

C|A|R|D|I **GRANTS**
PROGRAMME

Research Brief

**The role of telecare
in supporting carers
of older people**

Ageing population - ROI

- At the 2006 census, there were 468,000 people aged 65+ (11% of the population).
- By 2041, there will be 1.4 million aged 65 and over (22% of the population).
- Life expectancy is 76.8 years for men and 81.6 years for women.
- 95% of men and women aged 70 and over rate their health as very good (19%), good (50%) or fair (26%).
- 9.1% of people aged 65 and over are still in employment (Q2 2009).

Ageing population - NI

- In 2008, there were 248,500 people aged 65+ (14% of the population).
- In 2041 the 65+ age group is projected to make up 24% of the population.
- Life expectancy is 76.3 years for men and 81.3 years for women.
- 66% of people aged 70 and over rate their health as good (25%) or fairly good (42%).
- 9% of men aged 65 and women aged 60+ are still in employment (Q2 2009).

Policy on carers – ROI

- The *National Action Plan for Social Inclusion 2007-2016* recognises the role that family carers play in supporting government policy of caring in the home and community and suggests that carers require a range of supports including financial, education and training.
- The Equality Authority report *Implementing Equality for Carers* provides practical recommendations to ensure that carers are adequately supported.
- The National Partnership Agreement *Towards 2016* committed to the development of a National Carers Strategy. This has not yet been published.

Policy on carers - NI

- *Shaping the future of care together* is a UK-wide green paper which states the key objective of telecare as improving quality of life, keeping people safe in their homes and inspiring confidence.
- In 2008, the Minister for Health, Social Services and Public Safety announced £1.5 million for pilot projects to promote the development of new technologies to assist people to live at home over the following two years.
- *Caring for carers*, the NI strategy for carers recommends that information technology solutions be used to keep carers informed. It recognises that the health and well-being of carers is important, as is reducing the stress of caring.

Introduction

Telecare can be defined as the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes. It uses information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards. As well as helping older people to live in their own homes for longer, telecare has the potential to support and help family carers.

The proportion of over 65s on the island of Ireland is set to reach 29% of the population by 2041 (McGill, 2010). With the growing numbers of older people, new and innovative ways to help and support their carers are required. As of the last censuses, over 160,000 people in the Republic of Ireland (ROI) and over 184,000 people in Northern Ireland (NI) identified themselves as carers.

In order to explore the potential contribution of telecare in helping carers of older people, CARDI funded the development of a research network in 2009. It was led by Brigid Barron of Caring for Carers Ireland to assess the impact of telecare on carers of older people in terms of reducing stress and increasing quality of life. This research brief is based on the findings of the network as well as CARDI's own research in this area.

Key findings

- There are 160,917 carers in ROI, of whom 11% are aged 65 or over (Central Statistics Office, 2006). In NI, 185,066 people provide unpaid care, 12% of whom are aged 65 or over (NISRA, 2001).
- In ROI, half of 50-64 year olds with surviving parents provide help with household tasks to their parents (on average for 10 hours per week). Over one-quarter provide their parents with personal care, on average for 18 hours per week (TILDA, 2011).
- 70% of carers in NI experience stress as a result of their caring responsibilities (DHSS&PS, 2006)
- In NI, 18% of carers feel they are always under stress, while 21% are stressed very often and 30% quite often (DHSS&PS, 2006). In ROI, two in every five carers report experiencing stress or nervous tension in the past year (Care Alliance Ireland, 2008).
- 1.6 million people across the UK use monitored personal alarms and between 60-70,000 use the devices in ROI (Cullen et al., 2009).
- Evidence from Scotland shows that almost three quarters of carers (74%) felt that telecare equipment had reduced their stress levels (Beale et al., 2010).

What is telecare?

Telecare focuses on the social aspects for independent living. It is distinct from “telehealth”, which refers to remote monitoring of health, and “telemedicine” which involves technologies for healthcare professionals to exchange information.

A European Commission report (Cullen et al., 2009) defines three generations of telecare:

- First generation systems, including personal alarm systems and emergency response telephones, designed to reduce anxiety among older patients and reduce the use of primary healthcare services.
- Second generation telecare involves the enhancements of a basic alarm model with the addition of sensors for monitoring falls or temperature.
- Third generation telecare involves more advanced systems that gather large amounts of information from the person and home in order to support pro-active care service interventions.

A UK government green paper on the future of care stated a key objective of telecare as improving quality of life, keeping people safe in their homes and inspiring confidence (HM Government, 2009). The Scottish Telecare Development Programme also has the objectives of reducing admissions to hospital and long-stay care as well as facilitating timely hospital discharge (Beale et al., 2010).

Telecare has the potential to provide benefits for the target users, their family carers and the health and social care systems as a whole. However, it is not easy to definitively prove the benefits of telecare. Telecare is relatively under-researched and there are associated methodological problems in the existing research. There is very little work done on how telecare works in practice, *i.e.* the impact of telecare implementation on existing roles and responsibilities not just in terms of formal health and social care services, but also informal/family carers and social networks of older people. There are also ethical challenges involved, as telecare can involve surveillance and monitoring of people who are vulnerable, isolated or have diminished capacity (Delaney, 2011).

Carers and health

The ROI census data for 2006 shows that there are 160,917 carers, 18,152 of whom are over 65 years of age (11%) (Central Statistics Office, 2006). In NI, the 2001 census shows that 185,066 people provide unpaid care, of whom 12% are aged 65 or over (NISRA, 2001).

A survey of carers by the Department of Health, Social Services & Public Safety in NI showed that 18% of carers always felt under stress because of caring responsibilities. 21% were under stress very often and 30% were under stress quite often. This indicates that almost 70% of carers in NI experience stress as a result of their caring responsibilities (DHSS&PS, 2006). 26% of the respondents to the survey said that they never had breaks from caring, and over three-fifths had breaks only occasionally. Respite care or breaks from caring were the most common thing mentioned as important in supporting care giving. The 2010 NI Life and Times survey results show that 18% of people feel under pressure as a result of their caring responsibilities most of the time. 39% feel under pressure some of the time.

In ROI, 36% of carers report their health to be very good or excellent, compared to 45% of the general population (Care Alliance Ireland, 2008). This research suggests that carers are worse off in terms of self-reported health than others. Two-in-five carers reported having experienced stress/nervous tension and one-in-nine carers reported having their daily activity limited by ill-health or disability in the past twelve months. It is important to note, in this context, that the average age of carers in ROI is 74 years of age, so ill-health and disability is not necessarily linked to the caring role (Mc Gee, 2008). When family carers were asked to report negative impacts of caring on their health and well-being, nearly one-third reported that their health had suffered due to their caring responsibilities (Care Alliance Ireland, 2008).

On the other hand, a study by Carers Scotland found that people caring for 10 years or more were less likely to be in poor health than those caring for a shorter period of time. This indicates that carers can adapt to their responsibilities so as to not adversely affect their health (Carers Scotland, 2011). A study of carers of people with Parkinson's disease also indicated that stress does not build up over time and is not related to the length of time spent caring. Rather, it is based on other factors such as the intensity of care, type of condition of the person receiving care or personality of the carer (McRae et al., 2009).

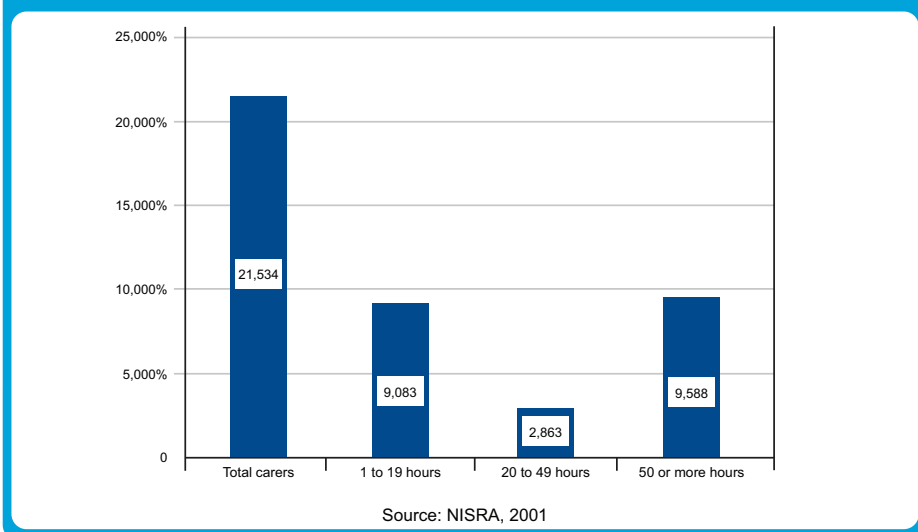
In summary telecare is most likely to benefit carers who feel under stress as a result of the work they undertake, or those who have leisure or recreational activities curtailed as a result of the time they put into caring. Isolated carers could benefit in particular, as could carers who have little or no support from friends or family.

Policy and telecare in NI

UK-wide, community alarms are provided to older people by local housing authorities and social services as well as the voluntary and private sectors. Around 1.6 million people, or 15% of the population aged 65 and over in the UK, are estimated to use social alarms (Cullen et al., 2009). In recent years, local authorities have been implementing second generation telecare services. Policy and funding initiatives have supported this, including the Preventative Technology Grant in England. The NHS Purchasing and Supply Agency also introduced a national framework agreement for purchasing telecare services in the UK in 2008 (NHS Purchasing and Supply Agency, 2008).

The strategic focus in NI, unlike in the UK, is on telehealth rather than telecare. However, Martin (2010) has pointed to the lack of an inter-agency and inter-departmental approach to the implementation of telecare in Northern Ireland, in contrast to the more coherent approach taken to telehealth. In 2008, the Minister for Health, Social Services and Public Safety announced £1.5 million for pilot projects to promote the development of new technologies to assist older people to live at home over the following two years. The European Centre for Connected Health was established at the same time by the NI Minister of Health to support improvements in patient care through the use of technology in health and social services. It focuses in particular on telehealth and remote monitoring of patients with chronic diseases (European Centre for Connected Health). Research conducted by Suzanne Martin for the NI Housing Executive viewed the lack of a telecare strategy as a significant barrier to bringing telecare into the mainstream of care for older people (Martin, 2010).

Figure 1: Carers over the age of 65 and number of hours caring per week in NI



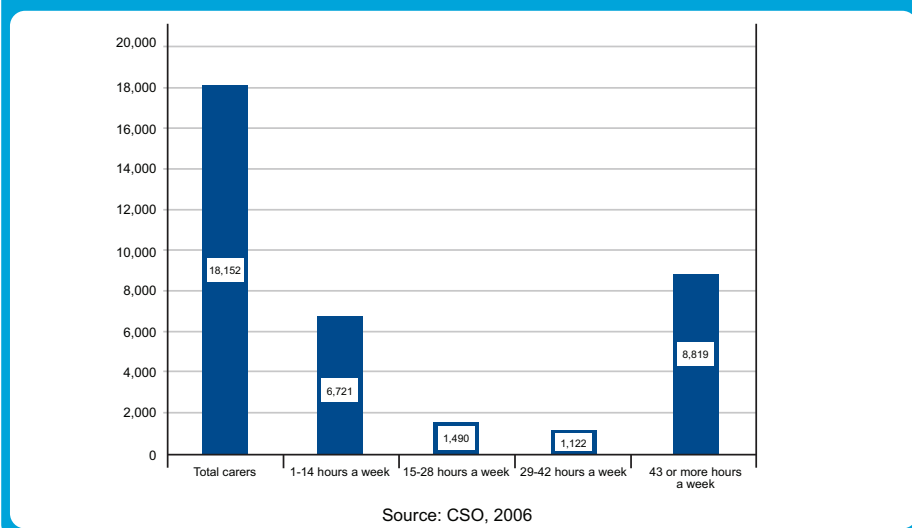
The NI strategy for carers (DHSS&PS, 2006) recommends that information technology solutions be used to keep carers informed about the latest information on caring as well as advice and tips on carrying out their role. It recognises that the health and well-being of carers is important, as is reducing the stress of caring. However, telecare is not part of the strategy.

Policy and telecare in ROI

Delaney (2011) found that a strategic approach to telecare which works across agencies and departments is similarly lacking in ROI. However, use of first generation telecare in ROI is relatively high compared to the rest of Europe (Cullen et al., 2009). The services are mainly provided by private suppliers, some of which are not-for-profit organisations.

The Seniors Alert grant scheme, introduced in May 2010 supports a monitored personal alarm, smoke and carbon monoxide detectors as well as external security lights and emergency indoor lighting. The estimated total take up is between 60,000-70,000 people, or 13-15% of the total population over the age of 65.

Figure 2: Carers over the age of 65 and number of hours caring per week in ROI



In terms of the more advanced generations of telecare, there has been very limited take up. Some private providers of alarms provide additional telecare services and there have been some pilot products conducted by not-for-profit organisations (Delaney, 2011).

At a policy level *Towards 2016*, the ROI social partnership agreement states that a key objective is the use of information and communication technology to improve the quality of life of older people and to assist them in independent living (Department of the Taoiseach, 2006). Furthermore, the Department of the Taoiseach chaired an interdepartmental group in 2008 which undertook work to develop a National Carers' Strategy. Progress on the strategy is now pending following election of a new government in February 2011.

Evidence on benefits

Telecare is relatively under-researched. It is also difficult to conduct randomised control trials as telecare has so many different technical, clinical, social and organisational elements (Delaney, 2011). However, some studies, notably in Scotland, have been conducted which provide evidence on the use of telecare.

An evaluation of four years of the Scottish Telecare Development Programme was conducted in 2010 (Beale et al., 2010). The research combined case studies, user and carer questionnaires and quarterly returns by health and social care partnerships. Overall, the study showed that savings of over £11 million had been made. 1,200 hospital admissions were avoided, with estimated durations of two to 20 days. In addition, a delayed discharge was avoided in 500 cases.

The questionnaires showed that 60% of respondents felt that their quality of life was either a bit better or much better than before their telecare equipment was installed. 35% said their quality of life had stayed the same and 5% said that it was worse. 27% felt that their health had improved while 55% said that their health had not changed. The most positive results coming from the assessment were that 93% of respondents felt safer and 70% felt more independent. 87% said that their families now worried less about them.

The carer questionnaires reveal that 46% of carers found their role quite stressful or very stressful. However, almost three quarters of carers (74%) felt that the telecare equipment in the programme had reduced their stress levels.

A national study into the benefits of telecare was published in ROI in 2011 (Graham et al., 2011). Overall, it pointed to a positive impact on service users, particularly in boosting the assurance and confidence of older people living at home. Assessments of the needs of service users were considered pivotal to the success to telecare.

Results from a major evaluation of telecare and telehealth initiatives across Europe will be available in early 2012 from the “Common Platform services for Ageing Well in Europe” (Common Well) project¹.

Family carers and telecare

Family carers are frequently the co-users or main users of telecare systems rather than the person in need of care. As a result, research into telecare which focuses on carers is similarly lacking. One recent piece of research in ROI (Keogh & Delaney, 2009) indicates that 27% of carers of dementia patients found their role much easier with the use of telecare, and 50% found their role a little easier². The research also found that while telecare benefits carers, there was little discernible benefit for dementia patients themselves.

A Carers Scotland study in 2009 found that carers had a very positive response to the installation of telecare services (Jarrold & Yeandle, 2009). The benefits described were:

- Reduced stress.
- Increased confidence about the safety and wellbeing of the person cared for.
- Having more opportunity to take a break from caring.
- Feeling better supported in the caring role.
- Improvements in the relationship with the person cared for.
- The ability to remain in paid employment.
- The study also found that the carers had access to only a limited range of telecare equipment and lacked information on what other equipment might be available.

Potential benefits of telecare

Carers who are providing significant numbers of hours of care have been identified as an at-risk group for poor health. The 2001 census in NI found that those caring for 50 hours per week or more were twice as likely to report poor health as the non-carer population and this was true across all age ranges (NISRA, 2001). Evidence from the UK shows that having a low income and having no respite breaks are major factors which contribute to poor health among carers (Carers UK, 2009).

Research indicates the benefits of telecare to carers in reducing the stress of caring and providing more respite care and increasing leisure time available. This is especially important for carers who have little or no formal support or support from family and friends and those who live in isolated areas with no network of support.

The Irish Longitudinal Study on Ageing (TILDA) found that just 3.5% of adults over the age of 50 in ROI receive state-provided home help services. People with impairments in activities of daily living (ADL) and instrumental activities of daily living (IADL) receive on average 118 hours of help per month usually from their spouse (TILDA, 2011). The amount of help given by family carers and low-levels of state support for home care indicate that there is a genuine need for support. The potential for telecare to reduce the number of hours of help given and reduce potential anxiety of carers is therefore notable. 23% of older carers in ROI do not have access to a car and 44% of family carers in ROI live in rural areas. This means they potentially face barriers in terms of physical and social isolation as well as lack of services (CSO, 2006). Telecare can provide additional support for family carers who are relatively isolated or have poor access to transport links.

² The sample size for the research was 25 respondents.

Conclusion

Technology is set to play an increasing role in how older people are cared for in our societies. It can make a positive difference to carers, contribute to affording individuals more control over their own lives, and is complementary to person-centred care (Martin, 2010).

Telecare is developing rapidly, and there are indications that uptake in Ireland, North and South, is increasing. In order to make the case for increased policy focus on telecare, there must be an evidence base which demonstrates the health benefits and cost benefits for public health systems. However, due to the complex nature of telecare, research to date has not been able to show clear health benefits to users and their carers or prove that there are additional cost benefits. The methodologies used to date have not been suitable and there have been small sample sizes. Nevertheless, more robust evidence on the benefits of telecare will soon be available, particularly through the Common Well project.

In terms of policy, Martin (2010) in examining NI and Delaney (2011) in examining ROI have identified a lack of a strategic approach which works across departments and agencies as a barrier to bringing telecare into the mainstream of caring for older people. With a strong evidence base on the benefits of telecare for older people and their carers, this strategy could be developed.

There are some indications from research that telecare can help to alleviate the stress of carers as well as giving carers more peace of mind when it comes to their loved ones, family or friends who require care. It also has the potential to provide carers with more leisure time. It is important that it is harnessed and applied in the right situations with the aims of helping older people remain independent and helping carers to best fulfil their roles.

Future research

Delaney (2011) argues that research on telecare must focus on a variety of target groups: clients; family carers; care providers and care systems. Further work is needed to clarify the role and contribution of telecare; the implications of increasing stress on family carers; and the impact on roles and responsibilities in care systems.

Among the key research actions proposed are to explore potential outcomes for service users and family carers; the impact on health and social care systems; take up and distribution of telecare; economic evaluations of telecare (cost-effectiveness, cost-benefit, etc.); and information sharing.

Network members

The members of the network for the *Assessing telecare for carers of older people* research project were:

- Brigid Barron, Caring for Carers (Principal Investigator)
- Sarah Delaney, Work Research Centre
- Assumpta Ryan, University of Ulster
- Helen Ferguson, Carers NI
- Maria Truesdale-Kennedy, University of Ulster

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References

Retrieved July 28, 2011, from European Centre for Connected Health: www.eu-cch.org

Beale, S., Truman, P., Sanderson, D., & Kruger, J. (2010). *The initial evaluation of the Scottish Telecare Development Programme*.

Care Alliance Ireland. (2008). *Health and Well-being of Family Carers in Ireland*.

Carers Scotland. (2011). *Sick, tired and caring: The impact of unpaid caring on health and long term conditions*.

Carers UK. (2009). *Policy Briefing: Facts about Carers*.

Central Statistics Office. (2006). *Census data 2006*.

Cullen, K., Kubitschke, L., & Rauhala, M. (2009). *ICT & Ageing: Users, Markets and Technologies*.

Delaney, S. et al. (2011). *Telecare research roadmap*.

Department of the Taoiseach. (2006). *Towards 2016: Ten-year framework social partnership agreement*.

DHSS&PS. (2006). *Caring for Carers: Recognising, Valuing and Supporting the Caring Role*.

DHSS&PS. (2006). *Survey of carers of older people in Northern Ireland*.

Graham, A., Lawson, B., & Bolton, D. (2011). *Home Solutions: A Study of the Application of Telecare Systems in Ireland*.

HM Government. (2009). *Shaping the future of care together*.

Jarrold, K., & Yeandle, S. (2009). "A weight off my mind": *Exploring the impact and potential benefits of telecare for unpaid carers in Scotland*.

Keogh, C., & Delaney, S. (2009). *Telecare Project: Interim evaluation results*.

Martin, S. (2010). *Research into the Future Housing and Support Needs of Older People. Electronic assistive technology – supporting older people within local communities*. Northern Ireland Housing Executive.

Mc Gee, H. e. (2008). Older People - Recipients but also providers of care: an analysis among community samples in the Republic of Ireland and Northern Ireland. *Health and Social Care in the Communities*.

McGill, P. (2010). *Illustrating ageing in Ireland, North & South*. CARDI.

McRae, C., Sherry, P., & Roper, K. (2009). *Stress and family functioning among caregivers of persons with Parkinson's disease*.

NHS Purchasing and Supply Agency. (2008). *National framework agreement for telecare*.

NISRA. (2001). *Census data 2001*.

TILDA. (2011). *Summary of Results*.

i The final report is cited as Delaney, S (2011)