Telecare & Assistive Technology Evaluation

HSE & Genio Dementia Programme (2012 – 2015)

Kevin Cullen, Sarah Delaney,
Philomena Stapleton, Richard Wynne,
Work Reserch Centre

WORK RESEARCH CENTRE

ISBN
978-1-907711-44-2 Paperback
978-1-907711-45-9 E-book

August 2016

Acknowledgements

We gratefully acknowledge the collaboration of the 4 demonstration sites in the telecare evaluation. These are: Living Well with Dementia, South Dublin; 5 Steps to Living Well with Dementia, South Tipperary; Community Action on Dementia, Mayo; and Kinsale Community Response to Dementia, Kinsale.

The 5 Steps to Living Well with Dementia project in South Tipperary led on the assistive technology evaluation, with assistance provided by WRC, and they will separately provide more detailed reporting on the results of that part of the evaluation.

Many thanks also to Fiona Keogh and colleagues from Genio, for their support throughout the work and their very helpful comments on the draft report.

Most of all, we are indebted to the persons with dementia and their families who took part in the research and so generously shared their experiences with us. Their thoughtful observations provide an invaluable insight into the role that telecare and assistive technologies can play in supporting persons with dementia and their carers.

Contents

Executive Summary

This report presents the results and conclusions from an evaluation of the telecare and assistive technology initiatives implemented by the four demonstration sites funded under the Genio Dementia Programme (2012-2015). Telecare and assistive technology are technology-based supports that can be helpful for people with dementia and their carers. In this report, we primarily use 'assistive technology' when referring to stand-alone equipment that is for use by the person with dementia themselves; we use 'telecare' when referring to systems that enable alerting of carers when the person with dementia has a need or is at risk.

The evidence from this research shows the significant contribution that both telecare and assistive technology made for many clients. Either or both forms of technological support may be helpful, depending on severity of dementia and each individual's needs and circumstances. As dementia is a progressive condition, timeliness of provision is important. Needs change over time, as does the likely relevance or not of particular forms of technological support.

The results support the case for telecare and assistive technology to be part of the mainstream suite of supports offered by dementia services. This could make an important contribution to the implementation of the National Dementia Strategy and the achievement of its objectives.

However, technology is not a panacea or a substitute for human care, and there is no 'one-size-fits-all' technological solution for the wide-ranging circumstances and needs of persons with dementia living in the community. Dementia services should discuss with persons with dementia and their families whether telecare and assistive technology may be helpful in their circumstances, keeping in mind that they may be of great value in some cases and less relevant or not appropriate in others. The person with dementia should be involved, to the greatest extent possible, in the selection and implementation of technologies. Achieving best outcomes, both for them and for family carers, should be the objective.

Telecare Evaluation

'Telecare' refers to remote provision of care and support to persons with dementia. This covers risk management and other supports provided by care services or informal carers who are not present in the home, as well as in-home arrangements enabling carers to provide care to a person with dementia from another room or part of the home and its environs. All four sites established pilot telecare services as part of their dementia programmes.

The study applied a mixed-methods approach, with gathering of both quantitative and qualitative data. The aims were to assess impacts of telecare for clients, examine operational issues around setting up the telecare pilots, and identify lessons to guide future practice in this field.

Client Impacts

The assessment of client impacts involved interviews with family carers of people with dementia who had received telecare, as well as key worker reports on outcomes for their clients. All clients who had received telecare within the timeframe of the research were invited to participate. The evaluation involved a total of 24 clients (persons with dementia and their family carers) from across the four sites, each with a tailored mix of telecare sensors and devices.

All 24 cases reported positive benefits from telecare, often major benefits.

> *"Number one I can sleep in my own bed again, which is marvellous. I mean at 60, sleeping on the floor on an airbed is no joke... And I've got the added benefit that I can go out for a bit of fresh air and sit down on my bench with a cup of tea."*
>
> *"We wouldn't have brought her home [from the nursing home] only for it."*
>
> *"This gives her independence. You can monitor but she still feels she is doing her own thing... Otherwise I'd have to be going in and out of the room all the time and that would drive her cuckoo altogether."*

In some cases there were also some negative impacts, including nuisance factors because of noisy or over-sensitive technology and, sometimes, dilemmas about the trade-offs between invasion of privacy and benefits for the person with dementia. In all cases, carers felt that the positives outweighed the negatives, often substantially.

Across the participants, there were a variety of tangible benefits and outcomes for persons with dementia and their family carers.

Types of benefits and outcomes

- Alerted carers to emergency situations, such as falls.
- Gave some persons with dementia more independence.
- Helped delay need to move to nursing home in some cases.
- Supported a trial return home from nursing home for one person.
- Enabled carers to give better help to the person with dementia.
- Allowed carers to have more and better sleep.
- Discouraged wandering in some cases.
- Central to sustaining caring in a number of cases.
- Gave full-time carers some time for themselves, to have some life of their own.
- In one case, carer could monitor wellbeing of person with dementia from work.

All key workers who reported on impacts for their clients concluded that telecare had addressed the targeted needs to at least some extent, and in some cases felt that there had been very substantial benefits for clients.

Value for Money

For the pilot projects, the sites funded the telecare from their Genio programme funding. The typical approach was to provide free installation and one year's service to clients offered telecare. Costs varied in accordance with the range of sensors and devices installed in the home, and the type of monitoring arrangement in place. The average cost was around €500 to €600 per installation. At these levels of cost, telecare would represent only a small incremental addition to the costs of a typical home care package, and the dementia services involved considered that telecare offered moderate to high value for money.

Implementing Telecare

Project managers, clinical leads and frontline staff provided assessments of their experiences of implementing telecare in the sites. The learning points from this may be useful for dementia services interested to develop telecare as part of their supports for persons with dementia and their families. Additional guidance on provision of telecare and assistive technology in dementia care is available in a related resource document at www.genio.ie/at_guide.

Implementing Telecare: Learning Points

- Effective ways of targeting/identifying clients who might benefit from telecare are important.
- There is a need to raise awareness about telecare, both amongst dementia service staff and in the wider community that they serve.
- Careful needs assessment, in consultation with the client and family, is important for specifying an appropriate telecare installation to meet their needs.
- As in other areas of dementia care, ethical issues are important. There is a need for protocols and guidance to ensure the involvement of persons with dementia to the greatest extent possible, and for development of skills for communication with persons with dementia.
- Model procurement frameworks and guidelines would be helpful where local care services are procuring telecare.
- Care services should keep in the loop after telecare installation, to monitor how telecare is working for clients and track whether needs are changing over time. There should be regular liaison between the care services and telecare provider. This could include feedback of data on telecare alerts and responses to the care services, where appropriate, and with client consent.
- Provision of formal telecare responder services as part of community dementia services should be considered, for example, for responding to alerts when there is no informal carer available.
- There is a need for overall quality assurance frameworks for telecare. These should cover all aspects of the service provision process, including guidance on most effective procedures for interworking between care services and telecare providers.

Assistive Technology Evaluation

This part of the research assessed client experiences with items of assistive technology (AT) that they had loaned from the Memory Technology Library set up by the South Tipperary site. The evaluation included a total of 20 cases and covered 27 items of AT.

These included:

- clocks and calendar clocks
- one button radios
- medication reminders
- motion sensor & pager
- memo minder and wander reminder
- simple mobile phones.

The results showed that the various types of assistive technology were very useful for many clients. In some cases they were just a little useful, and sometimes they proved not to be useful even in situations where they might have been expected to be. Overall, AT was rated very useful in 15 cases, a little useful in 8 cases and not useful in 4 cases.

Often useful...

I'd be in a bad way without it. I may think it was Monday, instead of Saturday...It would be a nuisance if I didn't have the clock. (Person with dementia)

Helped her memory a little bit, at least getting the news of local things, hearing something different, not just me talking to her. (Carer)

...didn't associate it with being a clock. Habit of looking at normal clock. Didn't register that it [calendar clock] was a clock. (Carer)

...she wanted to stick to the radio she has...likes familiar things...does not like anything new - wonders where it came from, who it belongs to. (Carer)

...but not always

Overall summary and conclusions

As in all research, certain strengths and limitations associated with the study should be borne in mind when interpreting the results. The sample sizes - 24 telecare users and 20 AT users - were relatively small and might not be fully representative of the overall client base. Nevertheless, the numbers are quite respectable for a field of research where small-scale qualitative studies are commonly reported.

A key advantage of the approach is that it provides a rich analysis of how these technological innovations actually work in practice for clients, and the concrete impacts that underpin global ratings of usefulness and benefit. The research shows how dementia care services effectively provided telecare and assistive technology that often made an invaluable practical contribution to the everyday lives of people with dementia and their carers.

Telecare and assistive technology should be included amongst the mainstream supports offered by dementia services. In conjunction with human care services, they can play a useful role in personalised care provision, supporting both the person with dementia and family carers.

Summary and conclusions

- The 4 sites successfully established pilot telecare services; one site successfully established a Memory Technology Library and a programme to loan assistive technology to clients for trial.
- The consortia expended considerable effort on this aspect of their programmes, and their experiences provide useful guidance for provision of these supports on a wider basis.
- Telecare and assistive technology provided significant benefits for many persons with dementia and family carers. Either or both may be helpful, depending on severity of dementia and each individual's needs and circumstances.
- As dementia is a progressive condition, timeliness of provision is important. Needs change over time, as does the likely relevance or not of particular forms of technological support.
- When effectively targeted and meeting client needs, telecare can provide good value for money; it would typically represent only a small incremental addition to the costs of a home care package.
- Telecare and assistive technology should be more widely available; the implementation of the Dementia Strategy could give focused attention to this field.
- Person-centred approaches with individualised technology packages work best.
- There is no 'one-size-fits-all' technological solution for the wide-ranging circumstances and needs of persons with dementia living in the community, nor is technology a panacea or a substitute for human care.
- Dementia services should discuss with persons with dementia and their families whether telecare and assistive technology may be helpful in their circumstances, keeping in mind that they may be of great value in some cases and less relevant or not appropriate in others.
- The person with dementia should be involved, to the greatest extent possible, in the selection and implementation of technologies; achieving best outcomes, both for them and for family carers, should be the objective.

1. Introduction

This report presents the results of the evaluation of the telecare and assistive technology activities of the four demonstration sites funded under the HSE & Genio dementia programme for a three year period between 2012 and 2015. These technology-based supports were one part of a range of person-centred supports developed and implemented within the four sites. The bulk of the interventions provided dementia support workers and innovative respite care.

1.1 Telecare and Assistive Technology

'Telecare' refers to remote provision of care and support to vulnerable persons. One potentially useful application of telecare is to alert carers if a person with dementia has a need or is at risk. This can be useful in situations where carers are not living with the person with dementia or are temporarily absent from the home. It can also be useful when carers are in the home with the person with dementia, for example, at night-time or when they are in another room or part of the home and its environs.

'Assistive technology' covers a broad spectrum of low-tech and high-tech equipment that can support and enable people with dementia in everyday life. Examples include calendar clocks to assist with time orientation, and mobile phones and radios designed to be simple to use.

There is overlap between the telecare and assistive technology domains. In this project, we primarily use 'assistive technology' when referring to stand-alone equipment that is for use by the person with dementia themselves; we use 'telecare' when referring to systems that enable alerting of carers when the person with dementia has a need or is at risk.

All four sites established pilot telecare projects. The *5 Steps to Living Well with Dementia* project in South Tipperary also developed a Memory Technology Library and implemented a programme to loan AT to people with dementia and their families for a trial period.

1.2 Focus of the research

A core focus of the research was to provide Genio and the consortia operating in the four sites with an assessment of the telecare and assistive technology initiatives. One aspect looked at whether and what types of benefits these supports delivered for clients, especially persons with dementia themselves but also their family carers. Another aspect looked at the processes involved for the sites in setting up the initiatives, particularly in the telecare area, focusing on the sites' own experiences and what they have learned that can guide future efforts in this field.

The evaluation also presented an opportunity to make a contribution to the wider knowledge and evidence-base in this field, by providing a richer understanding of how telecare and assistive technology work in practice to support persons with dementia living in the community and their family carers. This may be helpful in encouraging more attention to these areas in the context of the implementation of the Dementia Strategy. It may also be useful for the HSE and third sector services that support people with dementia, whether through dementia-specific services or the more general social care services for older persons.

2. Telecare evaluation - overview

This Chapter provides an introduction to telecare in dementia care, and presents an overview of the approach to evaluation of the telecare pilots implemented by the sites.

2.1 Telecare and dementia

In some countries, particularly England and Scotland, there has been a growing application of telecare to support people with dementia living at home in the community. There have been a number of pilot projects and trials, and these have reported positive results. For example, the Safe at Home project in Northampton concluded that people with dementia provided with telecare were less likely to enter long stay care and family carers had lower levels of stress (Woolham, 2005).

A considerable number of local authority social care services in the UK now offer telecare as a mainstream service for vulnerable older people and other client groups, and people with dementia are often specifically included as a relevant target group. People with dementia were also a client group identified for attention under the national Telecare Development Programme in Scotland.

In Ireland, the Alzheimer Society provided telecare to clients in some regions through an initiative funded for a period under the Dormant Accounts Fund. An evaluation found that the majority of carers participating in the project reported their caring role had become easier since the introduction of telecare (Keogh, 2010). The research also identified individual cases where telecare alerts had helped to prevent potentially dangerous situations for the person with dementia, including the prevention of a potential house fire and the early detection of wandering.

The HSE has implemented telecare in a number of small-scale pilots and local projects, with a focus more on vulnerable older persons rather than dementia, per se. Evaluations have shown positive benefits for clients and good value-for-money potential (Graham et al, 2011; WRC, 2015a). However, there is no wide-scale provision of telecare as part of HSE social care services at present.

Outside of the initiatives of the Alzheimer Society, there has been very little experience of provision of telecare for people with dementia and their carers in this country. As a result, there is little awareness of how telecare works in practice for people with dementia and how it can provide benefits.

2.1.1 Telecare in the Genio demonstration sites

All four sites included telecare as one of the elements of their support programmes for people with dementia. At start-up stage, some sites had a clearer view of what they would like to do in this area than others, but all were relatively unfamiliar with telecare and generally did not have existing telecare provision programmes within their care ecosystems that they could build upon.

In consequence, all sites experienced challenges in developing and implementing their telecare component. It generally took longer than expected to get to grips with telecare and establish an effective way of offering it to clients who might benefit.

Nevertheless, all sites managed to put in place a provision system for telecare under their Genio-funded programmes. Although the numbers of clients provided with telecare were less than initially projected, collectively the sites provided a sufficient pool of clients for a useful evaluation exercise.

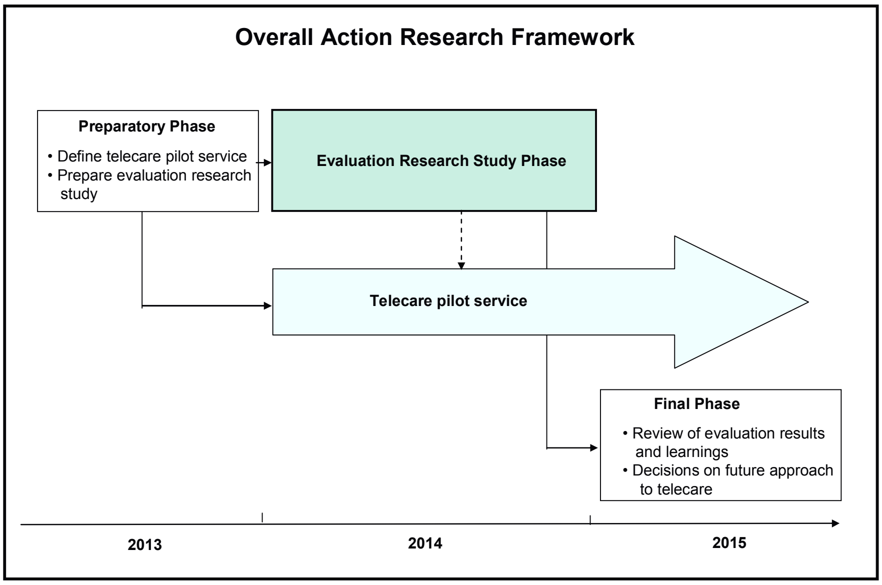
2.2 Overview of the evaluation approach

2.2.1 Aims and objectives

The research aimed to examine experiences and impacts of the implementation of telecare on a pilot basis within the care service ecosystems in the four sites. This would provide evidence to inform decisions about possible wider mainstreaming of telecare in the sites, as well as more generally in care services across Ireland. The more specific objectives for the evaluation research were to:

- assess client and service experiences and impacts in relation to telecare.
- document and assess the key processes involved in setting up and operating telecare in the care service ecosystems in the sites.
- capture and document the learning from the telecare pilots, especially that which can guide best practice in implementation of telecare to support people with dementia and their family carers.

Figure 2.1 Overall action research framework



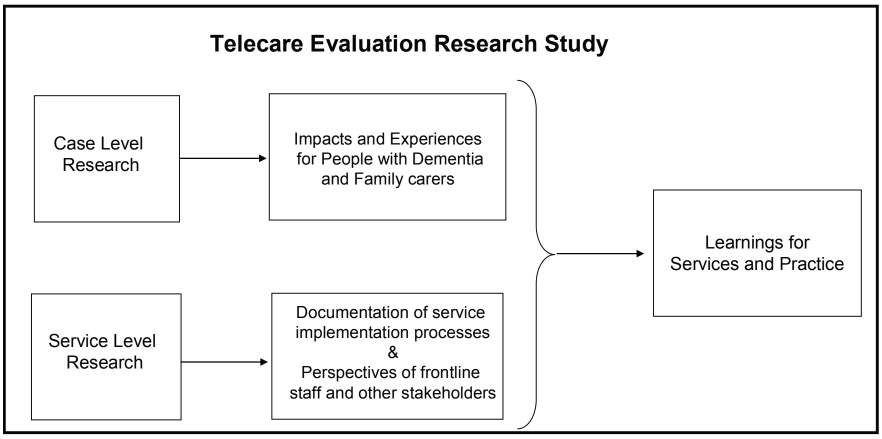
2.2.2 Research design

The study design applied a mixed-methods approach within an action research framework, with gathering of both quantitative and qualitative data. The schema shown in Figure 2.1 presents the overall action research framework.

The original plan was to complete the main data gathering during 2014. However, installation of telecare on a rolling basis during the year was slower than anticipated, and continued into 2015. Data gathering and field work with clients was therefore extended into the first half of 2015, in order to increase the number of telecare clients in the evaluation.

The design included measurements at case level and measurements addressing wider service level processes, as indicated in the schema in Figure 2. 2.

Figure 2.2 Case level and service level research



The following two Chapters present the results of the case level research (Chapter 3) and the service level research (Chapter 4).

3. Telecare: Impacts for persons with dementia and family carers

This part of the research aimed to provide an assessment of the extent and nature of the impacts of telecare at client level, as an input to the overall evaluation of the telecare component of the programme. A broader aim was to provide a richer picture and analysis of how telecare works in practice in the everyday lives of people with dementia and their carers than has hitherto been available.

3.1 Methodology

Client interviews provided the main source of data for assessment of impacts at case level. These were face-to-face interviews, using a structured interview schedule with a mix of closed and open questions (Annex 1). The instrument was developed specifically for this study, building on a more basic version utilised to evaluate telecare pilots in Ireland and other countries in a number of European projects (Mueller et al, 2012).

The interview covered six main areas:

- Background information on Person with Dementia & Carer(s).
- Client benefits / impacts.
- How the telecare was useful & worked in practice.
- Usability and reliability.
- Satisfaction with Telecare Pilot Project processes.
- Overall Satisfaction and Suggestions for Improvement.

The intention was to conduct interviews with both people with dementia, if they had capacity for this, and their family carers. However, in all cases, either the responsible clinicians or the family carers deemed that the persons with dementia receiving telecare did not have capacity to participate, so only family carers were actually interviewed. The plan was to conduct interviews after telecare was in place for about three to four months, to allow for a reasonable duration of experience with telecare whilst fitting with the projects' and the evaluation research's timeframes.

The design also anticipated, where possible, triangulation of the interview data with data from key worker assessments of client experiences/impacts and logged data from the telecare service on the occurrence of alerts and the responses to these. This report does not include analysis of logged telecare data as many of the clients had installations where such data was not captured by the telecare provider.

3.2 Sample

For the case level research, the aim was to include, subject to their consent, all clients provided with telecare by the demonstration projects within a timeframe that aligned with the logistics of the research phase. A total of 24 clients from across the four sites participated in the research. On average, telecare was in place for about five months at time of interview. The majority of cases had between three and six months experience of telecare when interviewed. A few had a longer experience of telecare, the longest a little over a year. In one case, the telecare was only used for a few weeks as it had ceased to be relevant after that.

3.2.1 Profile of the persons with dementia and their carers

Table 3.1 presents a profile of the 24 persons with dementia included in the research. Eleven of these were from one site, five each from two sites and three from the other site. The average age was 82, ranging from 70 to 93. A large majority (20 of the 24) were female. Fourteen (58%) were classified as having moderate dementia (defined for this purpose as people who can be left alone for a certain period at least); ten (42%) were classified as having more advanced dementia (defined for this purpose as people who cannot be left alone and need constant care). One third (8) lived alone and two-thirds (16) lived with others.

Table 3.1 Persons with dementia

Age	Mean	82.0
	Range	70-93
Gender	Male	4
	Female	20
Severity of dementia	Moderate	14
	More advanced	10
Lives alone	Yes	8
	No	16
Total		24

Table 3.2 presents a profile of the 24 carers included in the research. The average age of the carers was 55, ranging from 36 to 85. Just over one-half (13) of the carers were in either full-time or part-time employment. One third (8) were male and two-thirds (16) were female.

Most were caring for a parent or parent-in-law (17), five were caring for a spouse, and two were caring for another relative. Twelve of the carers lived with the person with dementia and the other twelve did not. In eight cases, the non-resident carer was caring for a person with dementia who was living alone; in four cases, they were caring for a person with dementia who lived with an elderly spouse.

Eleven of the carers were ‘full-time’ carers, essentially providing 24/7 care; the other thirteen were ‘part-time’ carers, although nevertheless often providing extensive hours of care. A large majority (17) were the main carer (6 of these were the only carer); four of the other seven shared the caring load jointly with one or more others, and three made a more limited contribution to care. Almost all of the carers (23) were directly engaged with the telecare, most (20) being the first contact in the event of an alert, or being the main user in the case of in-house systems.

Table 3.2 Carers

Age	Mean	54.9
	Range	36-85
Gender	Male	8
	Female	16
Relationship of person with dementia to carer	Parent / parent-in-law	17
	Spouse	5
	Sibling / other	2
Lives with person with dementia	Yes	12
	No	12
Caring commitments	Full-time carer	11
	Part-time carer	13
Carer role	Main carer	17
	(Sole carer)	(6)
	Shared caring	7
Employment status	Full-time	8
	Part-time	5
	Not employed	11
Total		24

3.2.2 Needs to be addressed by telecare

Each site identified people with dementia and carers with needs that telecare might be able to address. Two overarching themes applied across all or most of the cases: reassurance (mainly for the carer but in some cases also for the person with dementia); and enhanced safety and security for the person with dementia. Specific areas of risk or worry included: falls (either to detect when a fall occurs or to pre-empt falls in the first place); environmental safety (flood, fire, carbon monoxide); and wandering.

Needs to be addressed by telecare

Overarching themes:

- Reassurance (mainly for the carer; sometimes for the person with dementia).
- Enhanced safety and security for the person with dementia.

Specific areas of risk or worry:

- Falls (detection and prevention).
- Environmental safety (flood, fire, carbon monoxide).
- Wandering.

For some cases:

- Easing of the burden for carers.
- Allowing carers to keep an eye without disturbing the person with dementia.

There were two other themes that applied in between one-third and one-half of the cases. One was the easing of the burden for carers, for example, by enabling improved sleep at night, more degrees of freedom in their daily activities, or facilitating pre-emptive action to address issues for the person with dementia before they escalate. The other was to allow carers to keep an eye without disturbing the person with dementia.

3.2.3 Types of telecare

The 24 installations encompassed a variety of forms of telecare and types of functionality.

Each site implemented telecare in its own way, using telecare services from one or more selected providers. Two sites (South Tipperary and South Dublin) primarily implemented telecare services where alerts went to the telecare provider's monitoring centre and, when necessary, were then passed on to the nominated family contacts. One site (Kinsale) implemented a non-intrusive activity/lifestyle monitoring system that could be accessed online and, in some cases, directly alerted nominated family members on detection of a potential need on the part of the person with dementia. One site (Mayo) implemented two forms of telecare, one using audio-visual monitors and the other involving direct alerting of family carers when issues arise that may require attention.

Within sites, the specific telecare installations varied across clients in accordance with needs of the person with dementia and their family carers. The mode of support from telecare could be in-house (where the telecare supported family carers whilst in or around the home of the person with dementia) or remote (where telecare supported family carers who were providing care remotely, mostly in situations where the carer did not live with the person with dementia). In some cases, the installation included both modes, for example, where the person with dementia was often alone during the day but family members stayed overnight. Overall, there were nine cases with in-house mode, nine with remote mode and six with some combination of the two modes.

The installations also varied in the types of telecare sensors and other devices installed in the clients' homes. The most commonly installed devices were:

- bed/chair sensors
- property exit sensors
- environment sensors (flood, heat, smoke, carbon monoxide)
- audio-visual monitors
- falls detectors.

Other items installed in some cases included:

- pendants
- activity/lifestyle monitoring
- key safe
- bogus caller alert.

3.3 Results

3.3.1 Impacts of telecare

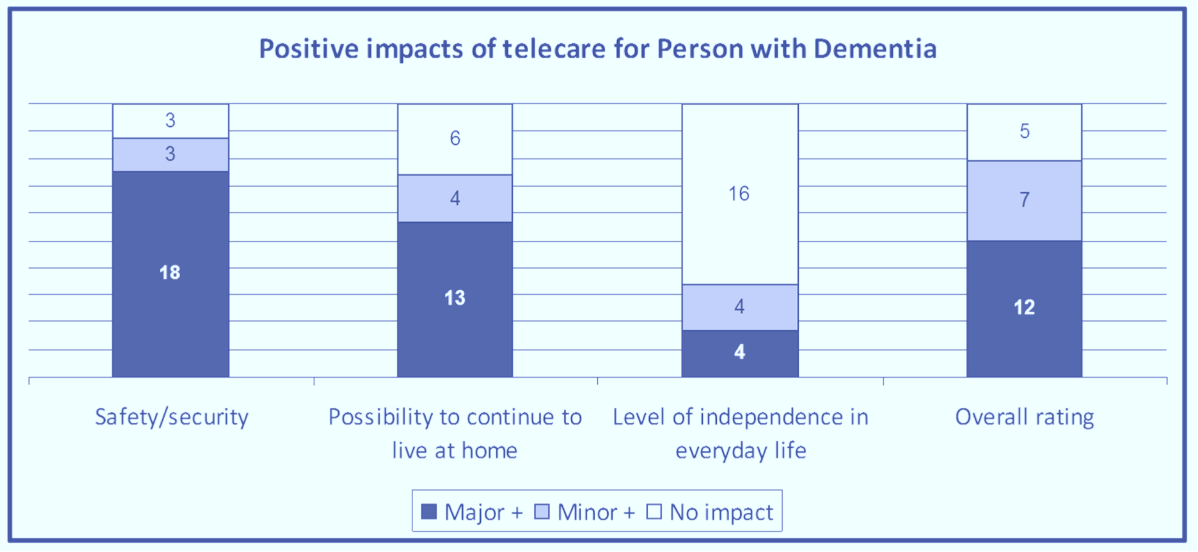
The research examined impacts of telecare for the person with dementia and the family carer. Questions covered both positive and negative impacts. The overall results were strongly positive. All carers, in all cases, reported positive benefits from telecare for themselves, and almost all reported positive benefits for the persons with dementia. Fifteen of the cases reported some negative impacts in addition to positive benefits. However, all of these said that the positives outweighed any negatives.

Key workers also provided their assessments of the extent to which telecare had addressed the needs that they had initially targeted before installation. They varied in how deeply they could assess this, depending on how closely they maintained contact with clients whilst telecare was in place, and a small number could not provide an assessment. Overall, all key workers who did provide an assessment felt that telecare had addressed the targeted needs to at least some extent, and in some cases felt that there had been very substantial benefits for clients.

Positive impacts

The results show strong positive benefits reported for both persons with dementia and their carers. For persons with dementia (Figure 3.1), carers most frequently reported positive benefits in the areas of safety/security (major positive impacts in 18 cases) and improved possibility to continue to live at home (major positive impacts in 13 cases). In one third of cases, carers reported positive impacts on the person with dementia's level of independence in everyday life.

Figure 3.1 Positive impacts of telecare for Persons with Dementia



There was variation in the extent to which carers felt that the person with dementia was aware of the telecare. In a majority of cases (16), carers felt that they had no awareness or just a little background awareness. In the other cases, carers reported that the person with dementia was aware of the telecare to at least some degree, with a small number being able to actively use the system to a certain extent.

Fall detector and intercom gives reassurance for person with dementia

"Once she knows that when she has the wristband on she knows that if she falls – it gives her peace of mind. It's just peace of mind that if she fell it goes off… it is great that you can speak to her - that it goes through the intercom and she is able to talk back." (Carer)

"....We felt that we could sleep at night – hugely beneficial. Knowledge that she was safe and that [we] would be alerted. We wouldn't have brought her home only for it." (Carer)

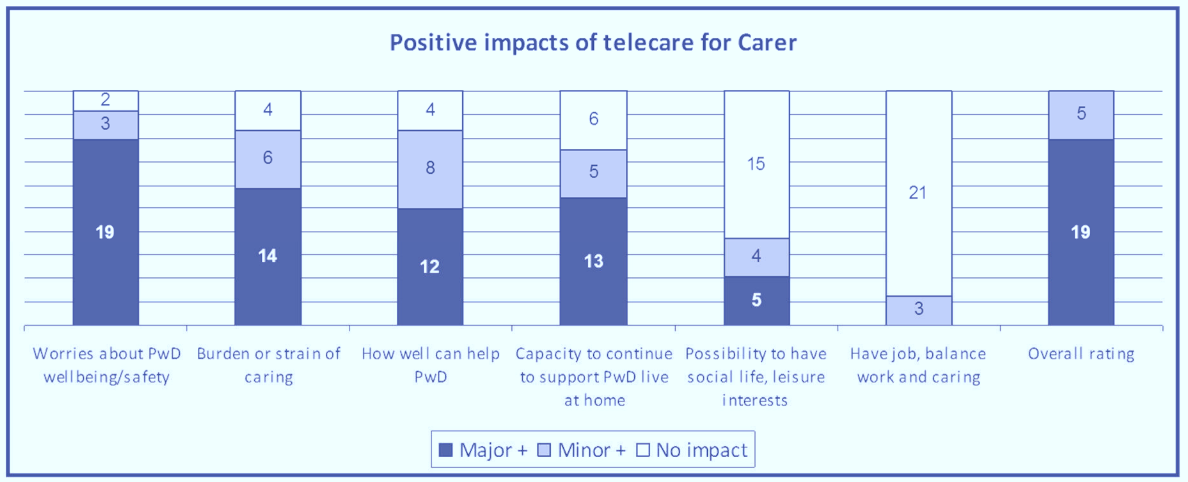
Telecare enabled return home from nursing home for trial period

Unobtrusive monitoring gives person with dementia more independence

"This gives her independence. You can monitor but she still feels she is doing her own thing.... I can watch what she's doing and not go near her unless I have to. Otherwise I'd have to be going in and out of the room all the time and that would drive her cuckoo altogether." (Carer)

For themselves, carers most frequently reported positive impacts on their worries about the wellbeing or safety of the person with dementia they were caring for, with major positive impacts in this area in 19 cases (Figure 3.2). Other frequently reported areas of positive impact were on carer burden/strain, carer ability to help the person with dementia, and carer capacity to support the person with dementia to remain living at home.

Figure 3.2 Positive impacts of telecare for Carers



Peace of mind for carers

"It is peace of mind to know that if she does go wandering and it's out of hours' time, you know, we will get an alert." (Carer)

"Number one I can sleep in my own bed again, which is marvellous. I mean at 60, sleeping on the floor on an airbed is no joke...

...And I've got the added benefit that I can go out for a bit of fresh air and sit down on my bench with a cup of tea." (Carer)

Carer can sleep in own bed, get outside for a bit

Supports caring while carer at work

".....while working you can check in on whether someone has gone out of the door or that there is movement in such a room in the house." (Carer)

"She'd have a risk of falling....I'd be afraid, you see she can forget to use the frame.....if I'm in the kitchen doing something or in the bedroom or anywhere around the house..... I can go outside to hang up my clothes now, without having the worry of it because I know it's going to beep. I can go out, my garden is out there, my flowers, and I can go out to that, and I can go out with peace." (Carer)

Carer can pre-empt person with dementia's falls.... ...and still get on with other things

Carer can get some rest and more sleep

"...it's a great help to the carers because it's difficult caring for somebody with dementia and it gives a little bit more rest. I mean carers need rest too. It's a lifeline really... And it means you can sleep..." (Carer)

"Oh, just that if there's an event on, if there's a party to go to, I can actually go, I don't have to stay the night with her." (Carer)

"Yeah, it has helped. I could go out, I'm not tied to watch duty." (Carer)

Positive impact on carer's possibility to have a social life

Given that telecare is primarily a monitoring and risk management support, the centre of gravity in terms of direct benefits is perhaps a little more towards the carer than the person with dementia. However, needs and benefits for persons with dementia and their carers are intertwined, and direct benefits for carers typically provide indirect benefits for persons with dementia. This may be in terms of sustaining the capacity of the carer to continue to provide care and enabling the person with dementia to remain living at home as long as possible.

Good for both person with dementia and carer

"... it was helping not just the patient, certainly most importantly the person that needed the care, and making sure that things were as they should be, or in as much as they could be normal, were normal for him..... And when [they] asked for it back I said "well we might be getting [him] back for weekends can I have it then?" Like that's how I felt about this little gadget. You know it's a powerful tool." (Carer)

"[Benefit for person with dementia] I would think so yes....It just means that I can get to him before he has an accident... So it means that I can spot him and I can be there you know... It's more for me, definitely. It was tremendous." (Carer)

Major benefit for carer, more minor (direct) benefit for person with dementia

Help person with dementia to continue to live at home

"Because really, before this, the way I was feeling was "I can't do this". So this (monitor) has helped the whole situation, you know. It works both ways. If I hadn't been able to look after him he wouldn't be able to be there you know... I was stressed out at night running up and down ...this has been my saviour you know. It's very good." (Carer)

"....she has had another year at home, which probably she mightn't have had if she had continued the way she was.... And another thing, you know like everything comes back on me? Well, say I had to go with one of the kids someplace... [if] it went off, and I don't answer the phone...there are two others to take the brunt of it. So it's a good thing that way as well..." (Carer)

Helped person with dementia remain at home...

...and brings other family members into the caring loop

One area of concern about telecare is the possibility that it may have negative impacts on the amount of social contact for the person. However, in this study most carers felt that telecare had no impact on the amount of contact they had with the person with dementia. In one case, contact had increased after telecare installation. This was an indirect impact in the sense that telecare had enabled the person with dementia to return home from nursing home care for a while, hence the increase in contact with the carer. In two cases, carers reported that contact had decreased a little. In both situations this was judged to be positive rather than negative, as it reduced unnecessary and unwanted check calls or visits.

Reduced unwanted and unnecessary check calls...

...a positive thing for both parties

I'd say I'm probably not ringing her up every day ...I'm not checking her all the time. [Contact decreased a little] that's in a good sense. That's not a negative thing. Because you have to remember that she doesn't like being under the microscope, so if I'm ringing up she's saying 'you're checking in on me again'..." (Carer)

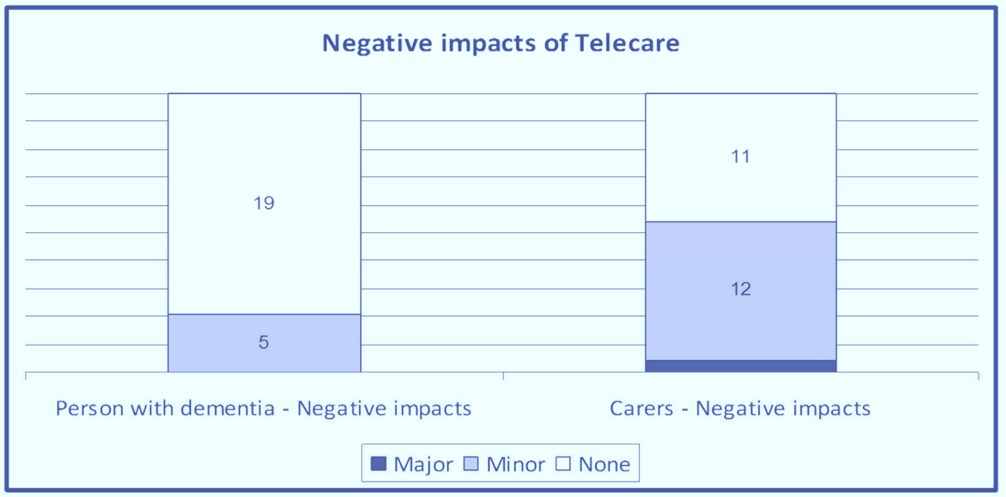
Negative impacts

Telecare is potentially quite a disruptive intervention because of the installation of technology into the home and its interaction with everyday lifestyles. As mentioned above, there have also been concerns about the possibility that it might lead to reduced social contact and more isolation for the person with dementia. The research interview therefore also explored whether there were negative impacts for the person with dementia or for the carer.

Negative impacts were much more commonly reported for the carers themselves than for the person with dementia. In all but one case, they judged the negative impacts to be minor rather than major. In the one case where it was reported as major, the issue was not so much a negative consequence of telecare, per se, but more to do with the absence of some functionality that the carer would have liked but was not part of the installation.

In total, there were 15 cases where carers reported negative impacts either for themselves or for the person with dementia that they cared for (Figure 3.3).

Figure 3.3 Negative impacts of telecare



There were no cases with negative impacts without there also being positive impacts. The carers in all 15 cases said that the positives outweighed the negatives, in many cases substantially so.

Nuisance impacts

In the main, the negatives tended to be nuisance impacts from disruptive aspects of the technology. Frequent and noisy alerts were a nuisance in some of the in-home installations.

Alarms keep going off...

... too noisy...

...beeping gets on your nerves

"It can get you a little bit frustrated when the alarms keep going off." (Carer)

"The only thing was that the thing [alarm unit]...when it's beside the bed, I'll tell you you'd nearly jump out the window when it goes off." (Carer)

"...beeping would get on your nerves at times. The bed thing you know, when it was going off a bit, it was a bit sensitive" (Carer).

"Sometimes he could ask what is going on and if he was in bad form he could get kind of "I don't like it" [when he sees the light flashing on movement sensor]... But then an hour later he's totally forgotten about it... we get it about a lot of things!" (Carer)

Flashing light on sensor

Pager losing charge quickly

"I have to watch that I have it plugged in. The charge, I think, kind of goes quite quickly. (Carer)

Dilemmas about invasion of privacy

In a few cases, carers spontaneously raised dilemmas about invasion of privacy through audio-visual monitoring of the person with dementia. They felt this was a negative for the person with dementia, albeit a minor one in the overall context of benefits and disadvantages in the situation.

> *"I suppose I'd have to say that I think that a camera being on me would disturb me, myself..." (Carer)*
>
> *"...so for her, speaking on her behalf, it's taken away her privacy. I think that is a negative for her. I'd say a minor because she is not doing anything that, you know, her privacy is taken away anyway I suppose..." (Carer).*
>
> *"...If she knew she wouldn't mind if she was getting the benefit from it, but as I say she is a very proud woman, she wouldn't want to have people looking at her...but for us it was brilliant." (Carer)*

Dilemmas about invasion of privacy through monitoring

Although carers who used this type of monitoring were more likely to report some negatives for the person with dementia, they were also more likely to report various positive benefits for the person with dementia and for themselves in their caring role. This included security/safety for the person with dementia and the possibility for them to remain living at home, and for how well the carer can help the person with dementia and carer burden/strain.

3.3.2 How telecare worked in practice

This section looks more closely at how telecare worked in practice in different circumstances and by addressing specific needs. Aspects of interest include the particular form of telecare in place, and how different types of sensors and other home devices worked.

Forms of telecare

As outlined in section 3.2, there were three main modes of telecare implemented across the 24 cases - in-house, remote and combined. Clients provided with in-house telecare tended to have more severe dementia and to have family carers living with them or staying over at night-time. Overall results in terms of benefits reported seemed equally positive for both groups.

In-house mode

In-house telecare involves alerting and monitoring arrangements that work within the house and its immediate environs. This mode is especially relevant where the carer lives with the person with dementia, or spends a substantial amount of time in the home (e.g. sleeping overnight). Sensors linked to a pager or other alerting systems for the carer are one form of this mode. Direct monitoring of the person with dementia using audio-visual equipment is another form. There were examples of both forms amongst the clients in the sample who had in-house telecare. All of these clients were persons with dementia at the more severe end of the scale used in this study (persons who cannot be left alone and need constant care).

Carer can 'nip things in the bud'...

...sorry didn't have it years ago

"... before I got it, I would be up and down every five minutes checking that he was in bed still, because he could be out or he could be getting dressed again, all sorts of stuff. And now I have it (audio-visual monitor) sitting beside me and I keep checking it and I nip that in the bud because it means I would have to start undressing him again. That went on for, oh I'd say it was a good 2 years of that... I was only sorry I didn't have it years ago... " (Carer)

"Well in the beginning, when we did use it, if I was in the bathroom I had the pager on me. Now she won't move off the chair, but then she was moving all the time, going very quickly in and out with the three-wheeler...when she was walking...it was good if I was ...out at the line, was upstairs, things like that... I'd say it all depends on their sickness or what stages they are at, you know. In the beginning it was good and it would have been good if it stayed that way..." (Carer)

Was helpful for a while

Remote mode

Remote mode telecare involves alerting and monitoring arrangements that support caring at a distance. This may be for carers who do not live with the person they are caring for or, in co-residence situations, where the carer is not at home for lengthy periods of the day. These systems involve sensors in the home of the person with dementia, or worn by the person, that trigger an alert when an issue arises. In cases where the person with dementia has sufficient capacity, they would typically also have a pendant or wrist-worn device so they can activate an alert themselves.

Sense of reassurance for person with dementia and carers

"...I find it very reassuring, not just the wrist pendant; I mean it's not guaranteed that she'd use it. ...probably more so is there's a carbon monoxide detector and a heat detector, I think, and I thought that they were good additions as kind of safeguards." (Carer)

"Well it's just, it's kind of psychologically I know the thing is there, that's really it. She hasn't had any drama; there hasn't been...a situation where the rescue services have to go in... It's a reassurance." (Carer)

> *"… when she did fall out that night….if we didn't have that sensor, I wouldn't have known….she was on the ground for 10-15 minutes, when I was contacted and I was over there, if we didn't have the sensor, it would have been – four hours? I'd recommend anyone to get one…"*
>
> *…not only was I alerted, but by the time I got over there, the monitoring service was still talking to her…so I thought that was particularly neat." (Carer)*

Bed sensor alerts carer to fall at night...

... call centre reassured person with dementia until carer arrived

Some systems operate through a monitoring centre, with alerts going to the centre, triaged by the call centre operators and passed on to the carers if necessary. Others operate by directly alerting the carer by a phone call or text message. There are also systems that allow carers to log-in and see patterns of activity in the home. There were examples of each of these forms amongst the cases with remote mode.

Frequency of activation

Amongst the 24 cases, nine had not (at least yet) received any alerts or had to take action as a result a telecare alert. In these cases, the primary mechanism of support was through providing background reassurance to carers that they would receive an alert if needed. In some cases, there was also the reassurance for the person with dementia that they could call for assistance or that the carer would be alerted in an emergency. The 15 other cases had experienced one or more alert and a need to take action to assist the person with dementia. Three of these cases had experienced just one such event so far. The other 12 had a number of such events or were using telecare for active monitoring in order to detect and, where possible, pre-empt problems from occurring in the first place.

Different sensors and equipment

Telecare can include equipment that enables the user to actively trigger an alert (e.g. pendant, bogus caller alert) and sensors that automatically trigger an alert (e.g. flood detectors, fall detectors). Active systems require a certain degree of capacity on the part of the user. Some of the 24 installations included both active and passive components, but most were passive systems.

Movement sensors

The telecare installations commonly included movement sensors of various types, depending on the situation and particular needs in each case. These included fall detectors, bed and chair sensors, property exit sensors, and dispersed movement detectors in a number rooms.

These types of sensors are more complex than environment sensors. They can work very well in some cases. However, sometimes they can be challenging to get working in an effective manner, to fit with the everyday life and activity patterns of persons with dementia and others in the home.

Bed sensors can work well...

"…. At night-time it's just brilliant, because even if I am in a deep sleep, and it beeps, I can go straightaway out to her." (Carer)

...but not always

"... You know you can be no sooner up in the middle of the night, you get back into bed, you no sooner get settled [and] this ...the alarm can go off again and you are up and down." (Carer)

"... bed pressure mat didn't sense when she was back in bed [this was a very light person]. Took it out after a while, too many false alarms." (Carer)

Door sensors very useful...

"... The rambling was an awful problem...I just put it [door sensor] to between 10 (at night) and 8 (in morning)...it was a great help in the winter anyway....you can speak to her from down here through the speaker unit. So instead of my having to run to her I can actually ask her through that and she can answer me and tell me what she is doing. So it saves me dropping everything and going. (Carer)

...but can present difficulties

"[At the beginning] Sometimes the system... went a bit flawed and we would get alerts and there wasn't any reason for them....and then there was the fact that we have to reset the alarm depending on who is staying with her or the timeframes....it's just another thing to have to think about. (Carer).

"The only thing is [other carer] leaving early, because two days a week she's out of here, sometimes before five o'clock. And the alarm goes off." (Carer)

Environment sensors

The range of monitored environment sensors installed included flood, heat, smoke, and carbon monoxide detectors. Whether or not they were provided, and what types, depended on the situation and needs in each cases. These relatively simple devices can be useful for safety purposes and for reassuring carers.

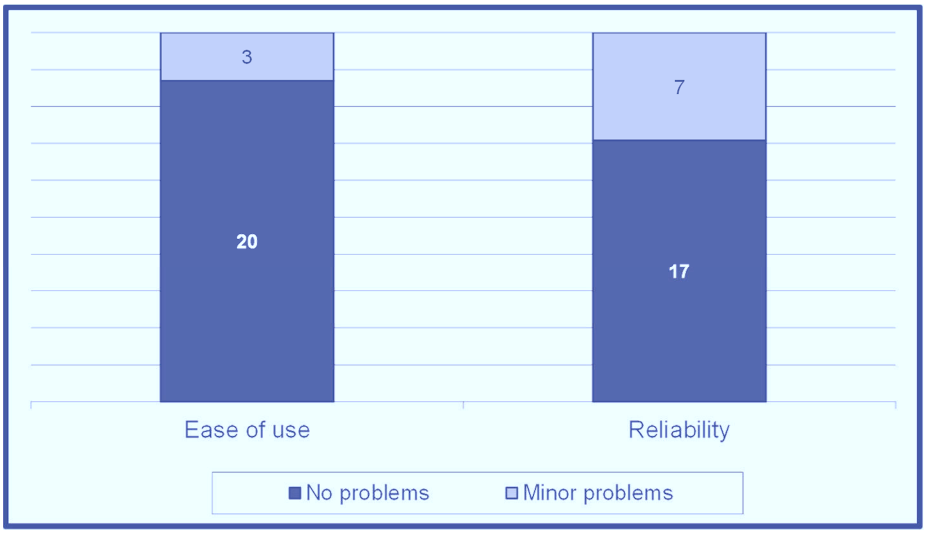
Flood detector reassures carer

"... it's like a background thing, there all the time...she has flooded things, you know, and just by chance I've been around." (Carer)

3.3.3 Ease of Use and Reliability of equipment and service

Figure 3.4 presents carers' ratings of ease of use and reliability of telecare.

Figure 3.4 Carers' ratings of ease of use and reliability of telecare



A large majority of carers found the telecare easy to use. Three reported minor difficulties in this area. In one case, the carer felt that the person with dementia did not have enough practice, to ensure they knew when and how to use the red button. Another carer had some difficulties with the property exit sensor and would have liked a control switch to turn it on and off.

The majority of carers had no problems with the reliability of the telecare, although in seven cases they mentioned minor problems in this area.

> *"Only once that the alarm [box unit] went off…. and I thought the battery was gone … I got a new battery and it didn't work. I think I had a while to wait [to get it fixed]… When it was out of order, I went back to my old scheme of hopping up and down to the room. Running in and out to the room at night. Yeah, you wake [up] every hour to go in and make sure he is alright." (Carer)*
>
> *"… [not sure] if it should have given me a text that time of no movement [when person with dementia had a fall]." (Carer)*

3.4 Summary of key findings

The results presented in previous sections provide a rich picture of the ways that telecare was helpful for the 24 clients included in the evaluation. They show that, when effectively targeted and implemented in a person-centred manner with individually-tailored technology packages, telecare can be a very useful support for people with dementia and their family carers.

Key findings

- All 24 family carers reported positive benefits from telecare, for the person with dementia and/or for themselves (in their caring role and other aspects of their lives).
- Telecare provided positive benefits across a range of client situations. These included:
  - in-home telecare, where the dementia was more severe and carers were co-resident.
  - remote telecare, where the dementia was less severe and the carer was not co-resident or not at home 24/7 with person with dementia.
- Most frequently reported areas of benefit for persons with dementia were:
  - safety/security
  - possibility to continue living at home.
- Most frequently reported areas of positive impact for carers were:
  - their worries about wellbeing/safety of person with dementia.
  - carer burden/strain.
  - how well they could help the person with dementia.
  - capacity to continue to support person with dementia to live at home.
- Carers also reported some negative impacts from telecare, more frequently for themselves than for the person with dementia:
  - for themselves, these were primarily nuisance factors associated with telecare, such as noisy alarms and over-sensitive movement sensors.
  - in a few cases of in-home telecare, carers felt that the invasion of privacy was a negative for the person with dementia.
  - in all cases, however, carers felt that the positives outweighed any negatives, often substantially.
- Across the 24 cases, many carers reported specific examples of situations where telecare had been important (e.g. detecting a fall or pre-empting a problem arising in the first place).
- Others had not (yet) experienced a specific incident, but gained positive benefits from the reassurance they got from having telecare in place.
- As dementia is a progressive condition, timeliness of provision is important. Needs change over time, as does the likely relevance or not of particular forms of technological support.

4. Telecare: Service level evaluation

This part of the evaluation assessed the experiences of implementing the pilot telecare services in the four sites. It examined the various elements involved in setting-up and operating a telecare service in the dementia service ecosystems established by the demonstration projects. A key objective was to identify lessons from the sites' experiences that would be helpful for guiding future development of telecare provision for people with dementia in Ireland. It was also anticipated that the contextual information about the pilot processes might contribute to the analysis and interpretation of results from the client impact assessment.

4.1 Methodology

There were three elements to the service level evaluation:

- client assessments of various aspects of the process of telecare provision for them.
- documenting how each site went about setting-up and operating their pilot telecare services.
- staff assessments of the pilot processes in each site.

The structured interviews with the 24 clients who participated in the research included questions on their satisfaction with a number of aspects of telecare service provision under the pilots. Each of the sites completed a template designed to describe key aspects of their pilot in a consistent manner, and the researchers conducted structured evaluation interviews with a number of members of staff from each site. Interviews were conducted with project managers, clinical leads and frontline staff. At least three staff members were interviewed in each site, with a total of 15 interviews conducted across the four sites.

4.2 Results

The pilot telecare programmes in each site offered funded telecare installations for suitable clients. Three of the sites (Kinsale, South Dublin, and South Tipperary) provided telecare installations for between 5 and 10 clients each, and one site (Mayo) provided more than 20 installations.

Across the sites, the composition of the consortia, as well as their overall programme objectives and modus operandi, influenced how they established and operated their telecare pilots. HSE services led the South Dublin and South Tipperary consortia. In South Tipperary, the telecare project was within the remit of the Community Mental Health Team, and led by Occupational Therapists from the team. In South Dublin, the telecare project was initially implemented through a pre-existing telecare initiative involving the Alzheimer Society; coordination was subsequently taken up by the HSE and led by the community Occupational Therapy service. In Mayo, the Alzheimer Society led the consortium; and, in Kinsale, K-Cord, a legal entity established for purposes of the demonstration project led the programme. In both sites, the telecare pilots operated through the demonstration project's structures, managed by nominated telecare leads.

4.2.1 Staff overall assessments of key aspects and outcomes

All sites managed to put in place a pilot telecare project as part of their demonstration programme. There was some variation in overall assessments of their experiences in setting up the pilots, and how successful they were in achieving the concrete objectives they had set. Respondents across the sites, and often within the same site, applied varying criteria in making these assessments. In some cases, the extent to which they had achieved their original (quantitative) targets was a central factor. In other cases, the assessment was particularly influenced by perceptions of the extent of effort involved relative to the results achieved.

Usefulness of telecare for clients and the care services

The staff interviewed for the evaluation research varied in how close they were to the day-to-day aspects of the telecare pilot, and in the extent to which they had direct knowledge of impacts of telecare for clients. Nevertheless, there was a consensus across respondents and sites that telecare had been useful for many clients.

Overall, the sites rated their telecare projects to have been between ‘fairly’ and ‘very’ useful for the care services and staff. The possibility to offer a new service, knowledge gained about telecare and the practical experience from the pilot processes were important areas of benefit for the services. Ratings were influenced to a certain degree by the respondents' assessments of the overall success of their projects and the issues that they had experienced. The nature of the consortium and the care ecosystem involved in the demonstration project were also factors affecting this. Some projects were more embedded in mainstream dementia care services than others, and had greater opportunity to incorporate lessons learned into their services going forward.

Value-for-money

For the pilot projects, the sites funded telecare from their project funding. The typical approach was to provide free installation and one year's monitoring service to clients offered telecare. Costs of installations varied in accordance with the number and types of sensors and other equipment installed in the home, and the monitoring/alerting arrangements in place, but prices were fairly similar across the telecare providers involved. The average cost was between €500-€600 per installation. In one site, the telecare provider installed the equipment on a rental basis but annual costs were typically within the same range as the other sites. In two of the sites, there were a small number of more complex installations costing close to €1200 each.

Overall, the sites rated telecare as providing between moderate and high value for money. This included the value for money of the benefits achieved for clients, and from the potential for cost savings for the services. Three sites gave ratings towards the high end of the scale. The lower rating in the other site was, at least in part, related to some of the challenges faced in setting up the telecare project on a satisfactory footing, and the amount of effort involved in this.

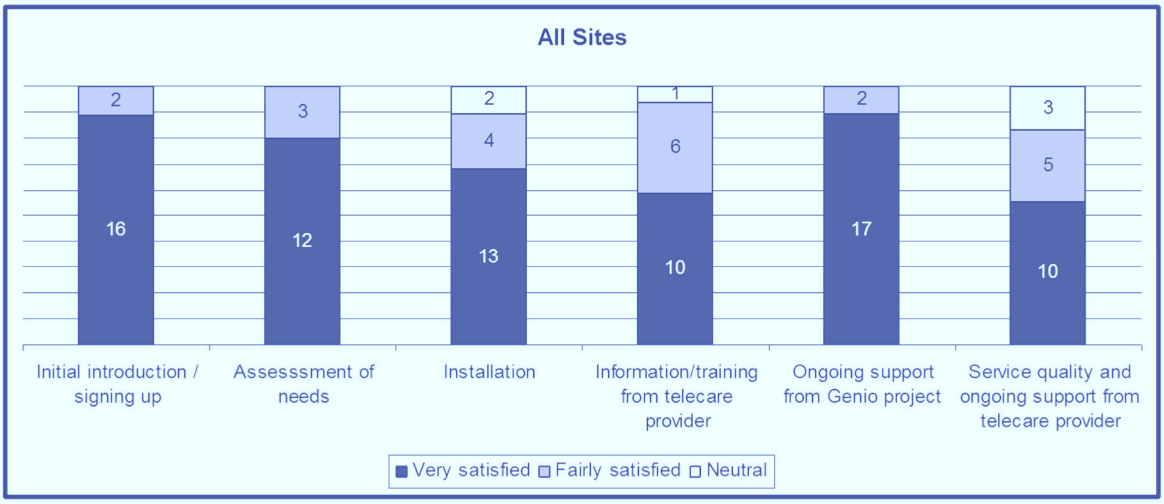
Plans to continue providing telecare

At the time of interview (mid 2015), all sites were giving consideration to mainstreaming or continuation of telecare provision for people with dementia. Efforts to seek continued funding or resource commitments to sustain the various aspects of their projects were work-in-progress at that time. There was some variation in the degree of commitment to pursuing opportunities for continued telecare provision, with this influenced by the composition of the consortia and the suitability of their particular care ecosystems for taking this area forward. In addition, at time of interview, the sites had not yet seen the results of the client impact assessment part of the research, and the strongly positive impacts for many clients that this identified.

4.2.2 Client assessment of specific elements of the pilot process and services

Overall, client assessments of the various elements of the pilot process and services were predominantly positive (Figure 4.1). They were most positive about processes that were within the remit of the care services, and a little less positive about processes from the telecare provider side. Nevertheless, even in the latter case, ratings were primarily positive, or at worst neutral rather than negative, and no clients expressed dissatisfaction with any aspect.

Figure 4.1 Carers' satisfaction with aspects of the pilot services

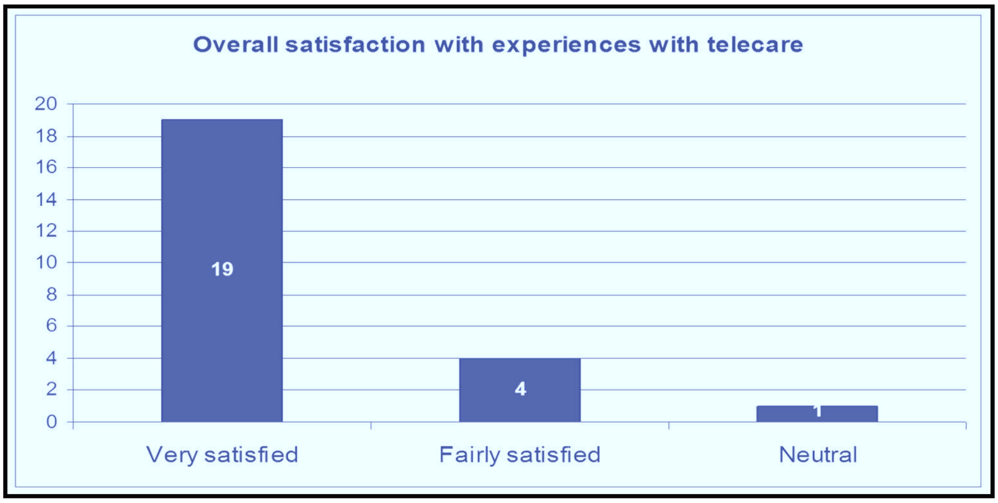


There was some variation across sites in the overall ratings by clients for all service process elements combined, although not very marked. No single factor appeared to underlie this, and the small number of clients in some sites make comparisons difficult.

Overall satisfaction and suggestions for improvements

Figure 4.2 presents carers' overall satisfaction with their experiences with telecare. Nineteen (79%) were very satisfied and all but one of the others were fairly satisfied. The satisfaction scale included both satisfaction and dissatisfaction options, but none of the carers said they were dissatisfied.

Figure 4.2 Overall satisfaction with experiences with telecare.



Respondents were also asked whether, on the basis of their experiences, they would suggest any improvements to telecare. They made quite a number of suggestions. Some of these could fall within the remit of the care services; others raise design issues that fall within the remit of telecare equipment and service providers.

Suggested telecare improvements - care services

- Provision of additional items:
  - bedside pressure mat as well as bed sensor.
  - property exit sensors on all exit doors, not just one.
  - system to alert carer when person with dementia leaves the room, like the (passive infra red) system the carer had seen in a care home.
  - gas cooker shut-off device.
  - solution for access to house if person with dementia leaves key in the door.
- Regular checking with clients to see how telecare is working.
- Ongoing review to assess whether needs are changing and what solutions might be required.
- Raise awareness about telecare (families, GPs etc) so that access is not just by chance.
- Homecare staff to be informed about telecare (e.g. to remind user to wear pendant).

For care services, the most common suggestions concerned provision of additional items that would be helpful for addressing clients' needs. Respondents also noted the value of regular checking to see how telecare is working and of ongoing review to assess whether needs are changing. Other suggestions included the need to more generally raise awareness about telecare so that access to it is not just by chance, and the need to inform and involve homecare staff working in the home.

For telecare equipment and service providers, respondents suggested improvements for each of the types of telecare implemented across the sites.

Suggested telecare improvements - equipment and service providers

In-home systems:

- easier/quicker way to switch off pager.
- adapting bed sensors to be more like baby monitors, so carer can hear what is happening.
- low energy / low intensity light to stay on all night; tamper proof.
- improvement of working of bed sensors / pressure mats.
- improved audio alerting system; alert 'on duty' carer but not rest of household.
- alerting system that indicates the alarm priority (e.g. like phone with different ring tones).
- system to record and report times of alerts, to help carer brief other carers on hand-over.
- extended signal/reception range, so not limited to closest rooms in the house.
- larger screen on audiovisual monitor; ensure that device in person with dementia's room does not make noise.
- placement of camera(s) and ease of positioning/adjustment to enable sufficient view; wall-mounted might sometimes be better, and more than one camera.

Monitoring centre / remote systems:

- ensuring that mobile phone numbers are included on the contact list, where appropriate; and first on the list if most helpful for carer
- regular calls by call centre staff to check that person with dementia is aware and knows how to use pendant
- on-off switch on base unit to give carer more flexibility (e.g. if door exit sensors installed).

Web-based activity monitoring system:

- enabling multiple users (carers) to access the system, when multiple family carers involved.
- include direct alerting of carers (e.g. by pendant).
- more control to change settings during the day, to adapt to changing circumstances.
- key-pad to change system settings when entering the house.

All systems:

- regular checking with clients to see how telecare is working.

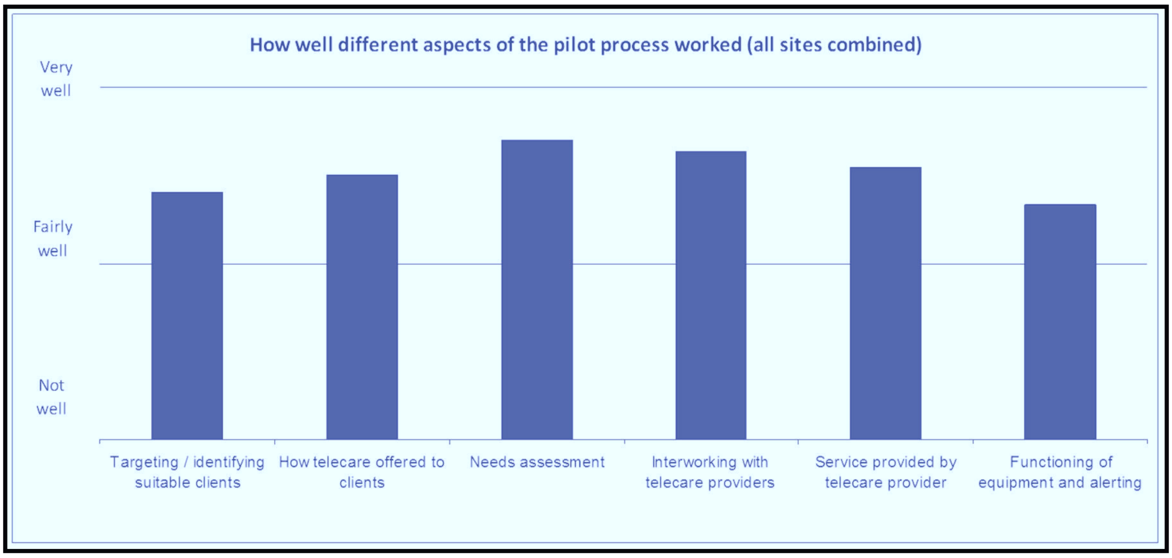
4.2.3 Staff assessments of specific elements of the pilot processes

The staff interviewed from the sites assessed a number of aspects of their telecare pilot processes. The aspects covered were:

- Targeting and identifying suitable clients
- How telecare was offered to clients
- Needs assessment
- Ongoing contact/review by care services
- Feedback of telecare data to care services
- Ethical issues
- Interworking with telecare providers
- Service provided by telecare provider
- Functioning of equipment and alerting.

Across the sites, respondents rated most aspects as having worked 'fairly' or 'very' well, as indicated in Figure 4.3.

Figure 4.2 Staff assessments of aspects of the pilot services



There was some variation between sites in their ratings of particular elements of the process. For example, one site gave lower ratings for processes involving the telecare provider. This was primarily linked to challenges experienced at the beginning in setting up an effective service agreement, and in organising the interworking arrangement between the care services and the telecare provider.

The following sections elaborate in more detail on some of these key processes, summarising how the sites implemented them, what issues arose and what guidance these experiences may provide for future practice.

Targeting and identification of clients that might benefit

Telecare is not relevant for all persons with dementia; its relevance depends on the nature of each client's needs, their support structures and their living situation. Targeting and identification of clients that might benefit is therefore an important aspect of telecare service provision.

All sites had included assistive technology and telecare as part of their planned suite of interventions under the HSE & Genio programme. As they began to more actively develop their ideas and approaches to this area, some sites identified a need for guidance on how to identify/assess clients for telecare. As part of the action research approach, the research team, in conjunction with the Alzheimer Society, organised and facilitated a joint workshop on this theme for the four sites. Staff from the Alzheimer Society who had experience in successful implementation of telecare for people with dementia contributed at this event. Some basic guidance was then circulated, outlining areas of need for people with dementia and their family carers where telecare can be helpful.

Approaches to finding clients and offering telecare

Procedurally, the sites varied to some extent in how they went about the process of targeting and identification of clients for telecare. One site considered potential suitability for telecare as part of the general assessment for care for all clients supported by the project; another site systematically reviewed all client records for telecare potential. Sites also sought referrals for telecare from key-workers familiar with their clients' practical living situation, as an ongoing process during their project. Key-workers included public health nurses, community mental health nurses and dedicated dementia support workers.

There was typically a certain element of 'push' from the projects' side in finding clients and offering telecare to them, in the sense that potentially suitable clients were sought rather than being self-referrals seeking telecare on their own initiative. This was due to low levels of awareness of telecare amongst people with dementia and family carers. To address this, most sites implemented technology awareness initiatives, including ongoing demonstration facilities and once-off awareness events.

Evaluation and issues experienced

Staff evaluation of how these processes worked was generally positive in all sites. The positive results from the client impact assessments would also indicate that the process was relatively effective in all sites, in that all clients and family carers identified, and ultimately provided with telecare, reported positive benefits.

Those involved in the projects felt that demonstration of telecare equipment and how it works is important, both for families and for frontline staff. Some sites felt that they ideally should have done this at an earlier stage in their projects. In one site, a substantial number of potential clients declined the telecare on offer (this was a fairly complex activity monitoring system) and they are conducting follow-on research to examine the reasons for this.

Retrospective screening of large numbers of clients for potential telecare suitability was time-consuming, and it was often difficult to identify clients with relevant needs from the existing client information. Ongoing screening and referral of clients as they came into contact with the services seemed more effective. The effectiveness of identification and referral of suitable clients also tended to improve as the projects progressed and experience with telecare increased.

Learning Points

- Effective ways of targeting and identifying clients who might benefit most from telecare are important.
- An approach that keeps telecare in mind on an ongoing basis, as a potentially useful support for clients, is likely to be most effective, beginning when they first become known to dementia services.
- The possible benefits of telecare should be taken into consideration as a matter of course for all clients; however, in doing this, it should be borne in mind that it may be very helpful for some, a little helpful for others, and may not be appropriate or helpful at all for others.
- There is a need to increase awareness and knowledge about telecare:
  - information and guidance on telecare for staff who are in contact with clients and well-placed to refer for telecare - what's involved, who and how it can help, etc.
  - awareness about telecare amongst people with dementia and their families.
- Engagement and discussion with clients and family is important, to really explore if telecare is of relevance; demonstration of telecare equipment and how it works can be very useful for this.

The interviews also asked staff from the sites about types of client or areas of need they felt telecare might be most helpful for. Relevant groups mentioned ranged from persons with early onset and mild to moderate dementia, to people at later stages of dementia and their carers. Also mentioned were moderate dementia with risky behaviours, persons with dementia who are wakeful at night, and carers suffering from sleep deprivation. Other groups suggested were clients worried about security and persons with dementia who also have other chronic diseases.

One essential ingredient of telecare is someone to respond (i.e. to go to assist the person) when an alert is raised that requires this. In the pilot projects, this role was undertaken by informal (family) carers but this approach presents a difficulty for people with dementia who do not have such supports. Care services could consider possibilities to provide formal telecare responder services in such situations.

Needs assessment and ethics

Telecare is a support that addresses everyday challenges for persons with dementia and their families. Every situation is different, depending on the issues posed by dementia, lifestyles and other factors. Careful needs assessment is essential in order to find helpful solutions that fit with the complexities of daily life and the best interests for all concerned.

Approaches applied in the sites

Although the sites varied in the details, there were basic commonalities across their approaches. Once the services identified a client who might be a candidate for telecare, they got in touch with them and their families to broach the possibility that telecare might be useful in their situation. There were a small number of self-referrals (i.e. direct requests from families who had attended demonstration events), but in most cases the initial suggestion came from the care services.

Following this, there was a more in-depth assessment of needs. This was to decide whether telecare was suitable and desired and, if so, to determine the specifics of the telecare installation that would address the needs. This stage of the process would generally involve the care services, the person with dementia and/or their family and, to a greater or lesser degree, the telecare provider.

The process was overseen by the telecare project leads in each site. In two sites, these were occupational therapists from the mainstream care services; in the other two sites, they were the project managers / coordinators for the project in the sites.

The telecare project leads generally made home visits and discussed the possibilities offered by telecare with the family. The sites with demonstrator facilities used these to show telecare to the clients to whom it was being offered. Some sites also had portable telecare demonstrator kits for showing to clients in their homes.

Role of telecare provider

There was some variation across sites in the extent of involvement of the care services in specifying the technical details of the telecare installation. In some sites, the care services led this and in others they adopted a more 'arms-length' approach, with the telecare provider more involved in working with the clients on this aspect. In a few cases, the care services and telecare providers made joint home visits, but this seems not to have been very common across the sites.

Involvement of person with dementia & ethical issues

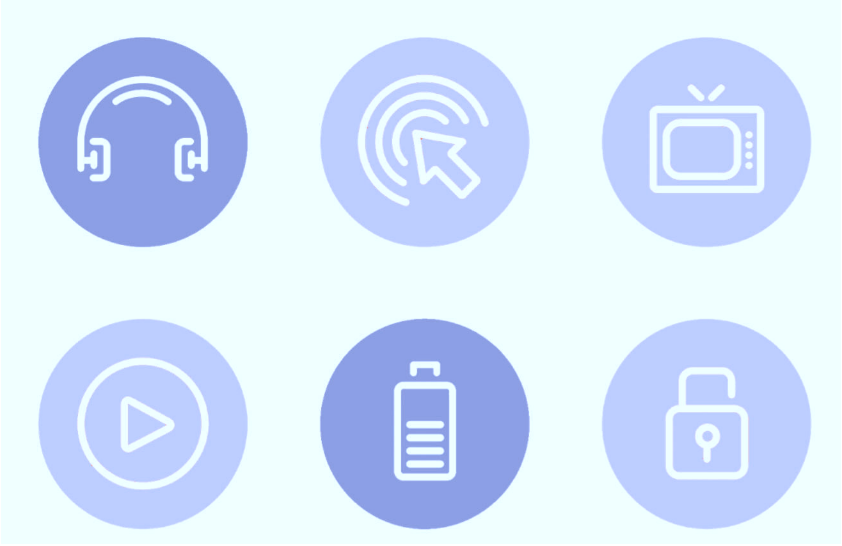
The care services tended to consider the person with dementia and their family carers in a holistic manner, aiming for a solution that would be helpful for both. All sites reported considerable effort to include, as much as possible, the persons with dementia in the discussions about telecare. This was not possible in some cases because of lack of capacity. Formal consents for telecare installation were generally provided by family carers.

Evaluation and issues experienced

Staff evaluation of how these processes worked tended to be positive in all sites.

Respondents generally gave positive ratings of the needs assessment process. One less positive experience was the effort spent on identifying clients from existing case lists and then finding that in practice their situations were not suitable for telecare. It was also felt that care service staff needed sufficient knowledge about telecare in order to conduct effective needs assessments. Related to this was the issue of the most appropriate role for the telecare provider in needs assessment and decision-making. One of the care professionals interviewed felt that it might be more appropriate not to have the telecare provider present for the first assessment.

All sites gave positive assessments of their efforts to involve the person with dementia as much as possible, although some respondents felt it could be challenging to keep the person with dementia to the fore at all times. Sites also generally gave positive assessments of their efforts to address ethical issues, although some respondents felt this area needed more attention.



Learning Points

- Careful needs assessment, in consultation with the client and family, is important in order to specify an appropriate telecare installation to meet their needs.
- Best practice requires person-centered approaches and individualised technology packages.
- Care service personnel require sufficient knowledge about telecare in order to conduct effective needs assessments.
- There is a need for guidance on the most appropriate role for the telecare provider in needs assessment and decision-making on the telecare. In practice, this varied depending on whether the sites embedded telecare within the care services or offered it to clients in a more 'arms-length' manner.
- As in other areas of dementia care, ethical issues are important in needs assessment and installation of telecare.
- There is a need for protocols and guidance to ensure the involvement of persons with dementia to the greatest extent possible, and for development of skills for communication with persons with dementia.

One issue mentioned was uncertainty about whose needs were being met, and whether the balance was more towards the carer than the person with dementia. People with dementia may typically go along with the installation of telecare rather than being active in the decision-making. It was also felt that the existing legislative framework around capacity and consent was inadequate. Another issue raised was the implementation of telecare systems that are still under development, and the need for clear explanation of the limitations of such systems to prospective users.

Follow-up with clients after telecare installation

Given the nature of telecare, there can be teething problems when the technology has first been installed (e.g. need for adjustment of the sensitivity or settings for movement detection sensors). Solutions that were hoped for may not always work out in reality. Needs change over time and telecare installations may require modification and, eventually, taken out entirely. In addition, information on alerts received and the responses to them can assist care services to identify needs and support care planning.

Approaches applied in the sites

All of the sites had arrangements to follow up clients after telecare installation, with some variation in the adopted approaches and in the closeness of the engagement of the care services.

In one site, the occupational therapy service kept telecare clients on an open case load and enabled clients and their families to contact at any time. There was follow-up telephone contact after a period of time. In another site, there was a monitoring call from the care services one week after installation, to check everything was working and that the client/carer understood the pack and could use it. There was also a three-month monitoring call to check the status of the client, and a six-month monitoring visit. In addition, there was feedback from frontline services in contact with clients during the time-frame. In other sites, the care services had less active ongoing follow-up of clients who had received telecare.

In two sites, there was an arrangement for the telecare provider to send reports on telecare alerts to the care services. In one of these sites, the telecare provider sent weekly reports to the care services, where they were reviewed and action taken when necessary. In the other site, the telecare provider sent monthly reports to the care services. The telecare system in one of the other sites did not log data on alerts and responses; in the other site, the system did log data but the arrangement provided access for the clients/carers rather than the care services.

Evaluation and issues experienced

All sites rated this aspect quite positively, although with some variation across the sites and sometimes between respondents within sites.

Ongoing contact/review of telecare clients by care services was generally assessed to have worked fairly well, although some respondents were a little less positive. In one site, this was because they had intended to make follow-up home visits, not just phone calls, but time constraints prevented this in practice. In another site, some respondents felt that their approach was too informal and that a more formal follow-up process would have been better.

The sites generally felt that it was important to have feedback to the care services of data on telecare alerts and responses. One of the sites where this was not in place felt that there should have been an arrangement for this, and more meetings and collaboration between the care services and telecare provider. In the sites that did have such arrangements, respondents made some observations on the process and suggestions for improvement. In one site, the data was not found very helpful and structured review might have been more useful. In another site, the initial arrangement anticipated quite extensive feedback to the care services. This did not work as initially expected, but improved when simplified after review. It was also felt that the care services should have a system for responding to patterns of alerts, to identify needs and take this into account in care planning.

Learning Points

- Care services should keep in the loop after telecare installation.
    - There should be structured systems in place to follow up with clients after telecare is in place, to monitor how telecare is working for them and track whether needs are changing over time.
    - In the sites that had these arrangements, follow-up was mainly by phone. Some respondents felt that home visits should also be conducted as part of this.
- There should be regular liaison between the care services and telecare provider.
- Where telecare is embedded within the care services, there should be arrangements for feedback of data on telecare alerts and responses to the care services.
    - Best practice would involve regular reporting of data by the telecare provider, in a format useful for the care services.
    - Care services should have systems for reviewing and responding to the telecare data, to identify needs and incorporate this in care planning.

Procuring telecare and quality of telecare service provision

The sites also provided assessments of a number of aspects of telecare service provision. This included:

- The procurement process
- Inter-working and cooperation between telecare provider and the care services
- Quality of the telecare service
- Functioning of the telecare equipment and alerting process.

In general, the sites assessed these aspects quite positively. Across the sites, ratings of the functioning of telecare equipment and the alerting process tended to be a little less positive than the ratings of the other aspects. In the main, this seems to be a reflection of the difficulties experienced with some types of sensors, particularly over-sensitivity and need for adjustment of items like fall detectors, bed and chair sensors, and property exit sensors.

One site expended considerable effort to put in place an appropriate service level agreement, to formalise a pre-existing local telecare arrangement and develop an effective working relationship between the care services and telecare service. In another site, the system procured was still undergoing development and improvement, with updated releases provided to clients who enrolled later in the project. Model procurement frameworks or guidelines would be useful for local procurement of telecare by care services, and there may be a requirement for a variety of frameworks to cover a range of procurement situations.

Learning Points

- Procuring telecare and establishing appropriate and effective service level agreements for telecare can be challenging for local care services, especially when doing this for the first time.
- Model procurement frameworks or guidelines would be useful for local procurement of telecare by care services. There may be a requirement for a variety of frameworks to cover a range of procurement situations:
    - when procuring mature, 'off-the-shelf', telecare services
    - where the telecare systems are at a more developmental stage, or where the care services wish to procure telecare in a flexible manner as part of a wider service innovation process.
- Care services also need to be aware that difficulties may arise with some types of sensors, even when procuring more mature telecare systems.
    - In particular, there can be over-sensitivity and need for adjustment of items like bed and chair sensors, and property exit sensors.
    - Care services should develop procedures for anticipating and effectively addressing such issues if they arise.
- More generally, there is a need for overall quality assurance frameworks for telecare.
    - These should cover all aspects of the provision of optimal services for clients and value for money for care services.
    - This includes aspects that fall principally within the remit of the care services and of the telecare services, optimal allocation of responsibilities between the parties, and effective governance arrangements.

More generally, there is need for overall quality assurance frameworks for telecare, ones that incorporate all of the aspects of provision of an optimal service to clients and value for money for the care services. This includes aspects that fall primarily within the remit of the care services and those that fall primarily within the remit of the telecare services. It also includes optimally allocating responsibilities between the parties and effective governance arrangements.

4.3 Summary of key findings

For their telecare pilot projects, the care services in all four sites were mostly starting from scratch. There were no well-established telecare provision systems to build-upon, and levels of knowledge and practical experience with telecare were low. Nevertheless, all sites managed to establish a pilot service and provide telecare to a number of clients.

Once the projects identified potential candidates, they conducted more detailed discussions with the clients and assessment of needs. There was variability across the sites in the extent of involvement of the care services and telecare providers in this, and their roles in the process. Guidance on best practice in this aspect would be useful.

As in other areas of dementia care, ethical issues are important. The sites generally felt that they had adequately addressed this aspect. Nevertheless, some staff members felt that there is a need to put even more effort into actively involving the person with dementia as much as possible. Protocols and guidance in this area would be useful, to ensure the involvement of persons with dementia to the greatest extent possible, and to support the development of skills for communication with persons with dementia.

For the pilot projects, each site engaged with telecare providers in their own way. Across the sites, there were a number of providers involved and a variety of types of telecare system. For mainstreaming of telecare more widely, model procurement frameworks and guidelines would be helpful where local care services are procuring telecare.

The sites varied in the extent to which the care services kept in the loop after telecare installation. In some sites, the care services had formal follow-up arrangements and some received regular reports on telecare activity from the telecare providers. In other sites, the process was less systematic and the telecare services were more at 'arms-length' from the care services.

In general, staff felt that it would be best practice to establish structured systems to follow up with clients after telecare is in place, to monitor how telecare is working for them and track whether needs are changing over time. Where telecare is embedded within the care services, there should be regular liaison between the care services and telecare provider. This could include regular reporting of data by the telecare provider, in a format useful for the care services for care planning purposes.

One of the essential elements of telecare is having someone to respond (i.e. to go to assist the person) when an alert requires this. In the pilot projects, this role was undertaken by informal (family) carers but this approach presents a difficulty for people with dementia who do not have such supports. In some countries, social care services provide a formal responder service in such situations, with on-call social care staff available to go to the home, and there is at least one local, small-scale initiative in Ireland. It would be useful to explore the possibility for wider provision of formal telecare responder services as part of community dementia services in Ireland.

There are a range of elements involved in the process of providing telecare as part of care services for people with dementia. These include needs assessment, installation and on-going review of how things are working; and there are a number of parties involved - care services, telecare providers, and persons with dementia and their families. There is a need for overall quality assurance frameworks for telecare. These should cover all aspects of the service provision process, including guidance on most effective procedures for interworking between care services and telecare providers.

Implementing Telecare: Learning Points

- Effective ways of targeting/identifying clients who might benefit from telecare are important.
- There is a need to raise awareness about telecare, both amongst dementia service staff and in the wider community that they serve.
- Careful needs assessment, in consultation with the client and family, is important for specifying an appropriate telecare installation to meet their needs.
- As in other areas of dementia care, ethical issues are important. There is a need for protocols and guidance to ensure the involvement of persons with dementia to the greatest extent possible, and for development of skills for communication with persons with dementia.
- Model procurement frameworks and guidelines would be helpful where local care services are procuring telecare.
- Care services should keep in the loop after telecare installation, to monitor how telecare is working for clients and track whether needs are changing over time. There should be regular liaison between the care services and telecare provider. This could include feedback of data on telecare alerts and responses to the care services, where appropriate, and with client consent.
- Provision of formal telecare responder services as part of community dementia services should be considered, for example, for responding to alerts when there is no informal carer available.
- There is a need for overall quality assurance frameworks for telecare. These should cover all aspects of the service provision process, including guidance on most effective procedures for interworking between care services and telecare providers.

5. Assistive technology evaluation

The *5 Steps to Living Well with Dementia* project in South Tipperary developed a Memory Technology Library (MTL) and implemented a programme to loan assistive technology (AT) to people with dementia and their families for a trial period. This part of the evaluation research was a joint effort between WRC and the MTL team. It included an evaluation of visitors' experiences of using the MTL and client assessments of items of AT that they had loaned from the facility.

This chapter presents some of the key results. The MTL team will provide more detailed reporting on their work in due course.

5.1 Client experiences with assistive technology

In the context of this report, the assessment of client experiences with AT provides an opportunity to extend the scope of the technology evaluation strand to encompass both telecare and standalone AT. Many of the standalone ATs aim to enable people with dementia to overcome some of the challenges posed by their condition, and thereby directly enhance their independence and quality of life. Telecare serves primarily as a monitoring and risk management support, where benefits for the person with dementia are often more indirectly achieved.

There is some qualitative research indicating how various types of AT can be helpful for people with dementia and their family carers (Alwin et al, 2013; Carswell et al, 2009; Cahill et al, 2007). The results from the evaluation of AT loaned from the MTL may provide a useful addition to this evidence base. The experiences from the MTL also made an important contribution to a guidance document on technology and dementia for care services, prepared as part of the learning component of the wider HSE & Genio Dementia Programme (WRC, 2015b).

5.1.1 Approach and methods

Data gathering was through structured interviews with clients who received AT items on loan from the AT library. The interview schedule covered: perceived usefulness of the AT; positive benefits and negative impacts; ease of use, reliability and appearance of the AT; desire to continue using the AT. Occupational therapists from the dementia service carried out the interviews after the clients had some experience of the AT in their daily lives.

5.1.2 Sample

There were twenty cases included in the evaluation. Table 5.1 provides details of the types of ATs they used. Assessments were available for a total of 27 items of AT, as some people with dementia received more than one item. For 13 of the cases, just one item of AT was evaluated; two items each were evaluated for the other seven cases.

For some items of AT there was more than one perspective available, and a total of 35 evaluation interviews were conducted. Five items of AT were evaluated by both the person with dementia and a family carer; and 3 items of AT were evaluated by the person with dementia only. Seventeen items of AT were evaluated by family carers only (in one case there were separate evaluations by two family carers). One item was evaluated by a family carer and by a pharmacist; another item was evaluated by a pharmacist and by a paid carer.

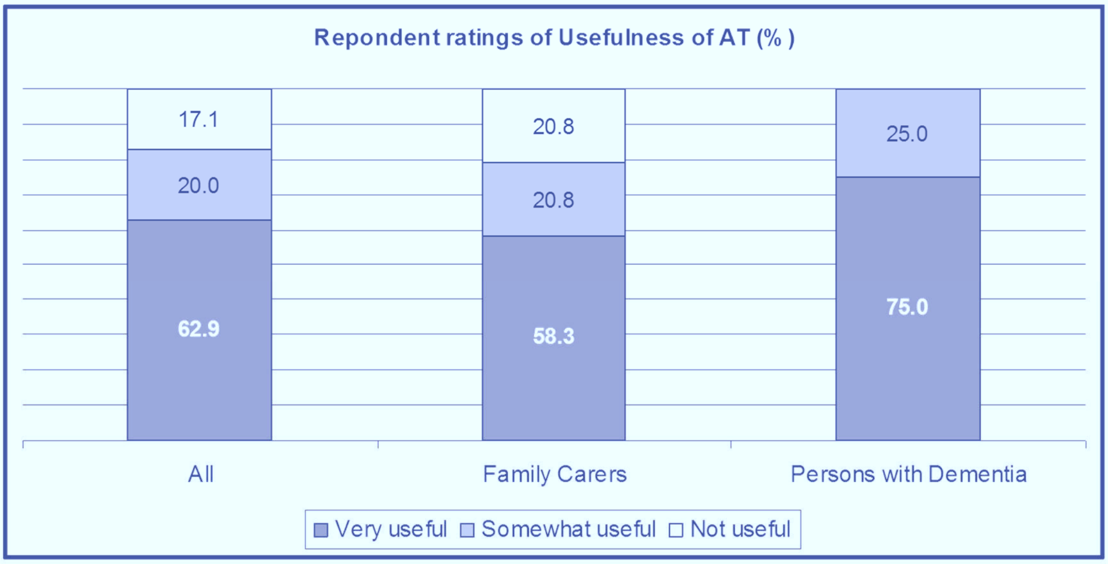
Table 5.1 ATs included in the evaluation

Clocks / calendar clocks (3 with whiteboards)	14
One button radio	5
Medication reminders	3
Motion sensor and pager	2
Memo minder / Wander reminder	2
Simple mobile phone	1
	27

5.1.3 Results

Figure 5.1 summarises the overall ratings by the respondents of the usefulness of the loaned AT, across all types of AT

Figure 5.1 Usefulness of AT

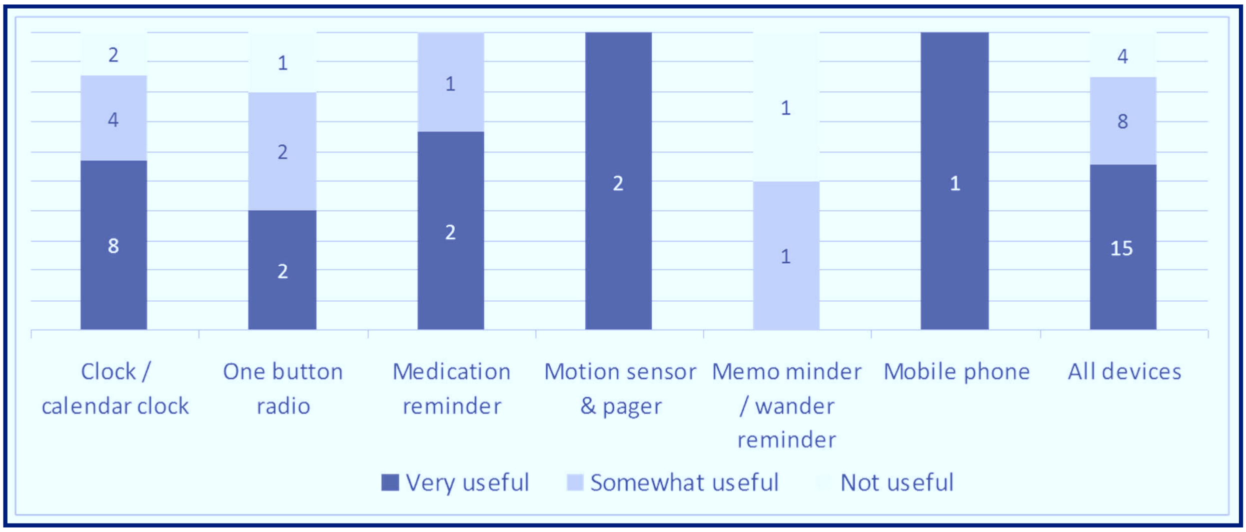


Overall, almost two-thirds of respondents (62.9%) rated the AT in question as being very useful, and one-in-five (20%) rated the AT as being somewhat useful. One-in-six (17.1%) rated the AT as not useful. Persons with dementia tended to give especially positive ratings, but there was high congruence between their ratings and those of family carers when ratings by both parties were available.

Figure 5.2 presents ratings of usefulness for each of the categories of AT, on a case-by-case basis. Where there was more than one respondent for an item for a given client, the averaged score is used for that item.

The 27 AT items evaluated were rated very useful in 15 cases (55.6%) and somewhat useful in 8 cases (29.6%). In only 4 cases (14.8%) were the ATs assessed as not useful. The results show that AT can very often be helpful, but every person and situation is unique, and AT is not guaranteed to always be a success.

Figure 5.2 Ratings of Usefulness of types of AT (average rating for items in cases where more than one respondent)



Key findings for the specific types of AT include:

- Clocks / calendar clocks (14): in 8 cases they were rated very useful (57.1%), in four cases somewhat useful (28.6%), and in two cases not useful (14.3%).
- One button radios (5): in two cases they were rated very useful (40%), in two cases somewhat useful (40%), and in one case not useful (20%).
- Medication reminders (3): one type of medication device was rated very useful in two cases; another type of medication device was rated as somewhat useful in one of these cases.
- Motion sensors and pagers (2): rated very useful in both cases.
- Memo minders / wander reminders (2): rated somewhat useful in one case and not useful in the other.
- Simple mobile phone (1): rated very useful in the one relevant case.

Examples of client experiences

The following are just a few selected examples of experiences with the two most frequently loaned ATs - clocks / calendar clocks and one button radios. The *5 Steps to Living Well with Dementia* project will provide more detailed reporting on the results.

Helping time orientation...

I'd be in a bad way without it. I may think it was Monday, instead of Saturday, and that's a regular occurrence. It would be a nuisance if I didn't have the clock. Otherwise I'd turn on the radio - but it might or might not give you the information. (Person with dementia)

Stopped all the questions - I didn't have to keep saying over and over what day it was. It was nice not to be asked. She used to knock on my bedroom door at night but this stopped once [the] clock was in place. (Carer)

....didn't associate it with being a clock. Habit of looking at normal clock. Didn't register that it [calendar clock] was a clock. (Carer)

...but not for everyone

Listening to the radio...

So easy to just press the one button..... [Avoids] changing channel by accident if pressed the wrong button. (Carer)

Helped her memory a little bit, at least getting the news of local things, hearing something different, not just me talking to her. (Carer)

[She] didn't want it; she wanted to stick to the radio she has, so has not tried it. She likes familiar things - she does not like anything new - wonders where it came from, who it belongs to. (Carer)

...but some prefer the familiar

5.2 Visitors' evaluation of the Memory Technology Library

Vistitors to the Memory Technology Library were asked to complete a short feedback questionnaire. There were 200 completed questionnaires available at the time of analysis.

Visitors included:

- HSE staff (81); also 7 who described themselves as both HSE staff *and* informal carer.
- Informal carers (41)
- People with memory problems (13); also 2 who described themselves as persons with memory problems *and* carers
- Voluntary organisation personnel (10)
- Nursing home staff (9)
- University staff and students on a study visit from the US (17)
- Other visitors not falling into any of the above categories (20).

5.2.1 How useful visitors found the visit to the library

The vast majority (97%) found their visit to the Memory Technology Library to be very useful.
A wide range of reasons were given, but some key themes were:

- Being able to see different pieces of equipment *in situ.*
- Provision of ideas on how to help people with dementia; being able to pass on ideas to clients and family carers.
- Generally raising awareness and providing information about assistive technology for people with dementia.

5.2.2 Finding technologies that might help them or people they were caring for

A large majority (86%) of respondents said they found potentially useful technologies during their visit to the library. Most of the rest either did not answer the question or said that the question was not applicable (because they were not directly engaged in helping with dementia at present, either personally or professionally).

A large number of technologies were identified. In analysing these, we have focused on visitors in the following categories: persons with memory problems; informal carers; HSE staff; voluntary organisations; and nursing home staff. There were a total of 161 visitors across these categories in the sample.

The most commonly mentioned types of technology were:

- clocks / calendar clocks (39.1%)
- monitoring, sensors and telecare (36.6%)
- adapted phones (14.3%)
- radios (14.3%)
- lost item finders (11.2%).

A wide range of other technologies on display were also mentioned by at least some visitors. Overall, there was strong interest both in monitoring/safety technologies and in more enabling technologies focusing on helping people with memory problems to overcome some of their difficulties.

The main types of technology mentioned also tended to feature strongly in the patterns for each of the separate groups, with a certain amount of variation across the groups. One finding was the strong interest amongst nursing home staff in enabling technologies, especially clocks / calendar clocks but also some of the other devices.

6. Conclusions and discussion

This Chapter summarises and presents key conclusions from the research, and discusses the strengths and limitations of the study.

6.1 Substantial benefits for people with dementia and family carers

The evidence from this research shows the significant contribution that both telecare and assistive technology made for many clients. Either or both forms of technological support may be helpful, depending on severity of dementia and each individual's needs and circumstances. As dementia is a progressive condition, timeliness of provision is important. Needs change over time, as does the likely relevance or not of particular forms of technological support.

Technology is not a panacea or a substitute for human care, and there is no 'one-size-fits-all' technological solution for the wide-ranging circumstances and needs of persons with dementia living in the community. Dementia services should discuss with persons with dementia and their families whether telecare and assistive technology may be helpful in their circumstances, keeping in mind that they may be of great value in some cases and less relevant or not appropriate in others. The person with dementia should be involved, to the greatest extent possible, in the selection and implementation of technologies. Achieving best outcomes, both for them and for family carers, should be the objective.

Across the participants, there were a variety of tangible benefits and outcomes for persons with dementia and their family carers.

Types of benefits and outcomes

- Alerted carers to emergency situations, such as falls.
- Gave some persons with dementia more independence.
- Helped delay need to move to nursing home in some cases.
- Supported a trial return home from nursing home for one person.
- Enabled carers to give better help to the person with dementia.
- Allowed carers to have more and better sleep.
- Discouraged wandering in some cases.
- Central to sustaining caring in a number of cases.
- Gave full-time carers some time for themselves, to have some life of their own.
- In one case, carer could monitor wellbeing of person with dementia from work.

6.2 Strengths and limitations of the research

As in all research, certain strengths and limitations associated with the study should be borne in mind when interpreting the results. The sample sizes - 24 telecare users and 20 AT users - were relatively small and might not be fully representative of the overall client base. Nevertheless, the numbers are quite respectable for a field of research where small-scale qualitative studies are commonly reported.

Another issue is the descriptive, cross-sectional study method employed in the study, and the primarily qualitative approach adopted. This has both strengths and limitations. A key advantage of the approach is that it provides a rich analysis of how these technological innovations actually work in practice for clients, and the concrete impacts that underpin global ratings of usefulness and benefit. Whilst it does not allow for 'before-and-after' comparisons on standardised outcome measures, the triangulation of perspectives (clients and key workers for telecare; persons with dementia, family carers and other stakeholders for AT) adds strength to the results and the conclusions that can be drawn.

6.3 Conclusions

The research shows how dementia care services effectively provided telecare and assistive technology that often made an invaluable practical contribution to the everyday lives of people with dementia and their carers.

Conclusions

- The 4 sites successfully established pilot telecare services; one site successfully established a Memory Technology Library and a programme to loan assistive technology to clients for trial.
- The consortia expended considerable effort on this aspect of their programmes, and their experiences provide useful guidance for provision of these supports on a wider basis.
- Telecare and assistive technology provided significant benefits for many persons with dementia and family carers. Either or both may be helpful, depending on severity of dementia and each individual's needs and circumstances.
- As dementia is a progressive condition, timeliness of provision is important. Needs change over time, as does the likely relevance or not of particular forms of technological support.
- When effectively targeted and meeting client needs, telecare can provide good value for money; it would typically represent only a small incremental addition to the costs of a home care package.
- Telecare and assistive technology should be more widely available; the implementation of the Dementia Strategy could give focused attention to this field.
- Person-centered approaches with individualised technology packages work best.
- There is no 'one-size-fits-all' technological solution for the wide-ranging circumstances and needs of persons with dementia living in the community, nor is technology a panacea or a substitute for human care.
- Dementia services should discuss with persons with dementia and their families whether telecare and assistive technology may be helpful in their circumstances, keeping in mind that they may be of great value in some cases and less relevant or not appropriate in others.
- The person with dementia should be involved, to the greatest extent possible, in the selection and implementation of technologies; achieving best outcomes, both for them and for family carers, should be the objective.

Telecare and assistive technology should be part of the mainstream suite of supports offered by dementia services. This could make an important contribution to the implementation of the Dementia Strategy and the achievement of its objectives. In conjunction with human care services, they can play a useful role in personalised care provision, supporting both the person with dementia and family carers.

References

Alwin J, Persson J and Krevers B (2013). *Perception and significance of an assistive technology intervention - perspectives of relatives of persons with dementia*. Disability and Rehabilitation Journal 35(18): 1519-1526

Cahill S, Begley E, Faulkner JP and Hagen I (2007). *"It gives me a sense of independence" - Findings from Ireland on the use and usefulness of assistive technology for people with dementia.* Technology and Disability 19: 133-142.

Carswell W, McCullagh PJ, Augusto JC et al (2009). *A review of the role of assistive technology for people with dementia in the hours of darkness.* Technology and Health Care 17(4): 281- 303.

Graham A, Lawson B and Bolton D (2011). *Home Solutions: A study into the benefits of telecare for older people choosing to remain at home*. Dublin: Health Service Executive.

Keogh C (2010). *Telecare Project: Interim Report.* Alzheimer's Society of Ireland.

Mueller S, Meyer I, Kubitschke L and Delaney S (2012). *Better and more efficient care through ICT-enabled integration of social care and healthcare services: experiences from two European projects.* Int J Integr Care. 2012 Apr-Jun; 12(Suppl1): e81.

Woolham J (2005). *The Safe at Home Project: Using Technology to Help People with Dementia Remain Living in their Own Homes in Northampton.* London: Hawker.

WRC (2015a). *Evaluation of telecare for older persons in North Leitrim - West Cavan. Report on CAWT pilot programme.* Dublin: Work Research Centre

WRC (2015b). *Implementing Assistive Technology in Dementia Care Services: A Guide for Practitioners*. Dublin: Genio. Available at: www.genio.ie/at_guide

Annex 1: Telecare client interview topics

Client background Information

- Demographic and living situation information

Benefits and impacts of telecare

- Person with dementia:
    - Positive benefits
    - Awareness of telecare
    - Negative impacts
    - Specific areas of impact
- Carer
    - Positive benefits
    - Expectations of telecare
    - Negative impacts
    - Specific areas of impact
- Do benefits outweigh negatives, or vice versa
- Impact on amount of contact between carer and person cared for

Telecare in practice

- Aspects especially useful, including specific examples of incidents
- Aspects not useful or caused problems
- Frequency of receiving calls or alerts, and perspectives on this
- Frequency of having to take action as a result, and perspectives on this

Usability and reliability

- Ease of use of telecare equipment and monitoring service, and any difficulties
- Reliability of telecare equipment and monitoring service, and issues arising

Satisfaction with the Telecare Pilot Project processes

- How telecare was introduced by the care service and the sign-up process
- Assessment of needs
- Installation of telecare
- Information and training on telecare
- Ongoing support from care services
- Ongoing support and service from telecare provider

Overall

- Overall satisfaction with experiences with telecare
- Suggestions for improvement of the telecare equipment and service

About Genio

Genio is an independent, non-profit organisation based in Ireland. We are driven by a vision of a society that benefits by valuing all of its citizens. Genio brings together Government and philanthropy to help develop better ways to support disadvantaged people to live full lives in their communities. So far we are working to improve the lives of people with disabilities, mental health difficulties and dementia.

Disclaimer

The views expressed in this report should not be taken to represent the views of Genio, the Genio Trust or of its funders: the Atlantic Philanthropies, the Department of Health and the Health Services Executive. Any errors and omissions are the responsibility of the research team.

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

GENIO

wrc
WORK RESEARCH CENTRE