



'A weight off my mind'



Exploring the impact and potential benefits
of **telecare** for unpaid carers in Scotland

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equality

empowerment

partnerships

CARERS provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

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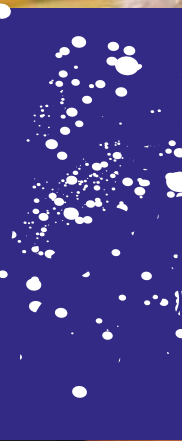
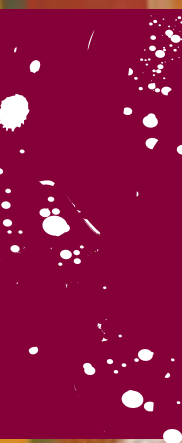
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assistance

support

advice



Executive Summary

The research for '*A Weight Off My Mind: exploring the impact and potential benefits of telecare for carers in Scotland*' was commissioned by Carers Scotland with funding from the Scottish Government's Telecare Development Programme. It was conducted in 2009 by CIRCLE (*Centre for International Research on Care, Labour and Equalities*) at the University of Leeds.

The findings reported here are based on an exploratory study which included interviews and focus groups with carers using telecare and interviews with key stakeholders involved in telecare delivery in Scotland. The report focuses specifically on carers' experiences of telecare and builds on CIRCLE's previous research. It was commissioned to strengthen the existing research on carers and telecare.

The Scottish Government, through its *Joint Improvement Team*, has made a substantial investment in developing telecare services throughout Scotland in the last few years. While other research has examined the costs and benefits of telecare for the health and social care system, this study identifies the significant benefits telecare has for carers and for their caring situation.

Telecare covers a wide range of equipment from personal pendants to complex environmental controls and is available, usually, in response to an assessment of the needs of the person being cared for. Telecare services have been developed in all 32 local partnerships in Scotland.

Main findings

All carers in the study had telecare installed in their caring situation and all reported very positive experiences of using telecare. Carers taking part all welcomed the introduction of telecare into their caring situation and identified a wide range of positive effects of telecare on their caring role and circumstances. Their confidence

in the quality of the telecare service they received was high. Most carers felt telecare had increased their own quality of life and that of the person they cared for. Key benefits included:

- Feeling more relaxed and less stressed
- Feeling more confident about the safety and wellbeing of the person they cared for
- Having more opportunity to get away from their caring situation and take a break from caring
- Feeling better supported in their caring role
- Improvements in some aspects of their relationship with the person they cared for
- For some carers, the ability to remain in paid employment

Many carers in the study nevertheless had access to a quite limited range of telecare equipment and felt they lacked information about what other equipment might be available.

Professionals involved in developing telecare provision and supplying and fitting telecare equipment identified a number of barriers to the implementation and mainstreaming of telecare in Scotland. These included a perceived lack of awareness among some health professionals about the value and availability of telecare, and the limited numbers of referrals to telecare services which arise from this.



values

strategic vision

accessibility

Conclusions

The report concludes that, given the significant benefits identified by carers in this study who had direct experience of using telecare, the following additional actions and approach would be both appropriate and timely:

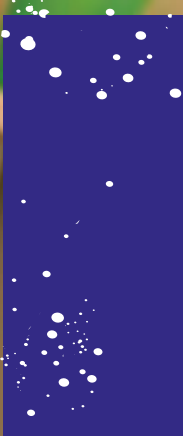
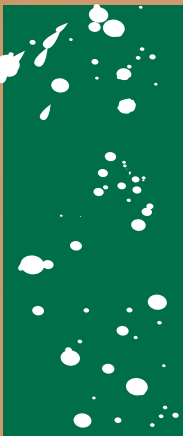
- More needs to be done to raise awareness amongst carers and professionals about the full range of telecare options.
- Information about new services and about the latest available technology needs to be provided regularly to carers.
- Charges for telecare need to be reviewed to make them more equitable and consistent throughout Scotland.
- More investment is still needed to establish telecare as a mainstream component of the health and social care system in Scotland.

It is clear from the wider scientific literature on this topic that technology will be crucial in addressing the practicalities of delivering care and support to Scotland's growing number of older, sick and disabled people, most of whom wish to remain in their own homes.

By harnessing science and technology, avoidable costs can be cut out of the health and social care system, and the incidence of common hazards which threaten personal wellbeing – falls, accidents, and inadequate management of long-term conditions, including dementia – can be reduced.

Using telecare effectively and appropriately can also enhance personal relationships and help in retaining the strong human values – dignity, respect, care, and concern – which need to remain at the heart of Scotland's approach.

The carers' perspectives on telecare highlighted in this report should add urgency to a collective commitment in Scotland to achieving the best possible outcomes for all, as major strategic decisions continue to be taken in the development and delivery of the nation's health and social care system.



1. Introduction

This report presents the findings of new research commissioned by Carers Scotland from CIRCLE (*Centre for International Research on Care, Labour and Equalities*), University of Leeds. The study seeks to provide policy makers, commissioners of services, professionals and voluntary sector agencies with additional information about carers' experiences of caring situations where telecare is in place. It aims to contribute to a greater understanding of the potential of telecare to alleviate pressures on carers, and to inform decision making about the future of care and support.

1.1 About telecare

Telecare is

*'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, using information and communication technology to trigger human responses, or shut down equipment to prevent hazards'*¹



Telecare includes a growing range of equipment, often categorised into 'first, second and third generation' telecare.

- **First generation telecare** is the equipment used in Community Alarm Systems. It has a 'user-activated' element (often a push-button pendant), which alerts a response centre where staff can make arrangements for someone, usually a carer or neighbour, to attend the person's property.
- **Second generation telecare** refers to more advanced telecare systems which use technology to monitor the home environment, lifestyle and patient vital signs. It introduces sensors and detectors into community alarm packages, typically smoke, gas, water spillage and temperature sensors, and some equipment designed to measure patient health. Sensors continuously record data about movement in the home, the use of electrical appliances, and other activities, making second generation telecare a more sophisticated mechanism for managing risk/improving users' quality of life.
- **Third generation telecare** is even more technically advanced, and uses broadband, wireless and audio-visual technology. The third generation of equipment offers the potential for virtual consultations between the patient in their own home, and a health worker or doctor elsewhere. The technology can enhance opportunities for people who are unable to leave their homes, and also has features which can help them keep in contact with family and friends via video technology.

1.2 Telecare in Scotland

Over the last few years *Carers Scotland* has been working with the Telecare Development Programme's Joint Improvement Team (part of the Scottish Government's Health Directorate) to explore options for making use of the latest developments in telecare in ways which will benefit carers as well as those they care for. The Joint Improvement Team was established in 2004 to work directly with local health and social care partnerships across Scotland. It facilitates and administers the national programme on behalf of the Board of the Telecare Development Programme (TDP). Its work is consistent with the aims of the *Strategy for Carers in Scotland* to support carers who look after sick, disabled, vulnerable or frail relatives or friends, and works towards



promoting a better delivery of support to carers – as set out in *Care 21: the future of unpaid care in Scotland*².

Developing a telecare agenda is now a key area of inter-agency focus for health and social care in Scotland. Through its Telecare Development Programme the Scottish Government has invested £16 million over

four years (2006-10) in developing telecare services, allocating resources to all health and social care partnerships in Scotland. The TDP has sought to address a number of key objectives, with the overall aim of helping more people to live at home for longer. The Joint Improvement Team outlined the role telecare is expected to play in meeting the challenges of providing care in the future, and the anticipated wider benefits it will produce for health, housing and social care in *Seizing the Opportunity*³. Supporting carers to continue caring is identified as an important aspect of this. 'A Weight off my Mind', and the exploratory study on which it is based, addresses these specific aspects of telecare policy and implementation in Scotland.

The Scottish Government's investment in telecare also aims to:

- increase awareness of telecare and its benefits
- increase the use of telecare in mainstream service provision
- improve assessment procedures for service users who might benefit
- train service providers' staff to incorporate telecare within care packages
- ensure telecare services are delivered to recognised standards
- enhance innovation in telecare services

Of particular relevance for this report, the TDP identified telecare as having the potential to reduce some of the pressures on carers and to provide them with more personal freedom⁴. The Scottish Government's investment in telecare has been welcomed by carers' organisations in Scotland, as it signals both a commitment to developing innovative ways of tackling social care issues and acknowledges the specific needs and experiences of carers. It is also an issue being considered in 2009 as part of the review of Scotland's carers' strategy, which the Scottish Government has indicated it hopes to publish in spring 2010.

unpaid care

increasing need

poor health

1.3 Profile of carers in Scotland

The 2001 Census counted 479,934 carers in Scotland, 9.6% of the population. This number is expected to rise to 1 million by 2037⁵. While the majority (59%) of carers are women, 41% of those reporting regular caring roles are men. The peak age for caring is between 50 and 64, and in this age group one in five women (19%) and one in seven men (14%) are carers, representing a third of those who provide unpaid care. It can also be noted that:



- More than half of carers in Scotland are people aged 16-49 years (32% of all carers are women, and 19% are men, of this age, as shown in Figure 1)
- Carers who care for 20 or more hours per week are more likely than other people to:
 - be in poor health
 - have a limiting long-term illness (LLTI)
 - be living in the same household as a person with a LLTI
 - live in social housing
 - have no access to a car
 - have no formal qualifications
 - (for carers of working age) not to have a paid job. (Table 1)

Among Scotland's total population of just over 5 million people (5,168,500)⁶, almost one million (978,400) live with limiting long-term illness (LLTI)⁷. Those who provide unpaid care for this large and growing group have been estimated to save the Scottish health and social care system around £7.68 billion per year⁸. As shown in Table 1, many of these carers are people combining their caring roles with paid employment. As we have reported elsewhere, almost 100,000 are men combining caring with full-time employment, and almost 80,000 carers are women in this same situation⁹. A further 68,000 Scots (almost 60,000 of them women) manage their caring role alongside a part-time job. Even among people of working age who care for 50 or more hours per week, one third of the women (34%), and well over one third of the men (39%), also have paid jobs.

Figure 1. Carers in Scotland by age and sex (%)

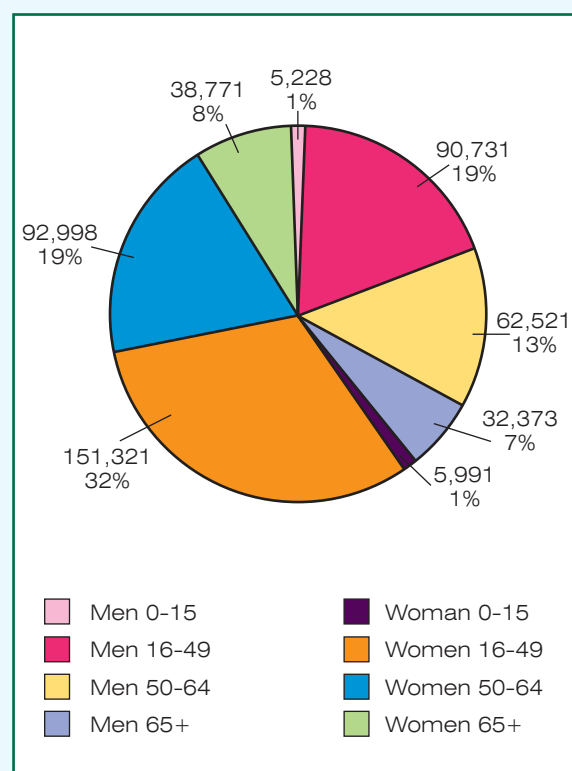


Table 1 Characteristics of carers in Scotland¹⁰ (% of all in category)

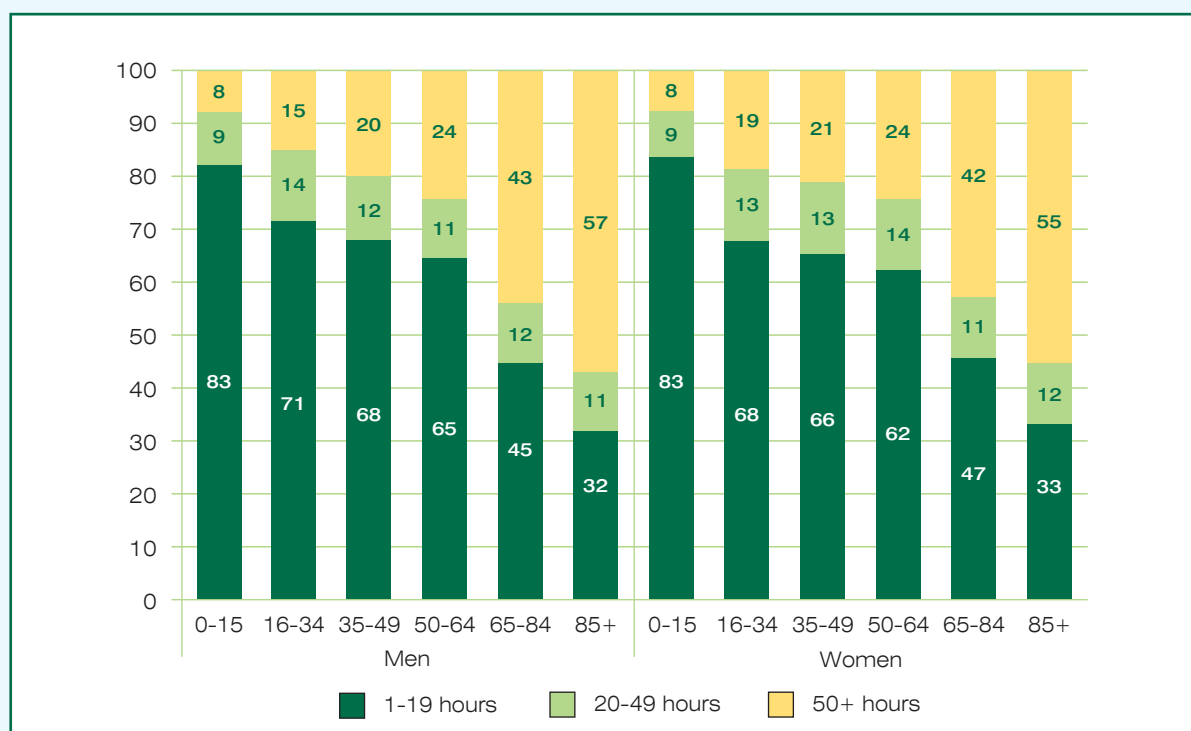
	Male non-carers*	Males caring for:			Female non-carers*	Females caring for:		
		1-19 hours	20-49 hours	50+ hours		1-19 hours	20-49 hours	50+ hours
ALL CARERS								
Carers in poor health	9	9	14	22	10	8	13	19
Carers with a LLTI	19	23	30	44	21	19	25	35
Co-resident with a person with LLTI	19	35	76	91	18	26	53	90
Social housing	23	17	35	40	26	18	33	38
No access to car	22	14	27	29	29	18	27	35
CARERS OF WORKING AGE								
No qualifications	28	24	46	49	25	21	39	50
In paid employment	73	78	58	39	67	75	55	34

Sources: 2001 Census data supplied by the General Register Office for Scotland © Crown Copyright; 2001 Census Individual SAR, Office for National Statistics (2006).

*Data in these columns are provided for comparative purposes and show the percentage of non-carers with the same characteristics.

NOTE: The data in this table relate to carers of all ages. Non-carers include some people who require care, so it is not surprising that carers providing less than 20 hours of care per week are in a similar state of health. However this table clearly shows that carers providing care more intensively are typically in poorer health than other carers / non-carers.

Figure 2. Carers in Scotland by age, sex and weekly amount of care provided.



Source (Figs 1 and 2): 2001 Census data supplied by the General Register Office for Scotland. © Crown Copyright.

care at home

sustainability

effective

Recent projections of population growth suggest that the number of people aged over 65 living in Scotland is likely to increase by 44% (493,000 people) within the next 20 years (from 1,117,000 in 2006 to 1,610,000 in 2026)¹¹. As the proportion of people aged over 65 years grows, and with it the number of people with a LLTI and / or acute health problems associated with older age, the need for care is also expected to increase. It is also estimated that by the age of 65 nearly two thirds of people will have one LLTI and that 27% of people aged 75-84



will have two or more LLTIs¹². Because in Scotland growth in the number of older people is so large compared with the projected increase in people of working age (an estimated increase of only 100,000 within the next 20 years¹³), providing care for the growing older population is likely to become problematic unless new approaches are adopted. These demographic factors, coupled with increasing and related fiscal pressures, mean that providing paid care for those

who will require it in the future merely through existing health and social care arrangements is likely to be unsustainable. It also seems certain that the unpaid care given by family, friends and neighbours will continue to be the mainstay of the social care system. How to sustain and support Scotland's carers, alleviating any avoidable pressures on them, thus needs to be a central focus of policy developments in this field.

While telecare is not a panacea and cannot provide a complete response to these challenges, a growing body of evidence suggests it can offer additional sustainability in the health and social care system¹⁴. In particular, it has been identified as effective in:

- enabling people to stay in their homes for longer
- reducing the need for acute home care
- delaying admissions to residential care
- reducing the number of unplanned hospital admissions
- reducing the number of delayed discharges from hospital

These issues are especially important as they offer cost containment in the health and social care system as well as better quality of life for clients. As this report demonstrates, increasing the effective use of telecare also has the potential to improve the quality of life and wellbeing of carers, with potential benefits across the full spectrum of health and social care recipients. The focus of this report is on the views, experiences and perspectives of unpaid carers with direct experience of telecare support.

1.4 Telecare, carers and the future of health and social care

Previous research on telecare has demonstrated that an integrated telecare service offers significant financial benefits in the health and social care system and

for those who require support¹⁵. Numerous literature reviews, local evaluation studies and assessments of costs and benefits suggest that the value of telecare is not in dispute and far outweighs any negative concerns about its intrusiveness, undermining of privacy or the loss of personal contact (aspects which can in most cases be managed through careful implementation)¹⁶. Nevertheless, the precise **extent** to which telecare offers cost and efficiency savings for the overall health and social care system, by shifting expense from hospital and residential care to care solutions at home, remains the focus of continuing investigation.

Most telecare research has focused on service users' and professionals' perspectives, and on system effects and costs. In the new exploratory study reported here, however, the researchers were asked to focus specifically on whether unpaid carers derive any benefits from having telecare available to support them in their caring roles, and to specify in more detail what those benefits might be. This particular focus was chosen as the topic was relatively undeveloped in the literature, and the study was considered to be particularly timely and relevant.

It is now well established in the social policy research literature that carers' health, financial situation and opportunities for participation in everyday life are often negatively affected by caring, especially when the caring role is very intensive or continues for a long period¹⁷. New ways of supporting carers, particularly if they address this 'trio' of financial, health and social exclusion pressures, are thus very important. With telecare becoming more widely available and making a potentially important contribution to the health and social care system, its role in meeting the needs of carers, and in reducing the pressures on them, merits further exploration. Previous research has suggested that telecare might:

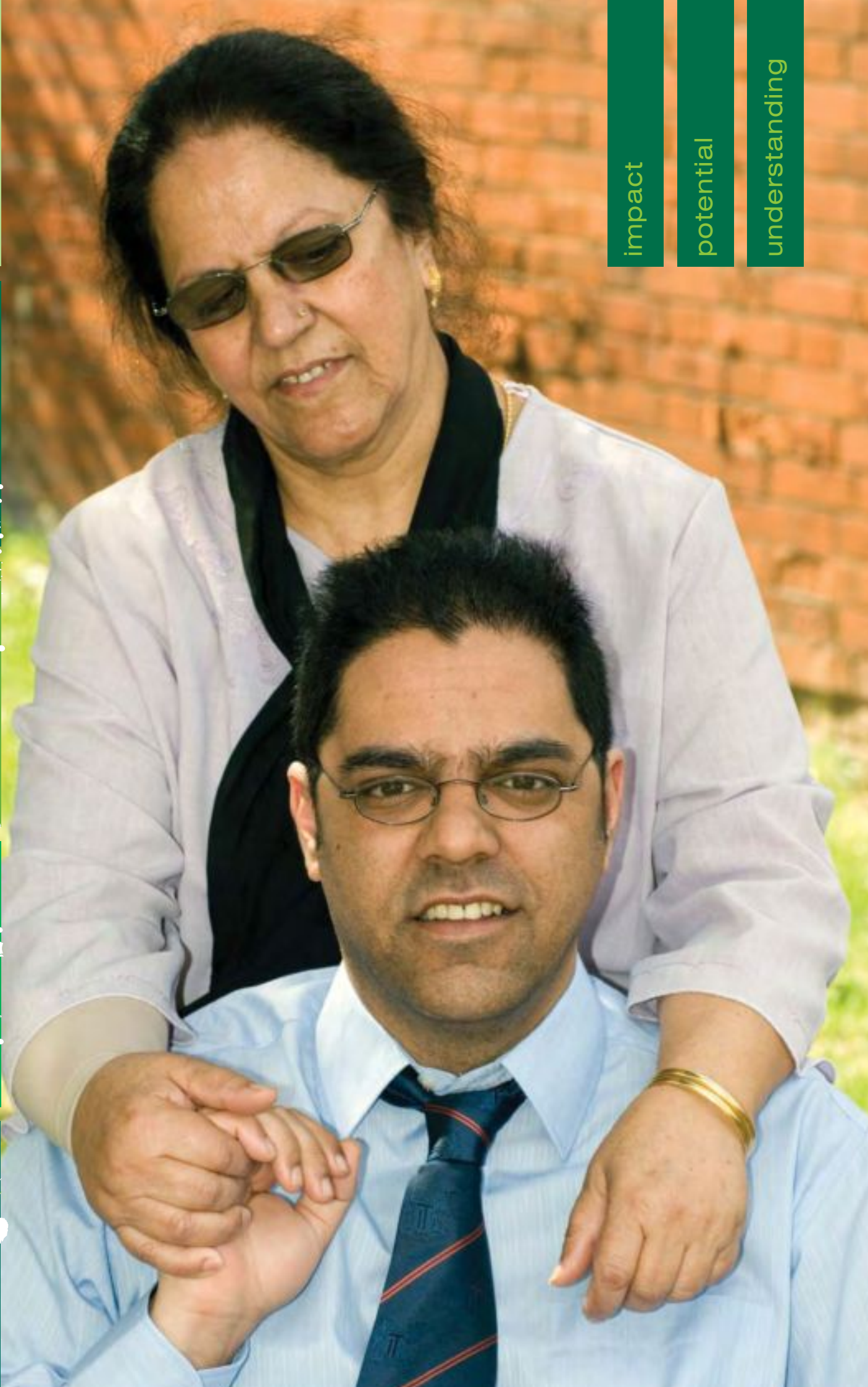
- reduce pressure on carers
- offer carers better support in their caring role



- enable carers to get a better night's sleep
- give carers peace of mind about the safety and wellbeing of the person they care for¹⁸.

This study of the experiences of carers in Scotland has investigated these claims with specific reference to the Scottish Government's commitment to promoting carers' rights and to extending the choices available to them, made explicit in recent policy developments and legislation¹⁹.

The report is organised as follows. Section two of the report describes the aims of the study and the methods used. Section three outlines current telecare developments in Scotland and considers a range of issues involved in implementing telecare. Section four represents the main body of the report and focuses on the experiences of carers who are using telecare, examining the effects of telecare as carers perceive them on their own health, wellbeing and everyday lives and on their relationship with the person they care for. It also notes their views about the impact of telecare on those they care for. In the final section of the report, we present our conclusions, based on the study findings, and make recommendations about policy implementation and development.



impact

potential

understanding

2. The study

2.1 The aims of the study

The study was designed to illuminate carers' experiences of and understandings about telecare, to highlight good practice within local partnership areas, and to explore the impact that telecare can have for a range of carers in Scotland. As already indicated, much of the current evidence about telecare relates to service users and to costs and benefits for the health and social care system. In focusing specifically on the benefits of telecare for carers, the study was informed and guided by CIRCLE's understanding of carers' circumstances, developed in a previous programme of extensive research on carers' experiences, which included research in Scotland²⁰.

The specific aims of the study were to:

- explore the impact (both positive and negative) that telecare has on carers in diverse circumstances
- identify the benefits and challenges associated with telecare for carers, and their perceptions relating to the impact of telecare on those they care for
- highlight the potential role of telecare developments in addressing challenges for carers which are posed by population ageing/improved survival rates among sick/disabled people
- develop a template for use by local partnerships, intended to assist them in implementing telecare services²¹.

2.2 Study methods

To explore the impact and potential benefits of telecare for carers in Scotland, the following methods were used:

- **Interviews and focus groups with carers**
Information was collected directly from carers with personal experience of using telecare in their own caring situation. Telephone interviews were conducted

with 30 carers, and focused on their individual caring situations and the impact that the introduction of telecare equipment had on their own lives. Three focus group discussions with carers provided an additional opportunity to explore the wider impacts and potential benefits of telecare for carers living in three different local partnership areas, and to establish some common themes emerging from carers' experiences.

- **Stakeholder perspectives** A series of informal interviews was conducted with a range of people whose professional roles gave them particular insights. Telecare Leads in a sample of local partnerships, staff involved in developing local strategies for the implementation of telecare, and a small number of representatives of telecare manufacturers provided additional information about policy and implementation issues in developing and delivering telecare in Scotland.
- **Observation** Observations were also important in clarifying specific aspects of how telecare services are delivered. The observational work was undertaken in co-operation with telecare installation teams, call handling response centres, and local partnership Telecare Leads.
- **Review of literature and documentation**
This drew upon existing sources, including academic publications, policy evaluation reports and expert presentations. It provided the wider context for our analysis of the potential benefits of telecare for carers, and an insight into current telecare initiatives and applications in Scotland. Sources consulted are listed at the end of this report.

innovation

efficiency

investment

3. The development of telecare in Scotland

3.1. Investing in telecare in Scotland

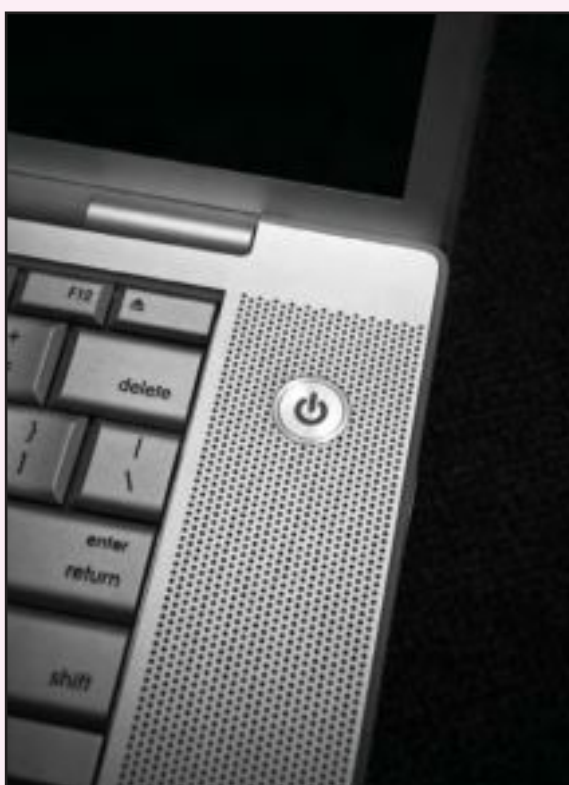
Aims of the national investment in telecare

As already noted, since 2006 the Scottish Government has invested a significant amount of money in developing a telecare agenda, providing resources for this to all 32 local partnerships in Scotland. The initial £8 million investment provided in 2006-8 through the TDP laid the foundations for many new telecare projects and investments. Many local partnerships continue to build on this investment, aiming to accelerate the adoption of telecare into mainstream care service provision, using the resources available²². The *Telecare Strategy for 2008-10* outlined the Scottish Government's plans to extend existing services to more people in Scotland by:

- enhancing innovation and telehealth/care convergence
- improving assessment processes for people who may benefit from telecare
- training staff using telecare
- increasing the awareness of telecare among carers and service users

Local partnership take-up and expenditure on telecare

In response to the Scottish Government's announcement of TDP funding, each of the Scottish local partnerships submitted a bid for funding for its own telecare project(s), based on a strategic plan in which proposed outcomes, key deliverables and the efficiency savings expected to result from TDP funding were identified²³. In allocating the available funds (using the Grant Aided Expenditure formula) to each partnership (Table 2), the Joint Improvement Team aimed to support each local partnership to develop its own tailored telecare scheme, with scope for innovative approaches responsive to the needs of local communities. Some details of how different local partnerships allocated their TDP resources are given in Boxes 1, 2 and 3²⁴.



BOX 1:

Glasgow Council

Telecare Development Programme funding allocated by the Joint Improvement Team (£911,102) has been spent on:

- Purchase of core packages for 750 service users (unit, pendant, smoke alarm, bed sensor, temperature extreme sensors)
- 150 enhanced packages (including fall, flood and gas detectors)

Table 2 Local Partnerships in Scotland: allocation of telecare funds 2006-2008

Local partnership area	Initial funding through the TDP (£s)	Local partnership area	Initial funding through the TDP (£s)
Aberdeenshire	316,248	Inverclyde	123,922
Aberdeen City	266,174	Midlothian	111,845
Angus	154,741	Moray	121,280
Argyll and Bute	141,953	North Ayrshire	131,140
Clackmannanshire	75,000	North Lanarkshire	452,127
Dumfries & Galloway	219,964	Orkney Islands	75,000
Dundee City	141,755	Perth and Kinross	190,825
East Ayrshire	181,500	Renfrewshire	241,048
East Dunbartonshire	143,260	Scottish Borders	159,932
East Lothian	82,401	Shetland	50,000
East Renfrewshire	125,176	South Ayrshire	157,400
Edinburgh (City)	565,711	South Lanarkshire	419,728
Falkirk	197,162	Stirling	122,527
Fife	485,376	West Dunbartonshire	142,429
Glasgow (City)	911,102	West Lothian	220,163
Highland	331,527	Western Isles	75,000
		Total investment in Scotland	£7,133,416

Source: Joint Improvement Team, *Summary of current and developing telecare services in Scotland, August 2007*. Available from <http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/telecare-publications/> (acc. August 2009)

BOX 2:

Moray Council

Telecare Development Programme funding allocated by the Joint Improvement Team (£121,280) has been spent on:

- Full-time project officer
- Training (including the development of a tele-learning module)
- Purchase and installation of equipment for 110 service users (at March 2008)

The funding will also enable Moray Council to develop its existing services:

- Enhancing the current Community Alarm System (additional sensors based on needs, including falls and occupancy sensors, and smoke, temperature, flood and gas sensors).
- Lifestyle monitoring of newly discharged patients by NHS staff.
- Further development of telehealth services for service users in more remote areas.

BOX 3:**South Lanarkshire Council**

Telecare Development Programme funding allocated by the Joint Improvement Team (£419,728) has been spent on:

‘Developing an ad hoc telecare service into a robust strategic infrastructure’, by:

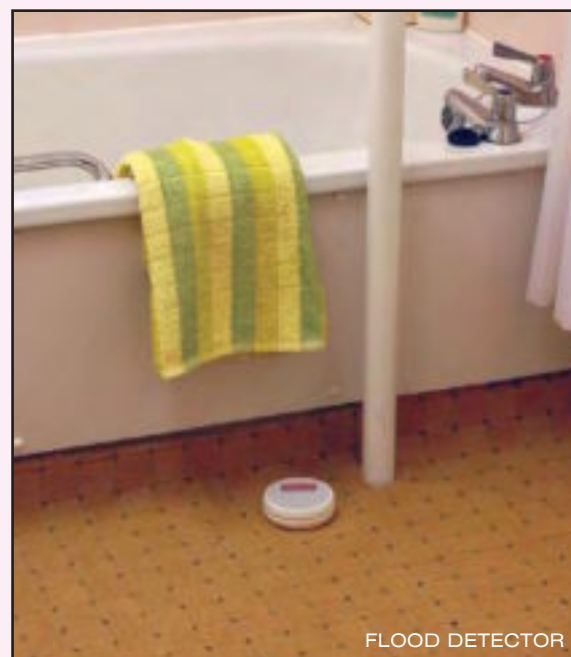
- Temporary telecare co-ordinator and telecare technician posts
- Publicity
- Training
- Additional resources for the response service
- Additional telecare equipment supplied in response to assessed need

This expenditure is providing telecare services to an additional 240 service users

Existing monitoring and evaluation of telecare in Scotland

The TDP investment in telecare in Scotland between 2006 and 2008 was evaluated by *York Health Economics Consortium* (YHEC) which published a detailed report of its findings in 2009²⁵. The evaluation looked specifically at whether the TDP had met, or was working towards, its eight key objectives, of which one was whether telecare was reducing pressure on carers. It concluded that the introduction of telecare in their caring situation had led to nearly three-quarters of all carers in the sample feeling ‘less stressed’. More recently, another report noted similar findings about carers’ responses to telecare, using case studies to illustrate the ‘transformational potential of telecare’ in improving the quality of life of service users and carers²⁶. Both these studies, using results derived from much broader investigations into telecare, indicate that carers value telecare. Here, a

primary focus on the impact and potential benefits of telecare for carers enables us to explore in further detail some of the specific ways in which having telecare in place may ease the pressures on carers, free them to lead everyday lives of their choice, and in doing so offer greater sustainability in the health and social care system.



FLOOD DETECTOR

3.2 Implementing telecare in Scotland: professionals’ perspectives

The interviews conducted with professionals enabled us to question representatives of telecare strategy organisations, telecare managers in local partnerships, representatives of telecare suppliers and manufacturers, NHS representatives with telecare responsibilities, and voluntary sector research leads about how they felt introducing telecare into health and social care provision in Scotland was affecting carers. A selection of local partnership telecare strategies, policy papers and local evaluations were also reviewed to provide more detailed understanding of implementation arrangements and issues.

3.2.1 Local partnership bids and approaches to telecare

Our analysis of documents relating to telecare schemes, projects and proposals in Scotland revealed some differences in local partnerships' approaches to developing telecare services. (See Boxes 1, 2 and 3 for examples.) Prior to receiving the TDP funding, some local partnerships had already established telecare services and these had been able to make considerable progress in delivering telecare to a wider range of recipients. By contrast others, using the TDP investment to put their initial telecare strategies in place, had suffered delays and (in a few cases) had struggled to implement a telecare service. Some of those interviewed highlighted this uneven progress in implementing telecare across the Scottish partnerships and the considerable variation in the numbers of referrals and installations achieved. For some interviewees, this situation was attributable, in part, to differences in high-level management support for telecare.



Where the support of a very senior manager was absent, they felt, the progress of the local telecare agenda had been impeded²⁷. By contrast, in those local partnerships where a strong high-level commitment to telecare was evident, impressive service improvements had been recorded. West Lothian's high-level commitment to telecare over a number of years was cited by several interviewees; this local partnership had already installed 'smart technology' in over 2000 homes before 2006²⁸. It was therefore able to use the TDP funds to build on this, further developing a fully mainstreamed service²⁹.

Several local partnerships have published annual reports on their TDP activity or have undertaken evaluations of it (usually available online) which have included monitoring the uptake of telecare in the area, collecting details of how telecare services are accessed and suggesting situations where telecare might be useful³⁰. These publications are designed to help carers and others seeking local information about telecare, and usually reflect a high-level commitment to mainstreaming telecare across a local partnership's service provision.

3.2.2 Carer engagement

The academic literature on telecare developments and implementation has often highlighted the importance of consultation with service users and other relevant parties. For example, based on interviews with 38 key informants with an interest in telecare – policymakers, clinicians, technologists, health service managers, researchers and patient advocates – Finch et al³¹ argued that priorities in this field are often 'assumed' rather than based on empirical evidence derived from service users, carers and professionals. Other writers have emphasised that if telecare services are to be developed to meet the needs of service users, policymakers need to consult all stakeholders (including carers and healthcare professionals), paying close attention to individual choice, surveillance, risk-taking and quality of service³².

In deploying the TDP resources made available to them, all local partnerships in Scotland set out new plans for a better integrated local telecare service. While raising awareness amongst professionals and service users often featured in their objectives, there is limited evidence in available documents of attention to *carers'* experiences and perspectives. Most information about local partnerships' telecare strategies and funding allocations lacks specific reference to any monitoring of carers' perspectives or of any outcomes for carers.

funding

managing

diversity



In interviews for this study, however, some representatives from local partnerships indicated that they intended to consult carers in the future, recognised the importance of raising awareness among carers, and wanted to secure carers' input to the development of future plans to mainstream telecare³³. Their stated intentions include inviting selected carers to attend local partnership telecare steering meetings and asking carers to contribute to decision-making processes. One local partnership had collected feedback from carers about the telecare service they had in place, although their responses had been used only for internal purposes.

3.2.3 Managing telecare

Our stakeholder interviews and review of available literature and documents highlighted funding, planning and 'cultural change' as key issues in the management of telecare policy. Most interviewees commented on funding arrangements, noting a lack of certainty about future funding plans (and that the TDP funding is due to end in 2010). The expectation that telecare will be mainstreamed, as an integral part of maintaining people in their own home,

has always been implicit in the Joint Improvement Team's funding commitments. Some interviewees nevertheless felt uncertain about how current telecare services would be resourced beyond 2010. They felt this situation was hindering local partnerships' ability to develop, plan and implement future telecare provision and projects. Some felt this was contributing to more general difficulties in the forward planning of health and social care budgets. Others noted local difficulties in allocating staff to key roles in developing and implementing local telecare strategy, a point also emphasised in other studies³⁴.

The challenges of implementing the 'cultural change' required to mainstream telecare, and some continuing divergence between health and social care priorities, were also cited as obstacles to developing future telecare provision. Some interviewees felt there was still some 'resistance' (within and between health and social care systems) to the development of integrated models of services for carers and service users. They felt this was inhibiting effective partnerships and could compromise the delivery of telecare services. Key points emerging from these stakeholder discussions included:

- a perceived lack of knowledge and awareness about telecare amongst health professionals, particularly GPs (seen as contributing to a lack of referrals for telecare services)
- resistance to telecare among some paid care workers (who were thought to fear telecare might reduce demand for their work, potentially threatening their jobs)
- a view that a lack of training and information about the purpose and use of telecare was holding back developments.

3.2.4 Delivering telecare

By contrast, other stakeholders involved in the delivery of telecare services were happy with current progress and with the systems in place locally to deliver telecare. In these

cases, local partnerships had set their own policies for distributing telecare equipment and identifying specific priority groups (based, for example, on need, age or condition). While some felt this may have created inequities in service provision, they nevertheless saw this approach as useful in enabling local partnerships to develop targeted and innovative schemes designed to meet local needs and to establish good practice in local delivery arrangements.

Our stakeholder interviews also highlighted differences in charging policies in different parts of Scotland. Data cited in the YEHC evaluation show, that in April 2007, 20 of the 32 local partnerships were charging for their telecare services, and that the amount charged varied considerably, even for the basic telecare package (from £1 per week to £6.50 per week³⁵). Further details of charges given in the same source also indicate variations in charging policy.

Despite the points made above, most professionals interviewed felt the emerging

infrastructure for delivering telecare in Scotland was appropriate, and that thus far the demand for telecare was manageable (a point made by several local partnership Telecare Leads). Some were nevertheless concerned that if demand for telecare increased significantly in the future, current staffing levels might not be adequate to respond to it.

3.2.5 Sustainability of telecare from the point of view of carers

All of the professional interviewees in the study felt telecare offered significant benefits to carers as well as to service users, and one Telecare Lead pointed out that, in her view, an effective social care system could 'no longer operate' without telecare. However, several felt not enough had yet been done to mainstream telecare, and that telecare was not yet secure as a sustainable aspect of the social care system. As we show in section four, carers in the study frequently commented on the major difference telecare had made to their caring role and expressed the hope that the service would be available indefinitely in their caring situation. Carers often felt telecare had made an enormous difference to their personal caring situation as these three examples show:

*I don't know how I would cope now
(without the alarm)*

It's given me more freedom.

*(Telecare) makes a difference.
It means that you're not on your own.*

Comments such as these make the positive difference telecare can bring to a caring situation, in both the short and the longer term, readily evident. The carers in this study were extremely keen to emphasise that they valued, and in some cases relied on, telecare in their personal caring situation. In the next section we explore their perspectives and experiences.



4 Carers' experiences of telecare

As we have emphasised, the perspectives of carers using telecare technology in their caring situation are the main focus of this exploratory study. The themes and issues discussed below emerged from our analysis of both the telephone interviews and the focus group discussions which were carried out with carers. The data collected in this section was collected between April and August 2009.

4.1 Characteristics of carers in the study

Carers were approached to take part in the study in a variety of ways: through Telecare Leads in Scottish local partnerships, via Carers Scotland, by approaching selected carers' centres, and through contacts with a number of social work departments. While this proved to be a time consuming aspect of the study (see Appendix A), it nevertheless yielded a sample of 30 interviews as well as 13 focus group participants. The approach produced a sample which included carers in a good range of caring

circumstances, although it was not designed to be representative of all carers in Scotland receiving a telecare service.

The 43 carers in the study lived in different local partnership areas in Scotland, representing a mixture of geographical locations (Table 3). Some lived in rural areas (e.g. Argyll and Bute) while others lived in urban areas and cities (e.g. Aberdeen, West Lothian). Most carers were women (n=38), and over half (n=23) were caring for a parent or parent-in-law (Table 4). However, some were carers of their spouse or partner or of a daughter. Just over half of the carers lived in the same household as the person they cared for (n=23).

Almost half of the carers in the study were currently in paid employment (n=18); of these, over half worked full-time hours alongside their caring responsibilities (n=10). As we saw above, combining care and paid employment is a common experience among carers in Scotland, and the study's evidence about this group is particularly noteworthy as many studies of carers draw



Table 3 Carers in the study, by location in Scotland

Local partnership area		Local partnership area	
Argyll and Bute	11	Inverness	1
Aberdeen	8	Moray	6
Ayrshire	3	Renfrewshire	3
Clackmannanshire	1	Stirling	1
Edinburgh	1	West Dunbartonshire	1
Falkirk	2	West Lothian	4
Glasgow	1	Total number of carers	43

Source: CIRCLE, study of carers using telecare in Scotland, 2009

primarily on those in full-time caring roles. Most of the carers who were not in paid employment identified themselves as full time carers (n=21). On average, the carers had been caring for the person they supported for 9.5 years (ranging across our sample from 6 months to 37 years)³⁶.

used equipment for longer than the average were referring to community alarm systems (with personal pendant). This equipment has been established in all parts of Scotland for a number of years, and is offered almost universally in Scotland as part of mainstream social and community care.

Table 4 Carers in the study, by relationship to person cared for

Relationship to person cared for		Relationship to person cared for	
Parent or parent-in-law	23	Other relative	2
Husband	12	Wife	1
Daughter	3	Grandson	1
		Total number of carers	43

Source: CIRCLE, study of carers using telecare in Scotland, 2009

Our sample thus over-represents female carers (who as shown above constitute 59 per cent of Scotland's working age carers), but otherwise offers a reasonable spread of caring situations in relation to employment status and the relationship to the person cared for.

Many carers in the sample had in place a rather limited range of telecare equipment. On average, they were caring for someone using two items of telecare equipment (ranging from one piece of equipment in 19 cases to eight pieces in one case). The most common telecare item in use was the personal pendant (n=28), but a large minority had other items in place, such as property exit sensors (n=13) and bed occupancy sensors (n=9). Other types of equipment included flood detectors, CO2 detectors, activity monitors and epilepsy sensors. As we show later, carers in the study did not feel they were especially well informed about additional telecare equipment, or other options which might be appropriate for them. However in some cases, personal choice (their own or that of the person they cared for) may have played a part in this.

The length of time the telecare equipment had been installed varied from 1 month to 10 years, with the average period of telecare use being 2.5 years. Most carers who had

4.2 Practical issues for carers

4.2.1 Information and access to telecare

All carers in the study had had some involvement in the decision to have telecare installed. Most referrals to telecare services had come from local social services and social workers (n=17) or from health professionals (usually occupational therapists [n=8] or community nurses [n=5]). A few carers had previous links with social services (as employees n=2) and knew about telecare, or had found out about telecare through their own research (n=3). However, most carers had not been aware of telecare before being introduced to the concept by a professional. Very few carers mentioned referrals directly through GPs (n=2) or as a result of a stay in hospital (n=2). This is consistent with some of the professionals' views that more could be done to increase awareness of telecare amongst health care professionals. One carer had initially received advice about telecare from a local carers' centre.

choice

reassurance

satisfaction

4.2.2 Satisfaction with telecare

Carers had a high opinion of the telecare equipment that had been installed, and few reported major problems; when they did have difficulties these problems had been easily rectifiable (battery bleeping or wrong initial settings). Most carers were satisfied with the type and amount of equipment they had in place; none claimed they required more support from telecare services or that any equipment they needed was unavailable to them. What did emerge, however, was a general lack of awareness amongst carers about whether other types of telecare equipment were available and how any additional equipment might benefit their caring situation. When asked about this, some carers indicated that they lacked information about new telecare services or recent developments in telecare. They were unsure about what was available, and some of those with more complex systems noted that other carers might not be receiving the same telecare support as they were.



Carers in the study welcomed the introduction of telecare into their caring situation, often describing the relief which accompanied a referral to telecare services and the installation of the equipment. One carer said:

It was required by that time, it took a weight off my mind.

Another claimed:

We were at the point where we needed more home care. I was totally stressed out. But once we got telecare it made a massive difference, it relieved a lot of pressure.

4.2.3 Installation of telecare

None of the carers had experienced any adverse disruption during the installation of the equipment, and the majority had been present when the equipment was installed. These carers all felt the equipment had been adequately explained to them by the installation professional. This stage was regarded as reassuring to the carers, who felt this was particularly important when the person they cared for had a condition such as dementia, which often meant they could not themselves fully understand (or remember) how to use the equipment.

4.2.4 Cost of telecare

Carers reported paying different fees and charges to cover (or contribute to) the cost of telecare. However, none of the carers in the study reported having to pay costs to install telecare. Although charges for home-based health and social care services in Scotland are regulated by COSLA³⁷ guidance, the charges applicable to telecare services are largely discretionary and different interpretations of the guidance by local partnerships have resulted in variable charging arrangements with respect to telecare services³⁸. At least 23 of the carers

reported that there was a charge payable to the telecare provider for the ongoing running cost of the equipment they used, paid either by themselves or by the person they cared for. However other carers in the sample (including some from the same local partnership) were receiving the same (or similar) services at no charge. The charges for telecare in the study ranged from £1.25 per week to £6.50 per week (for one item and five items of telecare respectively). However, differences in charging were not always associated with the type and amount of equipment installed. Charges seemed to be applied variably in respect of the same type of equipment; for example, the charge for personal pendants ranged from £5 per month to £16 per month. One carer caring for someone with eight different pieces of telecare equipment was receiving this whole service free of charge. A few carers had initially received telecare as part of a local initiative or a pilot scheme (n=2) but had found that costs were introduced at a later stage. Charges payable for telecare were typically paid either from benefits or direct payments received by the person cared for (n=5), or by the carer themselves, from personal funds (n=14).

Most carers considered the charge made for telecare to be fair and reasonable for the service they received, although many were surprised that some had to pay but others did not. They felt the service was proportionate to the price they paid, and felt it was worth it for 'peace of mind'. Comments included:

It's definitely a fair cost, excellent value for money.

Yes, it's very fair; I would be prepared to pay more in fact. The service is so invaluable.

A few carers did not share this view, however, and felt telecare ought to be made cheaper or free. The carers who wanted free telecare were often concerned



generally about the financial hardship some carers face. A few carers expressed anxieties about the possibility of charges for telecare increasing in the future. One stated:

To be honest, I probably wouldn't be able to afford it. We're on a very tight budget already, it would be really difficult.

Another pointed out that increasing the cost of telecare for those on a limited budget might disadvantage those who really benefit from it:

...it went up a lot all of a sudden and I thought, "I'm going to have to get rid of this." But I spoke to my mum, and she said she wanted it because she felt better having it there, so I decided to keep it.

peace of mind

confidence

reliability

4.2.5 Concerns about telecare

Notwithstanding the issues with costs, carers were (as mentioned before) generally very satisfied with the telecare equipment they were using. The majority were sure telecare had made an entirely positive contribution to their caring situation. A small number indicated that they had initially felt concerned that the equipment might be intrusive, but said their fears had been dispelled once they began using it.

Where concerns about telecare were expressed, they mainly related to the condition of the person cared for, and that person's ability to use the equipment. One carer claimed:

I was concerned about my husband who has dementia and whether he would trigger it when it was not needed.

Even in these cases, however, carers tended to add that they felt the benefits of telecare in their situation outweighed any concerns. One carer emphasised that

telecare had been of benefit not only to herself and to her mother for whom she cared, but also to others affected by her mother's care needs:

Before (the property exit sensor was installed), the neighbours would call me in the middle of the night if they saw my mother wandering... there was a certain amount of pressure and concern when it was like this.

4.3. Impact of telecare on carers' lives

4.3.1 Impact on carers' health and wellbeing

Given the positive experience of telecare reported in the study, it was important for the researchers to investigate how having telecare in place was affecting carers' everyday lives, health and wellbeing. The growing evidence base about carers' circumstances has confirmed a strong



relationship, especially for carers of working age, between caring intensively and/or over a long time and poor health³⁹. Carers' health often suffers when caring roles are demanding or sustained for long periods, through the physical, emotional and mental demands which caring can involve, especially in the absence of other support. The beneficial impact of telecare most often cited was that it offered the carer 'peace of mind' about the wellbeing and safety of the person they cared for. This reassurance enabled one carer to feel better able to care:

It (telecare) gives you peace of mind, and feeling fine, mentally, is a great help when you're caring.

Other carers had felt more confident about the person they cared for since having telecare in place:

I'm less worried about him falling.

Carers' confidence in the reliability and effective delivery of telecare services was high. Most carers said they felt sure that they, another named contact, or the emergency services would be alerted promptly if necessary. The only carers who did not seem certain about the reliability of the response service were those with no experience of needing to use the response alert – although even in this group, no-one appeared overly concerned about whether it would work as it should.

The perception that telecare support was dependable and reliable contributed to the overall benefits for carers. It left all carers in the study feeling reassured about the safety of the person they cared for, and consequently less worried when they were not with them. Many carers reported feeling 'less stressed', 'less anxious' and 'less tired', citing these as the main differences telecare had made to their health and wellbeing. Although generally carers did not report feeling healthier since the installation of telecare, it seems reasonable to conclude that reduced stress, anxiety

and fatigue were probably making a difference to their general health. To carers in the study, the benefits of having the equipment in place also meant they felt better able to deal with the responsibilities involved in caring. A few went further, identifying telecare as a 'life saver' which had come along at just the right time:

...I was on the verge of a breakdown before we got this help.



It is nonetheless worth noting that a few carers who valued telecare nevertheless criticised the time it had taken to receive the help they needed to manage their caring situation:

If I'd had the opportunity to have the equipment (earlier), it would've stopped me having a breakdown or my daughter having to go into care. It was too late by the time it came. (Caring) really has an impact on a carer's health... putting (telecare) in place at the right time would help carers so much.

flexible

freedom

less stressed

Overall, carers identified many positive impacts of telecare. Since having the equipment installed, almost all felt more confident, better supported and more reassured in their caring role. Most had a high degree of confidence in service delivery and in the reliability of the telecare equipment. This meant that some carers were able to take a break away from caring – even just to go to the shop – whilst feeling confident that they would be alerted in an emergency. This was noted by a few carers:

Telecare has given me more freedom. I don't have to worry so much about leaving to go to the shops.

Another carer noted:

I can sleep easier and work easier knowing that a call-out will happen if something is wrong.



4.3.2 Carers' ability to combine paid work with care

For some, telecare was particularly significant as it made a real contribution to their ability to participate in paid employment and maintain their family's financial stability. The eighteen carers in the study who had both paid work and caring roles said they felt telecare had impacted positively on their



PERSONAL ALARM

ability to engage in paid employment. Some of these carers emphasised feeling less tired, and reported that they no longer felt they were constantly 'on call' whilst at work. Telecare had enabled a few carers to remain in a job they might otherwise have had to give up, and (in one case) to gain employment. One explained:

...telecare has enabled me to maintain the hours that I work. It is difficult to get care workers who can cope with the level of care that my husband requires.

Another carer explained that having telecare support made it easier to work:

At the time it helped, when I worked, because it stopped me worrying so much when I was there.

There were also impacts on carers' free time and on their ability to take a break from caring. While many emphasised that telecare provided welcome support in their

caring situation, and was not a replacement for the care they gave, some benefited from telecare by being able to spend at least some time on their own – even if only within their own home. One explained:

It has allowed me to do more things at home, like crafts and reading a book. Before I would have to be constantly aware of my husband, it really invaded my own time.

Others benefited from simply having an uninterrupted sleep and being able to relax more. As one carer pointed out:

When you have a vulnerable person to care for in your house, it feels like you're on duty 24/7. So, it was wonderful, it allowed me to relax, gave me chill out time. I wasn't on alert throughout the night.



Others said they could now engage in activities without constant worry:

We are more active in the evenings or at weekends now; we know we will get contacted in an emergency.



CARBON DIOXIDE DETECTOR

Some carers in the study emphasised that they really welcomed the change telecare had made to their lifestyles and reported that it had given them free time they did not have before. Having telecare in place alleviated some of the stress associated with being away from the person they cared for. These benefits were particularly underscored by carers who lived in a different household from the person they cared for. However, even with telecare support, some co-resident carers in particularly intensive or demanding caring situations did not feel comfortable leaving the person they cared for alone, even for quite short periods of time.

4.3.3 Relationships with telecare service providers

Some evidence in the study suggested that carers' relationships with service providers, including health and social care staff, had also benefited from having telecare installed, although this was not an issue raised unprompted in the individual carer interviews. Many carers simply felt better 'supported' in their caring role by having telecare equipment in place in their caring role. One carer explained:

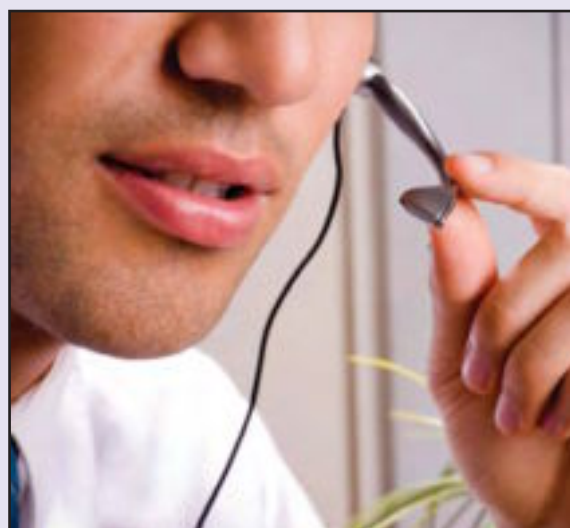
relationships

improvements

independence

It makes a difference that you're not on your own and that you can get in touch with someone if you need to.

Most carers reiterated this, and the majority felt that telecare personnel (including installation staff and call handling staff) were supportive, approachable and helpful. One carer described a very positive relationship with call handling staff, who frequently received call alarms from her mother (often up to 20 times a day). She felt their response demonstrated an understanding and approachable attitude. For her, this 'personal touch' contributed a great deal to her positive experience of telecare, and she also felt that her mother, despite frequently calling the response centre unnecessarily as a result of her dementia, was treated with respect and dignity. A few carers also reported direct contact with telecare managers/co-ordinators, indicating that, in some areas, a personalised telecare service was being offered, an aspect particularly appreciated by carers in the study.



4.4 Impact on caring

4.4.1 Relationship with person cared for

A few carers specifically noted that the introduction of telecare had had a beneficial impact on their relationship with the person they cared for.

The benefits that Andrew identified for both

BOX 4:

The benefits of telecare in a personal caring relationship: Andrew

Andrew has been caring for his wife, who has a debilitating progressive condition, for over twenty years. Recently, Andrew and his wife had benefited from the installation of a type of telecare equipment known as 'environmental controls'⁴¹. As a result, Andrew noted that there had been significant improvements in his relationship with his wife and he explained that this was because the equipment made it possible for her to become more independent.

As a result of the installation of this type of telecare equipment, Andrew's wife had regained control over some aspects of everyday life at home (for example, changing the television channel, and turning the lights on and off). Andrew was pleased that this had helped restore some of her personal autonomy, enabling his wife once again to do things which previously he had needed to do for her.

Andrew strongly believed that even small changes of this type had a significant impact on the wellbeing of them both. He commented that the equipment had the unexpected benefit of reducing dependency and the tensions associated with this, which had enhanced the quality of life for them both and removed some of the small irritations in life which could sometimes lead to stress or conflict.

himself and his wife were echoed in another similar case:

(Our relationship has) majorly improved. It's much less stressful ... it's on more of an even keel now.

My husband feels much less disabled than he did, and it relieves the pressure on us as a couple. It's been positive for our relationship.

Another carer noted a similar positive impact:

It's better. It's given him some independence back, because he doesn't have to rely on me as much.

The benefit of telecare in reducing some of the day-to-day demands of a caring role was clear. The additional positive impact on the caring relationship was highlighted by many of the carers, who emphasised specific advantages for each person as well as improvements in their everyday interactions and in the emotional aspects of their relationship. This finding, which has not been particularly noted in other studies, is especially important, as it is likely to affect not only individual wellbeing, but also the sustainability of caring relationships in demanding long-term care situations. Even a simple reduction in the number of times they needed to make checks, or to perform common household tasks, was experienced as an improvement in quality of life.

4.4.2 Caring roles and responsibilities

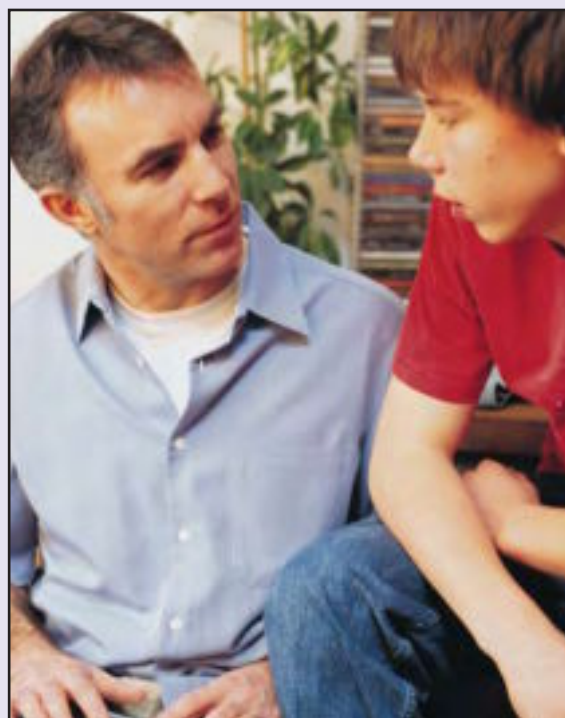
Most carers in the study felt that telecare equipment complemented their caring role, rather than reduced or replaced any caring tasks. Carers regarded the main benefits of telecare as providing added support and relieving some of the worry and stress of caring. A perception that telecare will replace or 'de-humanise' care has nevertheless often been highlighted as a possible concern of carers (and paid workers)⁴².

While this study in no way contradicts the view that telecare cannot replace the personal aspects of caring, it does confirm that telecare can help make demanding caring roles more manageable for some carers⁴³. As one explained:

My caring role is the same, but it is just easier and more manageable now. It is not a replacement for a carer, but it does replace the running up and down I had to do, to constantly check he was all right.

As noted here, most of the personal care tasks carers undertake cannot be replaced by telecare (and most would not want them to be). However the unremitting pressure on some carers (sometimes described by carers as a 'burden') can be reduced, because telecare can alert them, or others who need to know, when there is a problem. This impact on carers is a key advantage of telecare and of significant benefit to them.

Reassurance that an appropriate person or agency (as well as the carer), would be contacted in the event of an emergency seemed to have the greatest impact on



prevention

reassurance

breaks

carers. Some carers noted that previously they felt constantly 'on call' or 'on watch', to ensure the person they cared for was safe and comfortable. This often resulted in carers having to stay at home, or very close to home, in order to be available at very short notice. Having telecare in place, however, meant that, for one family, more time could be spent together on enjoyable family activities:

One of our family would usually have to be on 'granny watch' at all times in the evenings and weekends, but now we can go about our normal lives, knowing that we will get called if there is a problem.

This 'freedom' to have 'a life of one's own' was not achieved in all cases, and a few carers in this study emphasised that no amount of telecare could replace any aspect of the care they provided. In some cases this was because the person they supported had complex health needs or because they

did not feel comfortable leaving the person they cared for alone. These carers still valued the benefits of telecare, but indicated that providing 24/7 care was still necessary or a personal choice they made.

In some of the cases in this study, telecare was not intended to replace any caring tasks or responsibilities, but was put in place to offer safety, reassurance and peace of mind to the person requiring it. Thus fall detectors had been provided to some people because they were worried about the possibility of falling in the future, rather than to avoid entry to residential care or because they had fallen previously. Not surprisingly, few carers drew attention to the preventative aspects of telecare technology, although these are now a well-established benefit of installing some types of telecare. As reported elsewhere⁴⁴, falls in older people, which often cause a broken hip or thigh, are a major cause of seriously impaired mobility and admission to long-term care. While delays in attending an older person who has fallen increase these



risks, in Scotland West Lothian attributes much of its success in cutting average response times when a person has fallen (to 22 minutes, compared with the Scottish average of 4 hours) to its use of telecare⁴⁵. The benefits of anticipatory or preventative care have been acknowledged by the Scottish Government in recent reports. In *Better Health, Better Care* the Government announced a direct commitment to identifying new ways of preventing health problems before they develop, and evidently telecare could play a major part in achieving this⁴⁶.

4.4.3 Time spent caring

Most carers in this study did not feel the amount of time they spent caring was reduced significantly by having telecare in place. As already noted, telecare makes most impact by reducing the need for carers to repeatedly check on the person they care for, rather than by replacing caring tasks. However few caring situations are static, and one carer noted that even though telecare was now in place, the progression of her relative's illness meant she was spending more time caring than before. The changes and transitions in most care situations make estimating the impact of telecare on carers' time use particularly problematic, as 'before and after' studies cannot measure this aspect unless the need for care and support is stable and constant. This is rarely the case, as another carer, looking after someone with dementia, noted:

The pill dispenser was a great help, I didn't have to go round twice a day just to check she'd taken her medicine. However, I was getting disturbed a lot more in the night towards the end, with her setting off alarms and having to attend - usually for nothing.

This carer was grateful for the reassurance she had that, in a real emergency, she would be contacted.



Our study also suggests that telecare may be a valued support for those who are less confident about their caring situation or role. Examples here would include a carer who is reluctant to leave the cared for person with someone else, or who feels others providing occasional support are daunted by the responsibility or tasks which might arise. One mother who had been caring for her daughter for sixteen years felt telecare had enabled her, finally, to delegate some of her caring tasks:

Relatives and other family members can now come and care - and they feel more comfortable doing so with the telecare equipment in place.

In general, however, telecare seemed to have had relatively little impact on the amount of time carers spent caring. It was the benefits of having telecare, such as sleeping better and feeling less stressed, which caused the overwhelming majority of carers to say that telecare had helped them to continue caring.

4.4.4 Use of paid care and services

In the cases considered in this study, having telecare in place had not reduced the amount of support carers received (or needed) from paid home care support and

safety

wellbeing

confidence

services. Where home care was already in place, none of the carers we spoke with reported that this service had been reduced or removed as a result of telecare being installed. Carers saw telecare and homecare support as two very different forms of support, with quite different benefits. Homecare often gave carers a break from the physical tasks of caring, whereas telecare offered continuous support through reassurance about the person's safety, health and wellbeing. Carers who had support from home care workers did not report any problems for these workers linked to the telecare equipment. One carer noted that the telecare equipment 'enhanced' the role of homecare workers, as they also felt more reassured about the safety of the person when they were looking after them in their house⁴⁷.

It is important to note that people require different degrees and types of care to support them in their homes because of differences in their individual circumstances and needs. Telecare equipment is highly flexible; it can be used as individual pieces of 'stand alone' equipment or as part of a more complex or tailored combination of support designed to suit the specific needs of the person cared for and of those

providing care. For this reason it can be used flexibly alongside paid and unpaid care, and to enhance rather than replace contact with carers.

4.5 Impact of telecare on the person cared for

4.5.1 The perspectives of the person being cared for

A few carers noted that initially the person they cared for had expressed some concerns about telecare. Some carers gave examples where the person they cared for had at first found the idea 'daunting', or recalled that when telecare was first suggested they 'didn't think they needed it' or were concerned that it might not work properly. Like the concerns of carers themselves, these fears and concerns had typically been dispelled once telecare was in place and they started to use it. There was only one example in the study of a person requiring care reporting that they felt they were being 'watched' by the equipment; however this person was also very uncomfortable with people coming into the house to care for them, suggesting this may not have been a specific reaction to telecare. Such feelings were rare, however. Most carers in the study said the person they cared for had welcomed the introduction of telecare and was actively benefiting from using the telecare equipment.

4.5.2 Impact on their safety, health and wellbeing

Carers were able to identify many positive benefits of telecare for those they cared for. As indicated above, telecare also has important preventative benefits which carers themselves may not always appreciate or highlight. In this study, those supporting someone with dementia (or a similar condition) sometimes pointed out that the person they cared for was not fully able to conceptualise the purpose of telecare and as a result could not actively consent to (or



oppose) its introduction. This meant it was difficult for these carers to comment on changes in the cared for person's feelings.

Where carers were caring for people with other conditions, the consensus was that the cared for person usually felt safer, more confident and more independent once the telecare had been installed. Some carers believed telecare had enabled the person they cared for to remain in their own home for longer and had reduced the need for residential care. For others, telecare had given those they cared for more dignity and privacy. One carer explained:

My husband hated the feeling that someone always had to keep checking up on him when the home carers were in. Now he has more privacy, and they only have to check on him when the alarm goes off.

In this case, telecare had improved the quality of life for the person cared for. However, for those with conditions like dementia, which tend to progress despite telecare being in place, the benefits of telecare when the condition was very advanced were less obvious to care users. One carer pointed out:

Telecare only works at certain degrees of illness. It can become a hindrance when the condition gets worse; the voices used to confuse her and the equipment was less use.

Regardless of whether the person cared for could understand the purpose of the equipment or acknowledge any advantages of it, it was evident that in most cases telecare had major benefits for their safety. This was particularly evident for people with dementia who were sometimes reported to be leaving the house at night in circumstances which exposed them to great risk. Although there remains a clear understanding that telecare needs to preserve individual choice as well as to

monitor vulnerability and reduce risk, one carer explained that having this type of support had helped alleviate concern and protected her father from considerable harm:

It was a life-saver really. Before, dad had been escaping from the house regularly and the police, as well as the neighbours, would be out looking for him. Once he was found at a busy junction.

The other concerns carers mentioned about the introduction of telecare into situations where they were caring for someone with dementia, were two-fold; either they felt that the person they cared for would not use the personal alarm because they did not know what it was, or they feared they would use it excessively because of this. In reality very few of the carers had actually experienced either of these scenarios.

In sum, carers identified many benefits that telecare provided for themselves and those they cared for. Most carers reiterated that they would find their caring situation much more difficult if telecare were to be removed.



knowledge

opportunities

solutions



5. Conclusions and Recommendations

This report on the impact of telecare on carers shows that many carers experienced a positive benefit when telecare was introduced into their caring situation. The key messages to emerge about carers' experiences from this exploratory study are:

- 100% of carers in the study reported a positive experience of telecare
- Carers identified a range of benefits that telecare had in their caring situation:
 - fears about the possibly intrusive nature of telecare were allayed when telecare was used
 - more peace of mind
 - less stress and worry
 - a better night's sleep
 - the ability to retain paid employment
 - more opportunity to have a break away from caring
 - feeling better supported in their caring role
 - the potential to reduce some caring tasks
 - more confidence in the safety and wellbeing of the person cared for
 - an improvement in their relationship with the person they cared for
 - positive impacts on the person they cared for's safety, health and wellbeing and personal autonomy
- Carers have access to a fairly limited range of telecare equipment
- Carers pay different amounts for similar telecare equipment
- Carers appreciate direct contact with telecare lead officers and support from call handling staff
- Carers are very confident in the reliability of the equipment and that they would be contacted in an emergency
- Carers feel faster referrals to telecare services and enhancement of the equipment supplied would benefit those with dementia
- Even when telecare is in place, carers often continue to need home care services to support them in their caring role
- Telecare is not a replacement for the personal care provided by carers, but does make caring much more manageable for them.

From the perspective of telecare policy and implementation, it is thus critical to note the very high levels of carer satisfaction with the telecare services they received. However, some issues were raised by carers about their experiences. Here the key points to note include:

- Carers' knowledge about the types of telecare equipment available is low



5.1 Recommendations for policymakers

This exploratory study has identified clear benefits of telecare for health and social care systems, for service users and for carers. Its focus on carers, and their experiences of telecare, highlights specific issues which will need to be addressed if telecare is to fully benefit carers in Scotland.

- Steps need to be taken to raise the general awareness of telecare amongst carers in Scotland, both at a national strategy level and locally.
- More needs to be done to ensure that carers have access to appropriate information to enable ease of access to telecare services.
- Regular information and updates should be provided to carers about new or improved telecare developments or other types of equipment. (This could be delivered through a range of channels including local press, GP surgeries, health and social care facilities, libraries and local and national carers organisations.)
- More needs to be done to raise awareness of telecare and its benefits for carers amongst health and social care staff and employers. GPs, social workers, hospital staff and human resources professionals should be targeted to ensure help gets to carers at the most appropriate time.
- Carer awareness training should be widely available to health and social care staff, including GPs, social workers and nurses.
- For telecare to benefit more carers, and to improve efficiency in the health and social care system, new ways of identifying carers whose situation would benefit from telecare need to be developed.
- Telecare needs to become an integral part of community care and carer assessments. Consideration of telecare as an option should be integrated into



assessment protocols, including Single Shared Assessment protocols.

- Review and reassessment of individual telecare services should be provided to carers and those they support on demand. Periodic reviews, at regular intervals, should be used to ensure that telecare equipment remains appropriate and that service users benefit from enhancements and upgrades as soon as possible.
- Carers' organisations and other voluntary agencies should be supported to promote telecare to carers.
- Charging arrangements for telecare should be more transparent and equitable. Increasing the costs of telecare could disadvantage some carers who cannot afford it, although it is evident from this study that some carers willingly pay current charges, which they consider reasonable.

Conclusion

As the risks to the wellbeing of older, sick and disabled people and their carers in the future become better understood and more widely acknowledged, the scale, importance and urgency of the potential crisis facing health and social care systems is becoming very clear. As noted elsewhere, in addition to the pressures on carers, there are also significant risks to employers, businesses and the economy and to the general wellbeing of families and communities up and down the country to take into account⁴⁸. Practical issues in delivering care and support to much larger populations of sick, disabled and older people (almost all of whom will wish to remain in their own homes, with suitable support), require practical solutions.

The opportunity telecare offers can be a critical element in these. We know that, by harnessing science and technology to address the challenges of care in the 21st century, telecare can help reduce avoidable costs and reduce the incidence of common hazards – falls, accidents, the risks associated with diabetes, heart disease, hypertension, dementia and many other conditions. We know too that at present, most of the care of sick, older and disabled people in Scotland is provided by their unpaid carers – their families, friends and neighbours – who often pay a heavy price for the care they give. For carers, caring often means reduced income, strain on their own health and exclusion from the activities of everyday life which others take for granted. While most agree this situation is not acceptable in today's society, until recently solutions to address some of the problems carers face have seemed out of reach.

The potential benefits of telecare for carers probably go well beyond those identified in this exploratory study of carers in Scotland, many of whom were not yet able to access the full range of available equipment or the latest technology. Yet even with this limited technical support, some carers had found telecare life-changing, and most



acknowledged that it was life-enhancing for them. Telecare can be installed in virtually all homes with minimal disruption and unobtrusive equipment. It is inexpensive compared to most other solutions in the health and social care field, and through past strategic decisions, Scotland is now well placed to reap the benefits of its investments. This will mean fully embedding telecare into wider systems of care and support, and ensuring that as telecare moves into the mainstream, fairness, responsiveness and timeliness are guaranteed in the new systems being put in place. Listening to carers' voices, and engaging carers in shaping the way this support is designed and delivered will be a key mechanism in ensuring that Scotland's sick, disabled and older people and their carers get the support they need to participate fully in all aspects of Scottish society, protected from avoidable risks and free from unnecessary worry and stress.

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- ¹ From the definition used in the Scottish Telecare Development Programme, JIT (2008).
- ² Scottish Executive (2006).
- ³ Scottish Government, JIT (2008).
- ⁴ Beale et al (2009), Appendix A: p. ii
- ⁵ Carers UK (2001).
- ⁶ GROS (2009).
- ⁷ 2001 Census, Crown Copyright.
- ⁸ Buckner & Yeandle (2007).
- ⁹ Yeandle et al (2007a).
- ¹⁰ ONS (2006) The 2001 SARs are provided through the Cathie Marsh Centre for Census & Survey Research (Univ. of Manchester), with the support of the ESRC and JISC. All tables containing Census data, and the results of analysis, are reproduced with the permission of the Controller of Her Majesty's Stationery Office and the Queen's Printer for Scotland.
- ¹¹ GROS (2007).
- ¹² Long Term Conditions Information Programme, ISD Scotland quoted in Scottish Executive (2007a).
- ¹³ GROS (2007).
- ¹⁴ Yeandle (2009).
- ¹⁵ Yeandle (2009).
- ¹⁶ Yeandle (2009).
- ¹⁷ Yeandle et al (2007b).
- ¹⁸ Beale (2009); Yeandle, S. (2009).
- ¹⁹ For example in: Scottish Executive (1999); Scottish Executive (2006a); Scottish Executive (2006b), and in the **Community Care and Health (Scotland) Act 2002**.
- ²⁰ Yeandle et al (2007a).
- ²¹ This will be made available from December 2009 via the Carers Scotland and JIT websites.
- ²² JIT (2007).
- ²³ Beale (2009).
- ²⁴ Beale (2009), Appendix E.
- ²⁵ Beale (2009).
- ²⁶ Newhaven Research (2009).
- ²⁷ Newhaven Research (2009). This is consistent with the findings of the Newhaven Research evaluation study, which concluded that, in a significant number of partnerships, impediments to the adoption of telecare as a mainstream element of community care services meant that it remained a peripheral or pilot-based activity.
- ²⁸ Bowes et al (2006).
- ²⁹ See Beale et al (2009), Appendix E.
- ³⁰ E.g. Argyll & Bute Council (2008); Sargeant, E. (2008).
- ³¹ Finch et al (2005).
- ³² Percival & Hanson (2006).
- ³³ This point was made by two different Telecare Leads in Scotland.
- ³⁴ Newhaven Research (2009).
- ³⁵ Beale et al (2009), Appendix N: p. iii.
- ³⁶ A few carers did not provide this information and have not been included in figures given here.
- ³⁷ COSLA - The Convention of Scottish Local Authorities.
- ³⁸ For more information about COSLA guidance refer to: <http://www.cosla.gov.uk/attachments/execgroups/sh/shjun02item56c.doc>.
- ³⁹ See Buckner and Yeandle (n.d.) Figures 2 and 3. p7 and Yeandle et al (2007c). Figures 3.5 and 3.6 p23. Older carers' health has also been shown to deteriorate with increased weekly hours of caring (Buckner and Yeandle, 2005) Table 2 - although the oldest carers are often relatively healthy compared with others in their age group (which includes the sick, frail and disabled people they are caring for).
- ⁴¹ Environmental controls enable the person to control everyday domestic appliances using a remote control or voice activation mechanism.
- ⁴² Hanson & Percival (2006).
- ⁴³ Discussed in Yeandle (2009).
- ⁴⁴ **Help the Aged** (2007) in its **Preventing the Falls: Policy Statement 2007** stated: 'Falls represent the most frequent and serious type of accident in the over-65s, with one older person dying every five hours as a result of a fall. Falls destroy confidence, increase isolation and reduce independence. About 30% of older people living in the community fall each year, rising to approximately 50% for those aged over 85 and over. Over half of all those aged 75+ who have fallen say that their fall had a major impact on their daily activities for a month or more. After a fall, an older person has a 50% probability of having seriously impaired mobility and a 10% probability of dying within a year. The UK population is ageing and therefore the cost of falls incurred by the NHS and other agencies is expected to escalate: already falls cost our society almost £1.8billion a year' (p2).
- ⁴⁵ Bowes et al (2006).
- ⁴⁶ Scottish Executive (2007b).
- ⁴⁷ It was not possible to include interviews with home care workers in the study. Their perspectives on telecare are rarely captured in the research literature, and further investigation of how telecare affects (and might potentially enhance) their work is needed.
- ⁴⁸ Yeandle & Buckner (2007); Yeandle (2009).

Appendix A

Research methods

Research Design

The following research activities were completed by members of the CIRCLE research team between December 2008 and August 2009:

- Research instruments and supporting documents were developed re:
 - telephone interviews with carers
 - interviews with key informants
 - focus groups with carers
- Three focus groups, involving 13 carers, were facilitated in three different local partnerships in Scotland
- Telephone interviews were conducted with 30 carers living in Scotland
- 10 interviews with 'key informants' (professionals involved in the development and delivery of telecare) were conducted
- A focused review of literature relating to telecare was completed
- A web search of current telecare policy developments was completed
- Meetings were held with a range of telecare suppliers
- Telecare product development, installation and operational processes were observed (at a site where telecare equipment is assembled, during an installation of equipment in a Scottish service user's home, and at a telecare response centre in Scotland)
- Letters sent to local partnerships in Scotland (by the JIT and Carers Scotland, with the request to be forwarded to carers who had telecare in place¹)
- Carers Scotland's website, newsletter and mailings to its carer members, carers' centres and affiliate organisations
- Fliers distributed to delegates at a national conference focused on telecare²
- Selected local partnership social care departments (where staff were asked to contact carers known to be using telecare)
- Carers' centres and the networks of national carers' organisations

Challenges in conducting the study

Identifying and recruiting carers to participate in the research was challenging. In addition to the usual difficulties carers face in attending events (sourcing suitable alternative care for the person they care for spending time away from home, etc.) some local partnerships could not distribute letters to carers using telecare because they kept records only of the service user who had telecare in place. If the impact of telecare is to be fully evaluated, local partnerships will need to be in a position to actively support and facilitate carer involvement.

The absence of a suitable sampling frame from which to identify carers using telecare is likely to be a continuing problem unless this issue is addressed by agencies responsible for providing and installing telecare equipment.

Sample of carers

As there was no data available to use as a sampling frame, carers taking part in the interviews and focus groups were contacted via a variety of means:

¹Due to data protection issues names and contact details of carers were unavailable directly.

²Working Together: Telehealth and Telecare Conference, 24-25th February 2009, Airth Castle, Stirling.

Appendix B

Table A1 Scotland: total number of carers by Local Authority

Aberdeen City	16,758	Highland	18,505
Aberdeenshire	17,009	Inverclyde	8,167
Angus	9,492	Midlothian	8,187
Argyll & Bute	8,509	Moray	6,835
Clackmannanshire	4,812	North Ayrshire	13,486
Dumfries & Galloway	14,043	North Lanarkshire	33,219
Dundee City	13,942	Orkney Islands	1,706
East Ayrshire	12,454	Perth & Kinross	12,134
East Dunbartonshire	11,656	Renfrewshire	18,031
East Lothian	8,830	Scottish Borders	9,172
East Renfrewshire	9,206	Shetland Islands	1,968
Edinburgh, City of	38,876	South Ayrshire	11,385
Eilean Siar	2,813	South Lanarkshire	31,896
Falkirk	14,914	Stirling	8,129
Fife	33,808	West Dunbartonshire	9,879
Glasgow City	56,611	West Lothian	15,147

Source, 2001 Census of Population, Crown Copyright.

Finding out more:

This research was commissioned by Carers Scotland with the support of the Scottish Government Telecare Development Programme Joint Improvement Team. For more information contact:

Carers Scotland	www.carerscotland.org
University of Leeds CIRCLE	www.sociology.leeds.ac.uk/circle/about
Joint Improvement Team	www.jitscotland.org.uk/action-areas/telecare-in-scotland

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Carers give so much to society yet, as a consequence of caring, they experience ill health, poverty and discrimination. Carers Scotland improves carers' lives through information provision, campaigning, training and research. To find out more or to join us contact:

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