

Digital Exclusion and Technology Enabled Care in Scotland

A review of the literature on the impact of technology on older and disabled adults

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Introduction

Scotland, along with most of the rest of the world, has seen a consistent rise in the proportion of older people within its population in recent years. Ensuring a good quality of life for citizens in old age is a pressing public policy concern. It is also an issue that potentially carries a huge cost to the public sector and, as the longevity of the population increases, is one that is set to exacerbate.

It is anticipated that the use of Technology Enabled Care (TEC) with older, homebound and disabled adults could respond to this challenge by leading to a) a greater number of options in how people live, particularly in relation to living independently within their own homes, b) improvements in health, quality of life and digital inclusion c) reductions in the costs of delivering care and d) a reduced burden on families and informal carers.

Those most likely to be in receipt of care – older adults and disabled people – are also two of the most digitally excluded groups in the UK (Dutton and Blank, 2014). Strong links have also being found between digital and other forms of social exclusion (Helsper, 2012; Van Dijk, 2005; Warren, 2007). This means that those who could benefit most from going online (e.g. through reduced social isolation) are also those that are least likely to be active users of the internet.

This paper provides a review of the current literature on the use of TEC in the provision of care and support to older people and disabled adults, with a focus on these populations within Scotland. It was conducted as part of an evaluation of an Assisted Living Technology (ALT), known as Clever Cogs, developed by Blackwood Homes and Care (Blackwood) to support the digital participation of its clients and improve their quality of life. In 2015, Blackwood piloted the use of Clever Cogs within a small number of its care homes. This pilot was supported by the Scottish Government's Digital Participation team, which has also supported this evaluation.¹ This literature review is being published as a standalone output from the research.

Policy Context: Technology-Enabled Care in Scotland

The Scottish Government's definition of TEC refers to a situation "where outcomes for individuals in home or community settings are improved through the application of technology as an integral part of quality cost-effective care and support" (Scottish Government, 2016 p2). It includes but is not limited to, the use of telecare, telehealth, video conferencing (VC) and mobile health & wellbeing (mHealth) (ibid.). The government has adopted the term TEC to reflect a shift in focus from the technology itself to the care provided by that technology. The latest action plan states that the change in language recognises:

¹ The aim of the evaluation is to gather evidence of the impact of the technology on a range of stakeholders and assess whether the technology is a) socially valuable to clients and b) whether there is a business case for expanding the use of the technology more widely to support the care of homebound and disabled adults across Scotland.

- 1. The significant advances in technology, which mean that increasingly only one familiar device, or platform, can carry out multiple functions rather than having to use multiple and specialist devices; and
- 2. The emphasis needs to be on enabling care using the most up-to-date methods, and not on the technology i.e., any change needs to be service led and outcomes driven, not technology led.

(Scottish Government, op cit. p2)

Scotland has been at the forefront of research, development and delivery of technology in health and social care (Carretero et al., 2015). Scotland's flagship Technology Enabled Care Programme (TECP) was launched in 2014 by the Scottish Government as a three-year £30 million programme to 2018. It has five objectives:

- 1. Expansion of home health monitoring
- 2. Expanding the use of video conferencing
- 3. Creating a national digital platform framework
- 4. Expanding the take up of telecare,
- 5. Exploring the scope and benefits of switching current provision of telecare from analogue to digital telecare

The result of this (and preceding initiatives) means that there is now a significant number of ALTs now in mainstream use throughout Scotland. The Scottish Centre for Telehealth and Telecare lists 50 different projects that are underway. Scottish Government statistics show that over 80% of those in receipt of formal social care services already use telecare to support their independence at home (Scottish Government, 2016). In addition to the 115,000 or so in receipt of local authority commissioned/provided telecare, it is estimated that around 40,000 or so use housing association-provided telecare or privately provided telecare (e.g. Age UK) (ibid.).

Research questions

The review is presented in two parts. The first looks at the evidence relating to the need for this technology, the second to the evidence of the effectiveness and cost effectiveness of this type of TEC. It concludes with a summary of the findings and research gaps.

The research questions addressed in Section 1 are as follows:

- What social, demographic and policy needs are ALTs responding to?
- What do we know about the online activities of disabled people and older adults?
- What do we know about the needs of carers and the changing nature of unpaid care?

The research questions addressed in Section 2 are as follows:

- What is the state of knowledge on the potential of TEC to address the needs highlighted above?
- What is the state of knowledge on the benefits of going online to disabled people and older adults?

- Is there evidence that TEC initiatives are cost effective?
- Where are the gaps in the data and what can we conclude from the literature?

Review methodology

This is an analytic literature review i.e. it seeks to comprehensively answer a set of research questions. Bibliographic databases consulted included ProQuest, Wilson Select Plus, LexisNexis and Google Scholar. In the search, words and phrases related to ageing, disability and technology were combined to maximise the number of matches. Many articles were acquired by identifying relevant references from the bibliographies of literature reviews (e.g. Blashke, 2009) and related sources. Only English-language reports were included and it was conducted between April and June 2016. In the final selection, the emphasis was on empirical (i.e. data-based) reports, although other relevant work provided background and context. Studies were prioritised with experimental or quasi-experimental research designs but grey literature and non-academic evaluations were also consulted. These were accessed through general internet searches of key terms. The search was not exhaustive but should give a reasonable overview of the state of knowledge in each area and some general findings from the research.

One key challenge with reviewing the evidence in relation to TEC is that each system is often tailored to a set of needs and therefore contains different elements. This makes generalisations and comparisons challenging. A further difficulty is that there is substantial overlap between different terms: ehealth, telecare, telehealth, telemedicine, monitoring systems, assisted living, home automation, smart homes and home adaptations. Although the Scottish Government has adopted the term Technology Enabled Care, this is not usually reflected in the literature where there is much more fluidity in how terms are used. For example, in a systematic review of 'ehealth' initiatives by Black et al (2011), many of the initiatives are very similar to those reviewed by Ekeland et al (2010) in a review of reviews of telemedicine. The Ekeland review also included some initiatives that cover social care and therefore more like telecare. Searches were carried out using these terms, however it was not always clear how the terms were being interpreted and what elements were included in each study.

The aim of the review is to assess the evidence of need for TEC and the current evidence base on effectiveness (including cost-effectiveness). It is limited those aspects of Technology Enabled Care which are most relevant to the Clever Cogs system (telehealth/care, monitoring systems, internet access, and home automation). Neither does the review look at wider features of TEC such as Big Data.

Section 1: Evidence of need

This section discusses the evidence of need amongst disabled adults and older people. Four areas have been identified where TEC could play a role:

- Providing remote, high quality, cost effective care and support
- o Reducing digital exclusion amongst older and disabled people
- Reducing social isolation amongst older and disabled people
- Reducing the burden on unpaid carers

Each of these is an important policy agenda and will be discussed in turn in this section.

Demand for remote, high quality, cost effective care and support

Across the world, the costs associated with complex health and social care needs are expected to rise considerably in the coming years. In Scotland, there are several factors influencing this:

- An aging population. Scotland's population is continuing to age, with a 50% increase in over 60s projected by 2033 from a 2010 baseline (Scottish Government Social Research, 2010). By 2033, over 60s will make up about 25% of the population (Ibid.). There will also be more single people in the older age group in the coming years. By 2037, about 488,200 people aged 65 and over are expected to be living by themselves, which is an increase of 51 per cent compared to 2012². The rate of aging is somewhat more rapid than in other parts of the UK. The proportion of Scotland's population which is of pensionable age is projected to increase by 2.9 percentage points between 2010 and 2035, compared with a 1.7 percentage point rise for the UK (Scottish Government Social Research, 2010)
- Increase in the number of people living with chronic conditions. By 2030 life expectancy in the UK will increase by 4.2 years but healthy life will only increase by 2.6 years. This means there will be an increase in the number of adults with chronic medical conditions. Currently 13.6 million people in the UK suffer from some form of long term condition and by 2025 this number will double (McKinstry, 2016). It is estimated that the demand for social care will increase by 44% as a result (Lewin et al., 2010).
- Rising cost of care. The costs of conditions associated with aging continue to rise. Dementia alone is estimated to cost £24,647 per person per annum (Bourne, 2007). Age related public expenditure in the UK is projected to increase from 20.1% of GDP in 2007-8 to 26.6% in 2057 (Scottish Government Social Research, 2010).
- Changing nature of informal care. In 2011 there were about half a million carers in Scotland and this figure is expected to rise. However, this is unlikely to keep pace with the demand for informal carers as the pool of potential carers shrinks³

³ See discussion on this here <u>http://www.communitycare.co.uk/blogs/adult-care-blog/2012/11/demand-for-informal-care-is-rising-but-supply-is-set-to-fall-we-must-solve-this-conundrum/</u>

² Further information on these estimates can be found at: http://www.nrscotland.gov.uk/news/2014/house-estimates-2013

- Increased remoteness of older populations. A large proportion of the over-65s live in rural areas which makes the provision of services more challenging and costly (Philip and Heritage, 2003). Roughly a fifth of the population living in rural areas are aged 65 compared to 17% in the rest of Scotland. It is expected that in some rural and remote councils that the older population could reach 30% by 2033 compared to a 19% projection for Glasgow (Scottish Government Social Research, 2010).
- **Rising dependency ratio.** The ratio of non-working age people to total consumers in the economy is rising, meaning that the productivity of this relatively smaller pool of labour must rise to compensate for this. Scotland's dependency ratio is projected to increase from 60 per 100 to 68 per 100 by 2033 (Scottish Government Social Research, 2010)

The challenge of continuing to provide quality, person-centred care in the context of rising need is a substantial one. Experts predict that it is unlikely that governments will increase the funding of formal care for older and disabled people so as to match the expected growth in demand (Lewin et al., 2010). In Scotland, the funding invested in the Integrated Care Fund to 2018 means that this gap is less acute than in the rest of the UK but it is still only likely to keep pace with demand⁴. Digital-age tools have been proposed as possible resources that may improve the lives of disabled and older adults and family caregivers now and in the future.

Across Scotland, there has also been an increase in demand for care at home and more personalised care (Bell et al., 2007). This has been supported by the government, which recognises that institutionalised care is unaffordable as well as being undesirable (Task Force on the Future of Residential Care in Scotland, 2014). 'Aging in place' has been proposed as one method to reduce cost and maintain quality of life for the aging population (Tomita et al., 2010). The idea is to support adults in an environment of their choice in lieu of institutionalisation. The use of technology has been identified as an important factor in helping to meet this challenge, particularly in supporting the workforce to adapt to new models of care (ibid).

Digital exclusion in older people and disabled adults

As the scope and potential of the internet widens, as it becomes more ubiquitous and embedded in social, economic and cultural life, the costs of being excluded also rise. A motivating factor for reducing the digital divide is that those that could benefit most are losing out. The barriers to going online are well documented and include cost, motivation, confidence and a lack of skills (Dutton and Blank 2011). All potential users of the internet face these barriers, however, for certain groups, these are more pronounced. For example, a person with a disability is more likely to be on a low income, which exacerbates the cost barrier. An older person may have memory problems and find it harder to acquire a skill. Hence we see a concentration of certain demographics within the digitally excluded.

⁴ More information can be found at http://news.gov.scot/news/further-200m-to-support-health-social-care-integration

In 2013, for the first time the number of people aged 65+ that had used the internet overtook those that had not (Green and Rossall, 2013). Nonetheless, age is still one of the most significant determinants of digital exclusion in the UK (Dutton and Blank, 2014) and there is a decreasing likelihood of being online as you age. In the same year about half of British people with a disability were using the internet compared with 84% of the non-disabled population. This is consistent with the many other studies showing that people with impairments are less likely to use the internet or have access at home than people without impairments (Dobransky and Hargittai, 2006; Helsper and Reisdorf, 2016; Hollier, 2007; Kaye, 2000). The gap with non-disabled people is even wider when usage is compared for those that don't have access at home and instead rely on access in a public space, workplace or at the house of a friend or relative, suggesting that home access remains an important determinant of people's internet use (Tuikka et al., 2015).

As mentioned above, digital and social exclusion are highly correlated, with researchers arguing that these trends are structural and leading to the emergence of a 'digital underclass' as those offline become more entrenched in their exclusion (Helsper and Reisdorf, 2016). Where non-users meet multiple digital exclusion characteristics e.g. disability, old age and low income, the challenge of getting online is even greater (Choi and DiNitto, 2013). There is also evidence to suggest that poverty combined with these characteristics substantially raises the likelihood of being excluded (Green and Rossall, 2013).

A further barrier to access is that the internet is to some extent exclusive by design. For example, internet content has developed around the interests and priorities of younger, more affluent, English speaking users (Chen and Wellman, 2004). For older and disabled people the technology used to get online can also place them at a disadvantage. Jaegar describes the internet as 'inherently unfriendly' to people with many kinds of disabilities and reports that barriers to access and usage vary by type and extent of disability i.e. where a website offers opportunities for one group it excludes another (Jaeger, 2012). When online, a number of studies have found that disabled people are less likely to shop, bank, study, get news or search for jobs (Vicente and Lopez, 2010) but more likely to play games or search for health information (Tuikka et al., 2015). Outside of internet access, barriers also exist for other kinds of technologies, and access issues are often not considered in their design and implementation (Goggin and Newell, 2007; Jaeger, 2012). This argument would resonate with the idea that technology, as a social product, reproduces, rather than challenges existing inequalities including barriers to disabled people (Dobransky and Hargittai, 2006; Goggin and Newell, 2007). Rather than assuming technology will always offer solutions, it requires recognition of the fact that digital exclusion is embedded in, and reflective of, wider social exclusion.

At the same time, there is some evidence that if barriers to access can be overcome, the benefits from going online are greater for those with disabilities than the general population. A study by Taylor (2000) found that adults with disabilities were more likely to believe that it improved the quality of their lives, made them better informed and helped them meet people more than the general population. However, this is an old study and more recent data on the perceived benefits of the internet to disabled people would be beneficial.

Finally, it should also be reiterated that older and disabled people are not a homogenous group. For example, disabled people differ with type of impairment but also how it interplays with other barriers to digital inclusion that they might be experiencing (Tuikka, Kimppa and Suomi, 2015). Differences within the populations are sometimes unexpected. For example, older people with memory problems are 1.45 times more likely to be using the internet than individuals without problems (Green and Rossall, 2013).

Loneliness and social isolation amongst older and disabled people

Loneliness is increasingly a public health concern. It has been linked to a range of negative effects on health and mental health. For example, Hult-Lunstad, Smith and Layton (2010) conducted a meta-analysis of studies into loneliness and health and found that the influence of social relationships on the risk of death in the general population are comparable with well-established risk factors for mortality such as smoking and alcohol consumption and greater than the influence of other risk factors such as physical inactivity and obesity.

Those aged over 65 in the UK, are more likely than other groups to experience some form of social isolation or loneliness. There is a large body of evidence for loneliness in old age, and it is generally understood to be commonly experienced in this age group (some studies have suggested that up to half of all people in this age group have experienced loneliness sometimes or often (Dykstra et al., 2005).

It is also likely that loneliness in old age can become chronic. In the UK, one in ten over 65s say that they are always or often lonely, 41% say they feel out of touch with the pace of modern life and 12% say they feel cut off from society (Age UK, 2014). Other studies have shown that 15%–25% of older adults experience social or emotional isolation from others for many months or years (Cohen-Mansfield, Shmotkin, & Goldberg, 2009; Dykstra et al., 2005; Jylhä, 2004; Newall, Chipperfield, & Bailis, 2013; Victor et al., 2005). These studies suggest that those individuals following a trajectory of high, continuous or increasing loneliness showed relatively poor mental and physical health (Qualter et al., 2015).

In a large-scale study of people with physical disabilities related to chronic health conditions, Rocach, (2006), found high levels of loneliness. However, loneliness appears to be a particular risk for people with learning disabilities (Lippold and Burns, 2009). Studies in children with learning disabilities consistently find that 7 to 15 year old children with learning disabilities are more likely to experience loneliness than their classmates (Wiener, 2004). Research on the social life of adults with learning disabilities find low levels of friendship activities of those living in supported accommodation, and that friendship activities are more likely to be with other people who also have disabilities (Emerson & McVilly, 2004). Studies have also shown high levels of loneliness and isolation amongst adults with Autism Spectrum Disorder, a condition which is characterised by difficulties in social interaction (Tobin, Drager, & Richardson, 2014).

The caregiver burden

Although caring can be a rewarding and positive experience, caring long-term for an adult family member can have a negative impact upon carers' physical and psychological health. Primary carers of adults with a learning disability are more likely to experience higher levels of stress, anxiety, depressive symptoms (Seltzer et al., 2011) and physical health problems than their non-caregiving peers (Yamaki et al., 2009).

A recent report *Scotland's Carers* (The Scottish Government, 2015) reported positive mental health impacts from providing small amounts of care (4 hours or less) but that this declined as the amount of care increased. Carers who provide more than 35 hours per week are more likely to have lower mental wellbeing scores and exhibit signs of a possible psychiatric disorder than non-carers and those providing fewer hours of care. Those most at risk are also those in the most demanding caring situations e.g. providing higher levels of caring over extended period and co-resident/spousal carers (ibid.).

In addition, family carers are often older adults themselves. In Scotland, older carers are also the ones that are most likely to be providing more than 20 hours of care per week (ibid.). This group faces particular challenges including the long duration of their care giving roles, their own aging and that of the recipient of their care (Perkins and Haley, 2013). Older carers often have additional anxiety about the future of the person that they care for (Heller and Caldwell, 2006) and have been found to use the internet less than their younger counterparts to find information to help them with their caregiving activities (Perkins and LaMartin, 2012).

In the 10 years to 2011 the intensity of care has increased in Scotland (e.g. those providing 50 hours or more of care has increased from 24% to 27%), suggesting an increase in health and mental health risks for this group (The Scottish Government, 2015). In Scotland, high intensity carers are most likely to be drawn from the most deprived communities where risks of poor health are already greater (The Scottish Government, 2015). This has led to a rise in interest in 'technology as a care-giver' and in exploiting technology to assist existing care givers, for example where people are suffering from dementia (Haigh and Yanco, 2002 p39).

Summary

Scotland faces a sizeable challenge of continuing to provide high quality care to an increasing number of older people with rising health needs, many of whom live in rural and remote communities. Although not alone in this challenge, the predicted dependency ratio - the ratio between those of working and non-working age - is worse than in other parts of the UK. Whilst the personalisation agenda provides great opportunities for healthy aging, delivering this at scale also presents a substantial policy challenge. Those providing unpaid care are more likely to experience a range of negative health and wellbeing outcomes than the rest of the population and many are themselves older adults. Furthermore, socio-demographic changes suggest that more people will need to work in the formal labour market, and for longer, which over time will reduce the number of informal carers relative to demand.

TEC has the potential to respond, at least in part, to these needs. Although it is widely assumed that technology can improve the quality of life of those in receipt of care, this should not be taken for granted. For example, active technologies, such as internet access, will only be beneficial if they are being fully exploited by the user. As Blaschke (2009, p. 641) points out: "Appropriate social work practice in the digital age requires knowing what tools are available and their documented effectiveness and limitations." The next section reviews this evidence and makes recommendations for further research.

Section 2: Evidence of effectiveness

Recent years have seen a rapid increase in the development of Assisted Living Technologies (ALTs) in response to the needs set out in the previous section. Although a relatively new

phenomenon, there is already a very large literature in this field. The expected benefits are wide-ranging, covering health, quality of life, satisfaction and cost outcomes. Assessing the strength of evidence in relation to these outcomes is challenging for several reasons:

- 1. There is an enormous range of different technologies used in different clinical/care pathways for different conditions, with different levels of functionality, cost, usability etc.
- As discussed in the methodology section, definitions are fluid and used interchangeably: sometimes researchers use broad definitions to describe multiple features (e.g ehealth) and sometimes focuses on just one element such as home monitoring.
- 3. As the technologies are often quite new and the outcomes claimed quite long-term, there is a mismatch between the timescale of the evaluation and the ability of the technology to deliver.
- 4. Problems with implementation can frustrate attempts to evaluate the potential of the technology. As Mclean et al. (2011 p375) have observed "effectiveness depends on the context of the introduction of a specific system". Unpacking these contextual factors can complicate the aims of the evaluation.
- 5. Technology is constantly evolving, which means that evaluations go out of date quickly as the technology (and research approach) is superseded by a new iteration. Each new iteration benefits from the previous which means that the quality of interventions are improving but it makes it difficult to pin down the evidence as studies are quickly nullified⁵.

Following Blaschke, (op cit.) we have split interventions into three areas (a) smart home technology/home automation, (b) monitoring systems and (c) telehealthcare. However, the will be overlap, as some telehealthcare systems will incorporate the previous.

The definitions that we have used are set out below.

- Smart home technology: Technology which enables highly advanced automatic systems for lighting, temperature control, multimedia, security, windows and door operations and other functions within a home (Craven 2013, quoted in Tomita et al., 2010)
- 2. *Monitoring* systems: Related to smart home technology, but focuses specifically on sensors which that alert carers when the person receiving care enters or leaves designated areas. If provided by local authorities, generally this would be subsumed into Telecare.
- 3. Telehealthcare: The terms telehealth and telecare are often used interchangeably to refer to a range of services including remote physiological monitoring, medication prompts and aspects of remote care delivery. The Scottish Government incorporates 'telemedicine' e.g. video consultations, which are sometimes grouped under

⁵ For example, there are several experimental studies of telehealthcare underway at present. For more details see http://www.telescot.org

telemedicine. However, these are not included in our definition or telehealthcare and are therefore not included in the review.

This section also includes a review of the literature on the impact of digital participation for disabled and older people and evidence relating to cost effectiveness.

Smart home technology

A smart home is described as a house that has highly advanced automatic systems for lighting, temperature control, multimedia, security, windows and door operations and other functions (Craven 2013, quoted in Tomita et al., 2010). There is a reasonable amount of evidence that supports the benefits of the use of home automation. Blashke (op cit.) in her review suggests that the few published studies of smart homes suggest potentially important benefits. Smart homes also tend to be positively received by users (Mehrabian et al., 2015).

One randomised controlled trial (Tomita et al., 2010) found that at post-test, physical and cognitive functional status of smart home users was maintained while those for the control group had significantly declined. The difference was apparent in physical dysfunction, instrumental activities of daily living (IADL), mobility, and cognition. At the follow-up, among the treatment group, 80.4% were living in their own home compared with 65.7% for the control group.

Another study that looked at smart home technology with health-promoting exercise found that it could be an effective method for occupational therapists to reduce fall risks through encouraging an active lifestyle (Tomita and Nochajski, 2015).

A recent systematic review of studies of smart homes found that whilst many appliances are available there are only a small number of studies that investigated their effectiveness at helping the older adults to live independently at home. The review concluded that the technologies could accurately detect abnormal movement or behaviours and were appropriate methods to control various electronic devices but that evidence was lacking in other areas (Morris et al., 2013).

Monitoring technologies

These refer to sensors and warning systems that alert carers when the person receiving care enters or leaves designated areas. Whilst research in this field is widespread, it is still in its infancy and consists mostly of small-scale studies with only a few longitudinal ones that track long-term outcomes.

Many of these studies do show positive results (Altus et al., 2000; Chan et al., 2009; Kinney et al., 2004) but as Blasche (ibid.) points out, there are few with an experimental design. One quasi-experimental study, carried out by Holmes et al. (2007) examined such a monitoring system and found no significant impact on the number of falls or injuries, although the intervention group showed significant improvement in affective disorders over time. It was not clear however if this was due to greater staff vigilance or the use of the device. Wilson et al. (2009) conducted an RCT, which found that the treatment group was more likely to use equipment to maintain independence enabling them to stay in their homes longer. Other evidence suggests that adaptations and technologies that are delivered in conjunction with

other clinical interventions can enable elderly people to function in their homes for longer (Gitlin et al., 2006). One reason for the conflicting evidence may relate to the nature of the technology in question and differences in how they are implemented.

Telehealthcare

Telehealthcare systems are attractive to health and welfare agencies because they allow people with long-term illnesses to be remotely monitored, or to monitor themselves, at home. Studies have been particularly encouraging across a range of chronic conditions. As these studies are out of date quickly a selection of some of the most recent studies is provided in Table 1.

Condition	Findings	Source
Diabetes	Improved glycaemic control.	Marcolino et al. 2013
Respiratory conditions	Home telemonitoring of respiratory conditions results in early identification of deteriorations in patient condition and symptom control but evidence of clinical effects remains preliminary In most trials in which patients with asthma were enrolled, results showed significant improvements in patients' peak expiratory flows, significant reductions in the symptoms associated with this illness, and improvements in perceived quality of life.	Jaana et al., 2009 Paré et al., 2010
	hospitalisations may benefit but unlikely to benefit those with mild symptoms	Mclean et al. 2010
Congestive Cardiac Failure	Reduced causes of mortality but not reductions in hospital admissions	Inglis et al. 2015 Maric et al., 2009
Cognitive decline	Study supported the use of home health technologies for use in monitoring activities of daily living, cognitive decline, in	Liu et al., 2016

	older adults with complex needs.	
Anxiety and depression	Amelioration in the decline in users' mental HRQoL over a 12-month period Study supported the use of home health technologies for use in monitoring activities of daily living, cognitive decline, in older adults with complex needs. Found changes in depression symptoms in individuals who used the system regularly reached potentially meaningful levels	Hirani et al. 2014 Liu et al. 2016 Burton et al. 2016
Hypertension	Large number of RCTs including one in Scotland showed a 4.3mm reduction in systolic ambulatory	McKinstry et al. 2013
COPD	Recent RCT in Scotland demonstrated no impact of telehealthcare on time to admission or total admission time. Further research required.	McLean 2012

A recent systematic review found that evidence from high-quality reviews with meta-analysis indicated that taken collectively, home telemonitoring interventions reduce the relative risk of all-cause mortality and heart failure-related hospitalizations compared with usual care (Kitsiou et al., 2015). There is some evidence that systems that promote safety in the home can be effective in delaying admission to residential care and monitoring conditions with the aim of prevention (Barlow et al., 2007). Although the Liu et al. systematic review cited above did find many positive outcomes, it did not find any evidence for disease or fall prevention (Liu et al., 2016). Anecdotal evidence suggests that one reason for this may be that fall technology is about ensuring a quicker response, rather than preventing the fall itself.

Another systematic review of physiological monitoring technologies showed predominantly positive results in relation to behavioural changes such as medication, diet and exercise and disease management (van den Berg et al., 2012). In their review of evidence of telehealth, Blaschke et al also found that telehealth technology combined with home-based services may provide substantial benefits to chronic disease management, including positive changes in health perception, social functioning, mental health and medical compliance. According to Chan et al. (2009) telehealthcare can provide the infrastructure for coordinating

multidisciplinary care outside the hospital (scheduling visits with health staff and community health workers, automating collection of clinical findings and test results). A review of the evidence for outcomes of using technology by people with dementia found few benefits but some evidence of increased independence (Knapp et al., 2015).

According to Barlow et al. (op cit.), the most effective telehealthcare interventions appear to be automated vital signs monitoring (for reducing health service use) and telephone follow-up by nurses (for improving clinical indicators and reducing health service use). McLean et al. (op cit.) make the case that contradictory findings in some areas may relate differences in patient's self-efficacy at baseline i.e. those with a higher baseline may be less likely to benefit from frequent testing and reporting.

In 2011 the UK Department of Health reported on the results of a three-year programme to evaluate telehealth and telecare applications across the UK. The Whole System Demonstrator programme found that if delivered properly telehealthcare can reduce mortality, and reduce the need for admissions to hospital (Steventon et al., 2012). However, it did not improve quality of life or mental health outcomes (Cartwright et al., 2013), or bring significant reductions in service use (Steventon et al., 2013). Nonetheless, all areas have continued to use the technology suggesting that they perceive it to be of value. Anecdotal evidence suggests that the WSD was poorly implemented and suffered from the rigidity of involvement in a randomised trial.

In general, these studies indicate that the perceptions of those in receipt of care are very positive toward telehealthcare interventions, reporting them to be easy to use and providing mechanisms for increased information, support and other potential benefits. A limited number of studies have also showed improvement in caregiver burden (Toseland et al., 2004) and carer's stress and strain (Davies et al., 2013). A review of the evidence by Knapp et al reported reduced carer distress, burden and mental health morbidity. There is also evidence that caregivers are positive about the use of technologies to support their caring roles (Blaschke, ibid.). This was also the finding from an exploratory, qualitative study in Scotland, where carers reported improvements in quality of life, reduced stress, respite opportunities and improvements in some aspects of their relationship with the person they cared for (Jarrold and Yeandle, 2009)⁶.

We can conclude from these studies that TEC does have the potential to improve the quality of life, health and mental health of disabled and older adults. However, it is by no means the case that all types of technology achieve their objectives. First they need to be responding to a clear need (Knapp et al ibid. McLean et al. 2011). Second, the way in which they are designed and implemented is important and it is often the case that they are most effective when accompanied by other kinds of supports.⁷ They should also be evaluated relative to traditional forms of care to see whether the benefits outweigh the costs of introducing the

⁷ For best practice in implementing TEC see <u>http://www.jitscotland.org.uk/resource/assessment-of-the-csf-for-mainstream-adoption-of-tec/</u>

⁶ Carers Scotland provide resources for carers that want to use telehealthcare in their caring roles <u>http://www.carersuk.org/scotland/training-resources/technology/telehealthcare</u>

system and to identify any unintended consequences. Finally, as mentioned above, the limitation of the fast evolving nature of the technology is an important caveat that should be incorporated in evaluation design.

Digital participation

Improving communication and reducing distance between people has been identified as a major benefit to going online, yet analysis of OxIS data shows that living alone is consistently associated with non-use of the internet (Helsper and Reisdorf, 2016). In addition, those groups that are most likely to experience social isolation – older people, people with disabilities, and the unemployed – are less likely to be online. Skills for Care includes digital participation as a key aspect of ALT. Indeed, a key feature of the Clever Cogs system described earlier is the way in which it acts as an accessible gateway to the internet. It is therefore important to consider what impact the internet has on the social isolation and loneliness of people with disabilities, older people and their carers. We discuss each in turn.

Older people

Although the relationship between loneliness and internet use is complex (not least due to potential negative factors such as cyber-bullying and internet addiction (Kowalski and Limber, 2007; Kuss et al., 2014)) there is evidence that digital participation can reduce loneliness and social isolation, increase social capital and have other positive effects on mental and physical health. Several studies have found a significant relationship between online social interaction and an increase in social capital (Burke, Kraut, & Marlow, 2011; Burke, Marlow, & Lento, 2010; Mesch & Talmud, 2010a, 2010b; Wellman et al., 2001). These studies suggest that greater use of the internet is related to a significant increase in interpersonal connectivity, social engagement, and community attachment (Mesch & Talmud, 2010b). Across all groups in society, evidence suggests that broadly speaking, individuals who use the internet to create and maintain social ties expand their social capital. (Cserni and Tamlu, 2010).

Positive impacts have also been found for older people. A multi-country cross-sectional analysis by Lelkes (2013) found that over 65s who use the internet regularly have a lower chance of being isolated and higher self-reported life satisfaction, with greater benefit for those who use the internet every day. She concludes that personal social meetings and virtual contacts are complementary, rather than substituting for each other and that internet use may be a useful way of reducing social isolation. Several studies illustrate the importance of older adults using technology for social networking in order to feel more connected to friends and family thus enhancing psychological health (NAHM et al., 2004; Opalinski, 2001). One study provided preliminary evidence that interactive computer use with the right training conditions increased client self-esteem and reduced depression (Billipp, 2001). Clark (2002) describes the use of chat room interviews and online questionnaires as an intervention to increase social connectedness among community-dwelling older adults. Recent research by Aguilar, Boerema, and Harrison (2010) indicated that older adults felt that regular use of computers lead to decreased feelings of isolation. A study by Gatto and Tak (2008) is one of the few studies that discussed the perceptions of older adults regarding their use of technology. The study showed the potential usefulness of technology for searching health information, keeping up with friends and gaming. An evaluation of internet training for homebound older adults also

found a significant increase in satisfaction of contact with others at follow up (Bradley and Poppin, 2003).

People with disabilities

Accessing the internet has been found to significantly improved frequency and quality of social interaction in people with disabilities (Guo* et al., 2005; Kydland et al., 2012). One study found that internet use was associated with lower levels of loneliness (Sum, Mathews, Hughes, & Campbell, 2008), another that internet use serves as a significant predictor for measures of social integration as well as measures of psychological well-being (Berkowsky, 2012). For people with learning disabilities, Löfgren-Mårtenson (2008) identifies the internet as a way of having a private life away from interference by carers. This has also been reported in interviews conducted by McVilly et al. (ibid.). Chadwick et al. (2013) describe the internet's potential for self-expression, advocacy and developing friendships. Due to concern with safety online, safe Social Networking Sites are often identified. However, Holmes and O'Laughlin (2012) found that research participants did not necessarily want to have such restrictions imposed. Burke, Kraut and Williams (2010) found that 16 high-functioning adults with autism fostered successful, supportive relationships online. They also found that issues relating trust meant that it was difficult to maintain these relationships. In general, less is known about the online lives of people with disabilities and this is an area that could benefit from further research.

Carers

Research on the impact of internet use on carers is more limited, however, positive impacts have been found (Blackburn and Read, 2005), including on feelings of social isolation (Green and Rossall, 2013). Kinnane and Milne (2010) in a review of studies relating to carers of cancer patients describe several benefits, including the use of online support groups. They conclude that interactive internet applications have potential to inform and support carers in their role.

Cost effectiveness

Assessing the cost effectiveness of any medical or social care intervention is challenging due to the specific requirements of the underlying research design. There are far fewer studies that analyse cost effectiveness, which is reflected on the amount of space devoted to it here.

There are several studies that have found no evidence of cost effectiveness, including a systematic review of telemedicine and telecare (Mistry, 2012). The most that Elbert et al. could say in a review of 'ehealth' initiatives only found that they were 'promising' from a cost perspective (2014). The WSD programme mentioned above also found no evidence of cost effectiveness (Henderson et al., 2013) McLean et al. conclude that the evidence for cost effectiveness in Technology Enabled Care is limited except for low cost interventions such as telephone follow-up to improve attendance or text messaging reminders for monitoring (e.g. smoking cessation in the US (Smith et al. 2011)). Where studies exist, they "were often short term or did not consider the full range of perspectives (those of the patient, healthcare provider, and society)." (2011 p 375)

The challenge for these kinds of studies is that the costs of the technology and putting the infrastructure in place can be very high and it can take time for the benefits to come to fruition.

As McKinstry (op cit.) has written: "While the RCTs in HBP and diabetes provide strong evidence of effect, at least in the research setting, the introduction of any new system comes with a time cost, one which hard pressed NHS staff may feel they cannot contribute." As he points out, pilots need to be properly supported to cover increased workloads (McKinstry et al., 2013, p. 3).

Another issue relates to weaknesses in the study design. In some instances, interventions may be cost effective but it is difficult to show this compared with the traditional intervention. In this context, it should be remembered that a lack of evidence is not the same as no impact. A further issue is that some of the benefits may be small psychological benefits that do not have an impact on mainstream services. As McLean et al. pointed out, this may be a case for extending the range of stakeholders included in a cost analysis (for example using methods like Social Return on Investment) to ensure that benefits are being interpreted holistically. The evaluation challenges set out in the methodology e.g. the heterogenous nature of the technology and emergent nature of the evidence, make being certain about the outcomes, and therefore the cost benefit difficult.

Nonetheless, mainstream cost savings are an important driver of policy in this area and savings are potentially large. For example, falls are the largest cause of emergency hospital admissions for older people, and significantly impact on long-term outcomes, e.g. the need for long-term nursing care. According to Age UK, falls also account for 40% of ambulance call outs to homes for people aged 65+ costing £115 per callout in the UK⁸. The need to demonstrate savings, as well as social returns is important longer-term for this agenda.

There are several studies in the grey literature that have found positive cost benefit results. For example, Leeds City Council undertook analysis to highlight the cost-effectiveness of its telecare services based on analysis of care interventions both with and without ALTs. The research highlighted cost savings of approximately £2,330 per person per year that could be attributed to the ALT9. In the West Midlands a study of an automatic pill dispenser found a cost saving of £2,499 per person by reducing waste medication, ambulance call outs, falls and avoiding admissions to hospital against a service cost of £200. Clifford et al. (2012) found the average weekly cost of telecare was £6.25, compared to £167 for the average weekly care package for the sample pre-telecare. They estimated that the targeted use of telecare could lead to savings in the region of £3m to £7.8m for a typical council, or 7.4-19.4% of total older people's social care budget. Results from an evaluation of the Scottish Telecare Development Programme are also encouraging from a cost perspective. The results suggest that the initial funding of £6.8 million has led to savings to the Scottish health and social care budgets of approximately £11 million during 2007-2008 (Beale et al., 2010). More recently, the JIT estimate that TDP funded efficiencies over the period 2006-11 was approximately £78.6 million at 2011 prices. However, the authors note that these figures relied on actual care home and hospital bed reductions to ensure the savings were 'cash releasing' (Joint Improvement Team, 2016). This includes findings from a study by York Health Economics Consortium,

⁸ <u>http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true</u>

⁹ http://www.ageing.ox.ac.uk/download/60

which estimated that the intervention led to savings of £8,650 per patient with dementia (York Health Economics Consortium, 2013).

Summary

We can conclude from the above that there are substantial potential benefits from the use of TEC especially for aspects of smart home technologies and monitoring of chronic conditions for some outcomes. More evidence is needed in relation to other areas, especially those that lead to cost savings such as a reduction in the unit costs of hospital and care home stays. Whilst the evidence in relation to TEC and quality of life is somewhat mixed, the internet does hold substantial promise for reducing social isolation and loneliness amongst older and disabled people. It is clear that the introduction of a technology needs to be responding to a specific need and that the method of implementation also requires careful planning. A final challenge is to demonstrate that an intervention works at scale and that findings from a small study can be universally applied.

Concluding remarks

There is no doubt that innovation and technological advances have a role to play in responding to challenges facing health and social care. New methods of providing care to meet growing need are required. TEC interventions have been prioritised in services for older people and people with disabilities by government and industry for some time now. This review has assessed the evidence of need and the extent to which TEC can be shown to meet this need. It is by no means exhaustive and the authors welcome suggestions for any additional research that has not been identified.

What we can conclude is that whilst certainly promising, TEC is not a universal solution, rather it works in certain contexts and under certain conditions. It is important therefore to be clear about the theory of change for a given technology and to rigorously evaluate it against expected outcomes.¹⁰

There is a huge variety in the cost of different types of interventions and evidence in relation to cost effectiveness is particularly lacking. Developing the evidence base is essential to ensure that resources are spent in the areas where they are likely to deliver the most social value. With the challenges of supporting an aging population outlined above, achieving cost effectiveness is especially important and an area that requires further research. A final recommendation that would help improve the evaluations of these kinds of technologies would be to have clarity on terminology. As the UK moves towards adopting the definition of TEC, it would be useful if this was reflected in the academic literature and if greater consistency in technology was employed when conducting evaluations.

¹⁰ Critical success factors for TEC projects have been identified by the JIT and are available at this address: <u>http://www.jitscotland.org.uk/wp-content/uploads/2015/07/TEC-CSF-Workshop-Final-Report-July-2015.pdf</u>

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