2005) The effectiveness of assistive technology in supporting the independence of people with dementia: the Safe at Home project. London: Hawker Publications.
- Woolham J (2006) Safe at Home: the effectiveness of assistive technology in supporting the independence of people with dementia. London: Hawker Publications.
- Woolham J, Gibson G, Clarke P (2006) Assistive Technology, Telecare, and Dementia: Some Implications of Current Policies and Guidance. *Research and Policy Planning*, 24, 149-164.
- Woolham J, Gibson G, Clarke P (2007) Local responses to the preventive technology grant: findings from a two stage survey of local stakeholders. Available at: www.atdementia.org.uk



-
- Woolham J, Daly G, Steils N, Ritters K (2015) The evolution of person-centred care to personalised care, personal budgets and direct payments in England: some implications for older users of social care services. *Sociologia e Politiche Sociali*, 1, 145-62.
- Wray LO, Shulan MD, Toseland RW, Freeman KE, Vasquez BE, Gao J (2010) The effect of telephone support groups on costs of care for veterans with dementia. *The Gerontologist*, 50, 623-631.
- Wright D, Wadhwa K (2010) Mainstreaming the e-excluded in Europe: strategies, good practices and some ethical issues. *Ethics and Information Technology*, 12, 139-156.
- Xie J, Brayne C, Matthews F, Medical Research Council Cognitive Function and Ageing Study collaborators (2008) Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up, *British Medical Journal*, 336, 258.
- Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K et al. (2002) Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA*, 287, 2090-7.
- Yeandle S (2014a) Frail Older People and their Networks of Support: how does telecare fit in? Leeds: Centre of International Research on Care, Labour and Equalities, University of Leeds.
- Yeandle S (2014b) Researching Telecare Use using Everyday Life Analysis: introducing the AKTIVE working papers. Leeds: Centre for International Research on Care, Labour and Equalities, University of Leeds.
- Yeandle S, Buckle P, Fry G, Hamblin K, Koivunen E-R, McGinley C (2014) The AKTIVE project's social, design and prospective hazard research: research methods. Leeds: CIRCLE, University of Leeds.
- York Health Economics Consortium (2013) Telecare for People with Dementia: Evaluation of Renfrewshire Project – Final Evaluation Report. York Health Economics Consortium, University of York.
- Zetteler J (2008) Effectiveness of simulated presence therapy for individuals with dementia: a systematic review and meta-analysis. *Aging Ment Health*, 12, 779-85.
- Zwijssen S, Neimeijer A, Hertogh C (2011) Ethics of using assistive technology in the care for community-dwelling elderly people: an overview of the literature. *Aging Ment Health*, 15, 419-27.

The Policy Innovation Research Unit (PIRU) brings together leading health and social care expertise to improve evidence-based policy-making and its implementation across the National Health Service, social care and public health.

We strengthen early policy development by exploiting the best routine data and by subjecting initiatives to speedy, thorough evaluation. We also help to optimise policy implementation across the Department of Health's responsibilities.

Our partners

PIRU is a collaboration between the London School of Hygiene & Tropical Medicine (LSHTM), the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE), and Imperial College London Business School plus RAND Europe, the Nuffield Trust and the Public Health Research Consortium.

The Unit is funded by the Policy Research Programme of the Department of Health.

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



EUROPE

nuffieldtrust



Policy Innovation Research Unit

Department of Health Services Research & Policy
London School of Hygiene & Tropical Medicine
15–17 Tavistock Place, London WC1H 9SH

Tel: +44 (0)20 7927 2784
www.piru.ac.uk