# Policy Brief

Ulster University

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# Telecare solutions for older people and carers

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## Introduction

This Policy Brief is based on a policy-practice workshop 'Advances in telecare: new solutions for carers and older people', held at Queen's University Belfast on 9 June 2015. Jointly organised by the ARK Ageing Programme and Carers NI to mark Carers Week, the event brought together practitioners, policy makers and researchers across different sectors to explore how technology can assist older people and their carers in everyday life. The workshop was one activity of the ARK Ageing Programme Visiting Fellow, Professor Sue Yeandle, who was Director of CIRCLE, the Centre for International Research on Care, Labour and Equalities at the University of Leeds (now at University of Sheffield).

The workshop comprised presentations from four speakers, with questions and discussion. This Policy Brief outlines the main points made by each speaker and highlights issues raised in discussion.

## Context

The last 40 years have seen the emergence of a significant academic, policy and practice literature on the subject of carers and increased political attention to caring (Chappell, 1996; Johnson, 1998). From beginnings in the mid-1960s, decades of campaigning by United Kingdom (UK) carers' organisations (Cook, 2007) achieved landmark success in the UK benefits system with the introduction in 1976 of 'Carers Allowance' (then called 'Invalid Care Allowance'). In addition, progress has included recognition of carers in both social care and employment law (Clements, 2015) and in 1999, the first UK-wide national carers' strategy (DH, 1999). This was updated and redesigned in 2008, and 'refreshed' following the change of Government at Westminster in 2010 (HMG, 2008, 2010). A carers' strategy specific to Northern Ireland was first set out in 2006 and revised in 2011 (DHSSPS, 2006; 2011). These strategic policy frameworks acknowledge the vital contribution carers make.

Since the 1990s, carers have been accorded recognition and some rights in law, although in

health and social care these differ between the UK nations. With increased longevity and larger numbers of people living with long-term conditions, the number of carers has risen. In 2011, the Census of Population found there were 6.5 million carers in the UK (up from 5.9 million in 2001), including 214,000 carers in Northern Ireland (up from 184,000 in 2001); and these figures continue to rise (Buckner and Yeandle, 2015).

Understanding of caring is greater than before and the value and importance of carers' contribution is now officially recognised, but carers continue to face substantial challenges. Demand in the care system, and demands on carers themselves, are greater than ever before and still rising. Studies show that many carers take pride in and gain much from their caring relationships, but that they also suffer many negative impacts. If caring is unsupported and / or causes a carer to give up or reduce paid work, the outcome can be severe financial and emotional stress, long-term damage to health, and social isolation (Yeandle and Buckner, 2007; Ferguson and Devine, 2011; Northern Ireland Human Rights Commission, 2014).

Alleviating pressure on carers is now a policy aim of governments and campaigners, and technology has come to be seen as a way of achieving this. Telecare and related technologies in the home work by supporting older and disabled people to live more safely and independently. This is usually achieved by maintaining a 24/7 connection between them, or conditions in their home environment, and a monitoring centre. This can alert a carer living elsewhere, or who is not at home, to a need for help or can trigger an alarm to which paramedics, other emergency services or health professionals can quickly respond.

Telecare and similar technologies are not intended to replace carers, but can give them peace of mind and make them aware if something is wrong or they are needed. In studies, carers often report feeling positive about having telecare in place. One recent review found that 60 per cent felt telecare solutions had a positive impact on their caring role and gave them reassurance (Corbett-Nolan and Bullivant, 2012). Some research suggests more could be done to make technological support in caring situations effective and that the integration of technology, home

care services, family support and the wider health and social care system is far from complete (Yeandle, 2014). It is widely agreed, however, that current approaches to health and social care are not sustainable, and that technology and innovation must play a role in the redesign of care and support.

The four speakers who contributed to the workshop commented on a study of telecare, older people and those caring for them in England (Sue Yeandle); on a telemonitoring scheme in Northern Ireland's health and social care system (Soo Hun); on the use of GPS systems in occupational therapy to support people living with dementia (Karen Walls); and on Carers UK's work to support effective implementation of technology (Steve Peebles).

## 'Ageing Well?' Everyday life with telecare support

*Professor Sue Yeandle, Director, CIRCLE, University of Leeds and ARK Ageing Programme Visiting Fellow*

Sue began by asking, 'Are we doing enough to support carers to age well?' She highlighted statistics showing that carers are

at risk of a triple penalty: poorer health, financial difficulties and social exclusion, and the importance of connecting research, policy and practice. As a society, we could be proud of, and should support, the care that takes place in our communities. The findings of the AKTIVE project, which Sue and her team had recently completed, showed the importance of asking older people what they want, and of going beyond addressing the 'risks' they face. The study had shown that in late old age, identity can be challenged by frailty or the need to accept new circumstances. Therefore, our aim should be to support older people to remain, as long as possible, the person they feel they are, and want to be.

The AKTIVE project (Advancing Knowledge of Telecare for Independence and Vitality in Later Life) was based at Leeds University and was delivered in partnership with colleagues at the University of Oxford and two companies, Tunstall Healthcare (UK) Ltd and Inventya Ltd. AKTIVE explored the role of telecare in meeting the needs of older people with memory problems or at risk of falls. Using social research techniques and repeat household visits, it studied

older people and those involved in their care over a period of time (up to nine months). The findings confirmed that older people and their carers can benefit greatly from having well-chosen telecare equipment which is tailored to their personal situation. Some people in the study and their carers felt safer, less alone and that their relationships had improved with telecare being available. Some spoke of reduced conflict over safety and risk; others emphasised how reassuring it was to know that if something went wrong, they would quickly be alerted; some said telecare was vital in helping them get a much-needed break from their caring role.

The study showed that the type of human support an older person has affects how telecare or technology is used. Three types of caring networks were observed. In 'family networks', one or more family members were central to decision-making. This worked well if an older person had supportive local family, or if their ability to make decisions was affected by cognitive impairment. Some people, however, had families which had 'taken over' and the older person resented this, feeling their safety had been prioritised over how

they wished to live. 'Complex' caring networks were observed in some cases; these relied on a wider group of people: friends, neighbours, local community organisations or faith groups and other people who came to the home to provide care, clean or help with the garden and odd jobs. These complex networks tended to centre on the older person's preferred activities and way of life, and helped some people feel that they were supported and independent in their everyday life. A few people in the study relied on a 'privatised' network; these older people, sometimes helped by family carers, had bought equipment or domestic services, including care, on the private market. Some liked the control this gave them. Those benefitting from private support tended to be affluent people who could afford to buy all the help they needed.

Sue stressed that the systems and technology we develop need to work for people with different needs and wishes. She ended her talk by emphasising that telecare can be an efficient and effective way of helping some older people live their day-to-day lives, but is not an adequate solution in itself, and cannot replace human care and contact.

## Telehealth in action: Northern Ireland

*Soo Hun, Centre for Connected Health and Social Care*

This presentation focused on 'Telemonitoring', a six-year pilot programme (2011-2017) involving over 5,000 users in the Southern and Western Trust areas, and the recent 'E-health and Care Strategy' promoting the use of new technology and social media at a time of rapid technological advance. The telemonitoring programme was targeting older people in rural or remote settings who were likely to be isolated and can find it difficult to get to hospital appointments. Through the programme, people with health conditions receive and send data about their own healthcare. A range of services are covered, and users can speak to medical staff by phone without having to travel to hospital or their local surgery. The system helps in quickly identifying changes in a person's health condition, with benefits for the older person using it and any carers they may have. Soo noted some difficulties in gaining professional acceptance of telemonitoring, however, and said some management teams remain sceptical about the value of the service.

With the programme due to finish in 2017, Soo spoke about what has been learned through its implementation and her team's aspiration that it may change practice, support innovation and provide a valuable data platform, drawing attention to a useful report on users' experiences of telemonitoring produced by the Patient and Client Council in 2014.

## GPS use in dementia care - an occupational therapist's perspective

*Karen Walls, Clinical Lead OT, Dementia Services, Northern Health and Social Care Trust*

Karen's contribution focused on the 'Buddi' telecare system in an occupational therapy service for people with dementia. Buddi is a GPS-enabled device which a user can wear when out alone. Its main purpose is to reduce the risks which can arise if a person with dementia becomes lost when unaccompanied, or becomes confused, 'wanders' and cannot get home safely. The system was created to help promote independence and a better quality of life for those using it and their carers. Karen explained how the Buddi system was designed and tested, noting its capacity to

identify a 'safe zone' for a user, for example a radius of a mile from their home can be set. If the wearer goes outside the zone, the Buddi triggers an alert and a text or phone call is automatically made to the person nominated, usually a carer or family member. Karen explained that her team's work was still at an early stage: to date they had used it with nine of their dementia patients in the Northern Health and Social Care Trust. In discussion, workshop participants asked why the system had not been promoted by professionals in all Trusts in Northern Ireland, and showed interest in its wider uptake.

## Supporting caring through technology

*Steve Peebles, Product Manager, Carers UK*

Steve explained that people's expectations of technology and care are rising in a society where technological advances are occurring at a rapid pace. He pointed out that people today often research medical topics online and that many see this as an easier option than making an appointment to see their GP. Increasingly, GP appointment systems are available online, making booking easier for anyone using online systems to access.

New and wearable technology, such as 'smart' pendants and the 'Buddi' system, are gradually replacing older technology. Steve felt the current 'telecare' terminology was becoming a problem and that the discussion of technology and care was changing. A new App for carers, 'Jointly', had been introduced by Carers UK in recognition of the way people are now using technology. Steve concluded by noting the challenge of keeping up with the fast pace of change in the world of technology.

## Discussion

A range of different options of telecare and technology were highlighted in the workshop. Discussion and comments focused on how service providers and policy-makers could best use these systems to support older and disabled people and their carers.

*Information and awareness*
There was a sense of frustration about the limited awareness among professionals of the role telecare and technology support can play in helping someone stay at home, and avoid admission into residential care. Participants also highlighted the difficulty some service users had in learning how to use technology

effectively. The possibility of intergenerational sharing was highlighted; with younger people helping older people learn how to use modern technology, and younger people learning about the lives and experiences of people with long-term conditions including dementia.

*Funding*
Some contributors raised the issue of funding options and how telecare services could be funded. Sue Yeandle explained that when the AKTIVE project began, Leeds City Council provided a free telecare service for all older people who needed it. With a large reduction to its overall budget, however, it had later introduced means-testing and user fees for this service. Practice on charging and fees in English local authorities remained inconsistent. One participant thought paying privately for technology was acceptable for younger social care users, mentioning a parent of a disabled adult who was considering paying privately for telecare services as they were not available through the local Trust. Another contributor mentioned that the Irish Farmers' Association funds GPS devices for farmers, so that their location can be tracked, and thought something similar could be offered in social care.

*Benefits to users and carers*
The Buddi telecare system became a talking point of the seminar, as two of the speakers (Sue Yeandle and Karen Walls) had given examples of its benefits and positive impact for older people and their carers. By enabling a person with dementia to continue doing things they enjoyed independently, such as taking long walks alone, this type of device also benefitted their carers, giving them reassurance and peace of mind.

Other telecare equipment and systems in place in Northern Ireland were also mentioned, including a 'Good Morning Scheme' in which daily or weekly phone calls are made to people at home. This service had been shown to be important for older people who are living alone and may feel isolated.

The main focus of the seminar was on how telecare systems work for older people; several participants raised the issue of their suitability for other groups, such as people with long-term conditions or with learning difficulties or physical disabilities, but the speakers had not tested or researched telecare use with these groups. It was felt important that telecare and technology should be available

to meet the needs of the fullest possible range of people with care and support needs.

*Ethical and practical issues*

Some contributors raised issues about risk and safeguarding, and asked if using GPS technology might be a breach of privacy. Speakers spoke about the importance of seeking consent and of doing so soon after memory problems or dementia were diagnosed. There was also discussion about people wearing the devices they were allocated. Examples were given of how, in practice and in the research studies, flexibility and ingenuity were sometimes needed with GPS devices placed in coat pockets, jeans pockets and even in one case worn by the dog (when a person with dementia was walking their dog alone).

*Safety*

Many contributors to the discussion felt social care systems were too risk averse, and thought it might be better to build systems which focus on helping older people to build resilience, rather than focus on avoiding risk. Other comments related to ways of ensuring both older people and their carers benefitted from the safety benefits of telecare and similar technologies, and its applicability in residential care settings.

## Conclusion

As technology advances, people's expectations of care options and what is available to them also change. Technological advances affect strategic decisions in health and social care systems, and it can be challenging for all in the system to keep up with rapid technological progress. Learning 'what works' is crucial, and should include learning from international experience, with innovative and imaginative practice and redesign of health and social care systems a priority.

Awareness of newer telecare and related technologies is still limited, and many service providers and participants in the workshop felt that they lacked knowledge of potentially valuable options. It was agreed that attention to safeguarding, risk and ethical issues needed to be maintained. Many participants felt unsure where resources for these developments might come from in the contemporary financial climate. The seminar nonetheless emphasised ongoing change in health and social care arrangements in Northern Ireland and the importance of responding to technological advances to shape a future-oriented service in ways which would benefit older and disabled people and carers.

Further information on this event, including a video and presentation slides, are available at http://www.ark.ac.uk/ap/people/vfellow/sue-yeandle/telecare/

## Authors

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# Useful links

**ARK Ageing Programme** www.ark.ac.uk/ageing

**AKTIVE** www.aktive.org.uk/index.html

**Carers NI** www.carersuk.org/northernireland

**Carers UK** www.carersuk.org

**Centre for Connected Health and Social Care**

www.publichealth.hscni.net/directorate-nursing-and-allied-health-professions/european-centre-connected-health

**Centre for International Research on Care, Labour and Equalities (University of Leeds)**

http://circle.leeds.ac.uk/

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