

The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes

Working Papers from the AKTIVE project 2011-2014

## **AKTIVE Working Paper 1**

# Researching Telecare Use using Everyday Life Analysis:

# introducing the AKTIVE Working Papers

Sue Yeandle CIRCLE (Centre for International Research on Care, Labour and Equalities) University of Leeds

Advancing Knowledge of Telecare for Independence and Vitality in later lifE

Technology Strategy Board Driving Innovation



Published by CIRCLE, University of Leeds, April 2014

©University of Leeds, University of Oxford and the author ISBN 978-0-9928741-0-0

#### Online version: <u>http://www.aktive.org.uk/</u>

#### Also available from: CIRCLE

Centre for International Research on Care, Labour and Equalities University of Leeds, Leeds, LS2 9JT, UK

Tel: (+44) 113 343 4872

Web: http://www.sociology.leeds.ac.uk/circle

Email: <u>CIRCLEadmin@leeds.ac.uk</u>

### Acknowledgements

## Research, analysis and development of the working paper

Data discussed in this paper were collected and analysed by the researchers responsible for the AKTIVE fieldwork: Kate Hamblin and Emanuela Bianchera (University of Oxford) and Emma-Reetta Koivunen and Gary Fry (University of Leeds). With Sue Yeandle (who directed the AKTIVE project and edited the AKTIVE working papers), these colleagues also advised on the content and development of this paper. The author gratefully acknowledges their contributions.

#### Research participants

The research team is extremely grateful for the contribution made to the study by the older people who took part, sometimes in difficult circumstances, who allowed us into their homes, gave generous and thoughtful interviews, permitted us to observe their living situation and assisted us by completing diaries, taking photographs and in other ways helping us gain a full picture of their everyday lives. We also wish to thank their family members, home care workers and others involved in their care who agreed to be interviewed or observed or who completed questionnaires. These contributions were vital to the study, which would not otherwise have been possible. To protect the confidentiality and privacy of those who took part, all names, and some identifiable details, have been changed.

## Funding of the AKTIVE project

The main funding for AKTIVE was provided by the Technology Strategy Board (TSB), which developed the scheme through which the project was funded in collaboration with the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR). AKTIVE industrial partners Tunstall Healthcare (UK) Ltd and Inventya Ltd also contributed resources to the project. AKTIVE was originally funded under the name '*The Potential of Assisted Living Technologies for Older People at Home: creating a knowledge base for businesses developing technology for dementia and falls*', contract reference number 400215 / 2592-25185.

## 1 The AKTIVE Working Papers

AKTIVE (*Advancing Knowledge of Telecare for Independence and Vitality in Later Life*) was a collaborative project, funded by the Technology Strategy Board, ESRC and NIHR, to address challenges arising from population ageing and opportunities arising from technological progress.<sup>1</sup> Focusing on older people living at home with different types of frailty, it aimed both to enhance understanding of how they (and those supporting them) accessed, engaged with and used the 'telecare' equipment supplied to them, and to explore the consequences for them of doing so.<sup>2</sup>

The origins, structure, aims and research methods of AKTIVE are detailed elsewhere (Yeandle et al., 2014). As described there, AKTIVE was delivered by its partners<sup>3</sup> through a set of 'work packages': a literature review (AKTIVE Consortium, 2013); preliminary research with stakeholders, experts in telecare systems, carers and care workers<sup>4</sup>; systems mapping to identify who and what is involved in telecare systems; and exploration of available anonymised telecare monitoring data provided by two local authorities (Leeds and Oxfordshire) and their partners in telecare delivery. These work packages were undertaken while the central study, the 'everyday life analysis' (ELA) of older users of telecare was set up.

The ELA study involved repeat research visits over six to nine months with a sample of 60 older telecare users, plus investigation of design and risk issues and of the impact of equipment upgrading with selected ELA participants. Earlier results of the social research undertaken within the AKTIVE project were presented at two conferences arranged by the project partners (in May 2013 and April 2014) and at other events and meetings (Yeandle et al., 2014, Appendix II), while AKTIVE partner Inventya Ltd released its market research and related findings via the project website (www.aktive.org) in 2013 and 2014.

The AKTIVE Working Paper series, of which the present paper is Paper 1, comprises papers written during the final months of the project in spring 2014 by members of the AKTIVE social research team, and by some members of the AKTIVE Consortium (see Appendix I, Yeandle et al., 2014). The Working Papers were released in two phases: in April 2014, to coincide with the AKTIVE Final Conference (Papers 1 to 5); and in late May 2014, as the AKTIVE project concluded (Papers 6 onwards). Papers 1 to 5 are entitled:

- 1. Researching Telecare Use using Everyday Life Analysis: introducing the AKTIVE Working Papers
- 2. Frail Older People and their Networks of Support: how does telecare fit in?
- 3. Telecare and Older People's Social Relations
- 4. Coping with Change: frail bodies and daily activities in later life
- 5. Lifestyles in Later Life: identity, choice and stigma

<sup>&</sup>lt;sup>1</sup> ESRC, Economic and Social Research Council. NIHR, National Institute for Health Research.

<sup>&</sup>lt;sup>2</sup> The definition of telecare which guided AKTIVE is: 'equipment and detectors that provide continuous, automatic and remote monitoring of care needs emergencies and lifestyle changes, using information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards' (Scottish Government, 2009).

<sup>&</sup>lt;sup>3</sup> The four partners were: CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Leeds; Oxford Institute of Population Ageing, University of Oxford; Tunstall Healthcare (UK) Ltd; and Inventya Ltd.

<sup>&</sup>lt;sup>4</sup> 'Carer' is used to refer to people who provide their support unpaid, as a family member, neighbour or friend.



The research questions addressed in the ELA aspects of the AKTIVE study (Yeandle et al., 2014), covered:

- the contexts and characteristics of older people who use telecare;
- the telecare equipment used, and its significance for older people and those who support them;
- barriers to the adoption of telecare and the innovations needed to overcome these; and
- outcomes for older people and their carers when telecare is in place.

The wider AKTIVE project also looked at how telecare affects job design and job quality for home care workers, and at its implications for service providers, care commissioners and other workers attending them at home, aspects examined in the Consortium's other project activities and publications.

Guided by the stakeholder interviews conducted in the first year of the project, the team also sought to use the ELA study to understand, from the perspective of older people themselves:

- how different telecare delivery models may affect use of telecare;
- if older people and their carers / care workers hold conflicting views about telecare;
- how older people experience and view telecare assessment and re-assessment processes;
- how using telecare affects them financially;
- whether they view telecare as intrusive, or fear it may replace other care or lead to isolation;
- how telecare is experienced by two specific groups of older people, those susceptible to falls and those with memory problems or dementia;
- how they use and respond to the specific items of telecare equipment supplied to them; and
- whether (or not) they find the equipment enabling and supportive of their own choices in later life.

The ELA research method offered some specific advantages over other available methods. These relate both to how 'telecare' was conceptualised and to how the experiences and perspectives of frail older people (and those who support them) were examined.

AKTIVE conceptualised 'telecare' as a system of support comprising a mix of technologies and human inputs, seeing it also as an evolving set of products and equipment which could potentially be configured in many different ways (and upgraded or reconfigured over time).

To explore the specificity of how telecare is experienced when provided to frail older people, the ELA method, specially developed for the study, was: *longitudinal* (and able to capture changes in responses to telecare); *holistic* (it explored the perspectives of all the social actors in the situation); *person-centred* (it used 'life story' techniques and mixed methods to 'really get to know' the older people studied); *creative* (data collection included photographs, diaries and 'mapping' techniques); and *multi-disciplinary* (design and prospective hazard research approaches were used as well as social science methods).<sup>5</sup>

<sup>&</sup>lt;sup>5</sup> The ELA method also had limitations: some participants dropped out (ill health, death, moving); methodological flexibility meant data were not 'standardised'; and findings cannot be statistically generalised to all telecare users.



Its approach contrasts with many other studies, which often lack a longitudinal and holistic approach and conceptualise telecare in generalised or surprising ways (AKTIVE Consortium, 2013). It differed considerably, for example, from the approach taken to researching telecare use in the Whole Systems Demonstrators (WSD) study, ongoing when AKTIVE began, which used both a randomised control trial (RCT) of telecare (Steventon et al., 2013) and qualitative approaches (Sanders et al., 2012). The WSD RCT sought to measure the impact of telecare by exploring, as its primary hypothesis, that 'telecare could alter ... the proportion of people experiencing an inpatient hospital admission within 12 months'<sup>6</sup>, while the qualitative approach reported in Sanders et al. (2012) involved single research interviews with study participants and observational work based on shadowing health and social care professionals.

AKTIVE, through its distinctive ELA method, provided the research team with the opportunity to really 'get to know' and build relationships with the older people studied; to find out, over a period of 6 to 9 months, how the telecare support they were allocated affected them and others in their lives; and to explore with them their lifestyle preferences and how they wished to manage risk and specific situations which concerned them or those supporting them. Through this approach the study findings offer insights, understandings and explanations of attitudes, behaviours and perceptions relevant to how older people and those who supported them experienced, responded to, and in many cases benefitted from, having telecare in place.

This Working Paper is organised as follows. Section 1 introduces the paper and the study. Section 2 briefly describes the two telecare services studied, in Leeds and Oxfordshire, providing a context in which some of the differences seen in research participants' experiences and reactions can be understood. Section 3 describes the 60 frail older people included in the ELA sample, including their personal characteristics, their living situations and family circumstances, their health situations at the start of the study and some of the changes they experienced during the research contact. Finally Section 4 describes the different types and combinations of telecare equipment in place in the ELA households.

All papers in the AKTIVE Working Paper series draw on the ELA research findings, and each indicates which AKTIVE research questions it addresses. All AKTIVE publications based on the social research, together with other outputs based on the work of the AKTIVE project partners and consortium members, are available on the AKTIVE and CIRCLE websites (www.aktive.org; and www.sociology.leeds.ac.uk/circle).

<sup>&</sup>lt;sup>6</sup> The WSD study compared 'telecare' (a base unit and pendant alarm 'plus up to 27 peripheral devices') with 'usual care' (which was variable and could include 'pendant alarms and smoke detectors'), Steventon et al., 2013: 502. It concluded that telecare 'as implemented in the WSD trial ... did not lead to significant reductions in service use, at least in terms of results assessed over 12 months' (2013: 501). The authors of this article do not explain how they overcame the difficulties implied by the somewhat overlapping definitions of 'telecare' and 'usual care'.

## 2 The telecare services studied

Leeds and Oxfordshire, the localities where the AKTIVE study was carried out, were 'convenience' samples, selected mainly because they were local to the two universities, enabling a study involving extensive fieldwork to be delivered cost-effectively. The study also needed to rely on sustained collaboration with the telecare services involved in providing telecare equipment to the older people participating in the research. To achieve this, Leeds City Council (LCC) and Oxfordshire County Council (OCC) were invited to join the AKTIVE Consortium while the study was being planned, and both became sub-contracted members of it once the project's funding commenced.

These two localities offered valuable contrasts in the way telecare support was positioned within their local offer of care and support services for older people. When AKTIVE began in 2011, Leeds had recently made a significant additional investment in its long-established telecare service, having received a £1.1 million Preventative Technology Grant between 2006-2009, and choosing to offer telecare as a free, 'in-house' service to older eligible citizens. The Oxfordshire service was more recently developed. It had received £824,000 in Preventative Technology Grant allocations between 2006 and 2008, offered its service to users on a means-tested basis, and out-sourced many aspects of its delivery to external organisations. A consequence of its commissioning arrangements was that the service centred mainly on providing pendant alarms.

In Leeds, the service was provided by the Leeds Telecare Service, whose staff researched and sourced equipment from different suppliers; trained local authority staff and others involved in assessing older people's needs in telecare assessment; and installed and maintained the telecare equipment (which was provided on loan from the council) in clients' homes. Older people in Leeds usually accessed this free service through a social worker, health professional or voluntary agency.<sup>7</sup> They were not required to meet FACS<sup>8</sup> criteria and were not means-tested, as at that time charges for telecare were not applied. Before starting to use the service, they gave details of two friends or relatives who could be contacted in an emergency by LCC's 'Care Ring' response centre. 'Care Ring' monitored all telecare use and calls, and provided a back-up emergency response, which was also available to those unable to identify local contacts who could respond to them if they needed help.

LCC's telecare service was first established over 25 years ago, when the council pioneered a community alarm service, and was significantly enhanced after 2006 when the Department of Health (DH)'s Preventative Telecare Grant became payable to local authorities. From 2009, the service was a mainstream service funded through the LCC Adult Social Care budget, and in 2012/13 LCC released £1 million of capital expenditure to further develop it. Following a review of charging policies in 2012/13, LCC decided to introduce charges for

<sup>&</sup>lt;sup>7</sup> Older people in Leeds could also refer themselves directly as pendant alarm users.

<sup>&</sup>lt;sup>8</sup> FACS (Fair Access to Care Services) criteria are criteria established at national level which govern eligibility for services following assessment of social care needs (see <u>http://www.scie.org.uk/publications/guides/guide33/</u>).



telecare from January 2014<sup>9</sup> (and after the AKTIVE ELA data collection ended, these were implemented). In the year 2011-12, when the AKTIVE project commenced, the Telecare Service in Leeds had a capital spend on telecare equipment of £533,565. It made just under 2,000 new telecare installations during the year and had 4,381 current users, among whom around 700 used its Mobile Response service (LCC, 2012a). In March 2012, a report to the LCC Executive Board on aspects of the service noted that between April 2010 and January 2012 the number of telecare equipment users had more than doubled, rising from 2,069 to 4,203 (LCC, 2012b).

In Oxfordshire, telecare assessments, the installation of pendant alarms and (for most clients) the emergency response service, were outsourced from the council to a not-for-profit company. The service was first established in 2006, and by 2010 had 2,600 users (excluding those in sheltered housing), rising to 4,444 in September 2013 (OCC, 2013). The contract for telecare equipment supply and installation in Oxfordshire (apart from the basic pendant alarm) was held by Tunstall Healthcare (UK) Ltd, while the telecare monitoring service was 'contracted out' to a separate company. As in Leeds, FACS criteria were not applied in determining access to the telecare service, but in Oxfordshire users were means-tested, with those not eligible for free services (about 6% of clients) required to pay for the equipment rented to them.<sup>10</sup> Telecare charges in Oxfordshire varied according to the equipment supplied, the level of service provided and who provided it. Clients not eligible for free council services paid £5 per week for the basic pendant alarm service (with named family / friend responders) and £22 per week for a service without named responders (plus 'regular planned support'). As also described in other Working Papers, some telecare users within the AKTIVE study found the charging policy confusing, or said they were unsure, when they first began to use it, what charges would apply.

OCC viewed its telecare service as playing 'a significant role in supporting vulnerable people to remain independent at home, reducing the use of social care and hospital services' (OCC, 2013: 1). Its 'forecast spend' on the service for 2013/14 was £2.8 million, of which about 10% was expenditure on equipment, 42% on the 24/7 response service, 37% on 'planned support', 3% on the monitoring centre and 6% on assessments and reviews.

The differences between the two telecare services (during the ELA study) affected recruitment to the study (for example, most Oxfordshire participants had only a pendant alarm in place when they joined the study) and the outsourcing of parts of the service in Oxford meant some users and their families had dealings with multiple agencies. By contrast, in Leeds the service was wholly delivered by LCC (albeit through both 'Care Ring' and the Leeds Telecare Service). The absence of any financial assessments for telecare in Leeds meant users and carers there had a different experience of joining the service; and some Oxfordshire users told

<sup>&</sup>lt;sup>9</sup> Following this, LCC estimated that, of 10,000 clients with just a pendant alarm, 9,000 would pay £2.50 per week; of 4,000 clients with telecare 'peripheral monitors', 1,500 would pay up to £3 per week; of 100 clients with GPS tracking devices, 60 would pay up to £9 per week; and of 1,000 users of the telecare mobile response service (for those without nominated responders) 300 would pay £3 per week (LCC, 2013). LCC's consultation on its original proposals for introducing telecare charges drew responses from over 3,000 telecare users, and resulted in some reductions in planned charges and additional exemptions from charges (LCC, 2013: Appendix 3).

<sup>&</sup>lt;sup>10</sup> In September 2013, 94% of OCC telecare users received the service free of charge, while 147 paid for the basic service (average cost  $\pounds$ 4.94 per week) and 137 for the higher (Level 2/2) service (average cost  $\pounds$ 21.36 per week), and charges payable to the council in Oxfordshire were generating  $\pounds$ 190,000 per year (OCC, 2013).



researchers they disliked, or were confused by, the financial assessment element of the processes involved, particularly in cases where this had to be managed at a time of significant stress.

All participants in the AKTIVE ELA were asked about the other council-provided or privately paid for services they received, such as home care, help in managing housework, shopping, gardening or other regular chores, and help with personal care and related services. Where these were provided through local authority Adult Services, the information they gave could be triangulated against official records (where consent was given), and as part of the study some care workers and others supporting the ELA participants were interviewed, or completed written questionnaires (designed to collect their general experience of supporting clients with telecare in place).

Most participants had some help or support from family members or friends (Section 3). Working Paper 2 (Yeandle, 2014) explores how the telecare in place affected everyone involved in the older person's support and examines how far telecare is relevant to, or contributes to, the establishment of effective 'caring networks' around frail, and sometimes vulnerable, older people.

These aspects of the study were complemented by the service mapping work undertaken by AKTIVE Consortium member Peter Buckle, who led workshops and conducted study visits and interviews designed to identify all those involved in the operation of the systems of telecare under investigation, explore their effectiveness in identifying hazards and responding to risk, and reveal their key strengths and weaknesses. That work, together with data from the ELA visits in which older people and their carers spoke about their attitudes to, and perceptions of risk, is explored in Papers 6 (Hamblin) and 7 (Buckle), both forthcoming (May 2014) in this Working Paper series. Consortium member Chris McGinley, with his colleague Amanda Buckley, also visited a sub-sample of the ELA households, in their case applying design research methods and principles.

## 3 The older people studied

Research participant recruitment for the ELA was arranged through the two telecare services (Section 2), which approached people being assessed / re-assessed for telecare to enable 'new' and 'existing' users to be included.<sup>11</sup> Participants also needed to be aged 65 or older; to live in the community; and to have memory problems and / or dementia and / or to be susceptible to falls.<sup>12</sup> With their agreement, family members, friends, neighbours, carers or care workers supporting them were also included wherever possible. Up to six research visits were made to them at home, over up to a year, and those who remained in the study for at least six months, or who were visited at least four times, were included as full 'ELA' participants.<sup>13</sup>

At the end of the study, data were available for analysis on 60 ELA participants (Table 1.1). They included 39 women and 21 men. Most (41) lived alone, many being widowed (33) and a few divorced (8) or single (2). Of those living with others (19), most lived with their spouse (17), while the others lived with another family member. In addition to telecare, many participants had some home adaptations or assisted living equipment which had been installed to help them cope at home. This equipment included: hand or grab rails; 'hospital' beds; mobility scooters; raised seating; ramps; stair lifts; toilet supports; walking aids, wet rooms; and wheelchairs. Some also had key-safes to enable trusted visitors to enter their home.

## Table 1.1

Locality		Gender		Marital status				Living alone	
		Female	Male	Widowed	Divorced	Single	Married	Yes	No
Leeds	(n=24)	14	10	14	1	1	8	16	8
Oxfordshire	(n=36)	25	11	19	7	1	9	25	11
ALL	(n=60)	39	21	33	8	2	17	41	19

### Research participants, by gender, marital status and living situation at recruitment

Source: AKTIVE ELA database, CIRCLE, University of Leeds.

<sup>&</sup>lt;sup>11</sup> 'New' users were those due to receive telecare equipment for the first time, and 'established' users were people whose telecare equipment had been in place for about 12 months or longer. In Oxfordshire, DeNDRoN (an NHS body which supports research by facilitating the recruitment of participants for studies relating to neurodegenerative diseases) also supported the recruitment of some participants (Yeandle et al., 2014: Section 3.1).

<sup>&</sup>lt;sup>12</sup> Participants were included as having memory problems / dementia if: they had a relevant formal diagnosis; the participant, family members, carers or care workers informed the researcher of this or of undiagnosed issues; or memory problems were observed during ELA contact.

<sup>&</sup>lt;sup>13</sup> For details of each of the 60 ELA research participants, see Table A.1 in the Appendix to the Working Paper Series.



The study aimed to recruit, in roughly equal numbers, telecare users with two types of condition common among frail older people: being physically frail and 'susceptible to falls' (hereafter 'falls'), and having memory problems, with or without a diagnosis of dementia (hereafter 'memory problems'). Among the final sample, most (35) were affected by falls (but not by memory problems), 16 by both conditions, and 9 by memory problems (but not by falls). As described in Fry, 2014, Paper 4, many also had other conditions which affected their lifestyle, wellbeing, or meant they needed specific types of support.

Almost all participants (56 out of 60) were in regular contact with someone who could be defined as a carer (footnote 3), the research data on only four indicating that they were completely without such support. Only a minority of participants (24) had home care support in place when the study began. In a few cases this was 'reablement' (or similar) support, withdrawn after a few weeks.<sup>14</sup> Just 12 of the 60 participants used a day centre or similar support.

Almost all the older people studied had health conditions which were changing: often conditions which were gradually worsening (including dementia, diabetes, arthritis, cancer, heart failure and sight or hearing impairments). In a few cases a degree of recovery took place (e.g. following a broken hip or other injury); some new diagnoses were made (cancer, dementia); and some suffered additional injuries during the study. A few were hospitalised as a result of these changes and two female participants died before the study ended.<sup>15</sup> Thus in many cases, the researchers were visiting older people whose frailties or impairments were worsening, or (for the 17 living with a partner) who lived with someone in this situation.

Family and housing circumstances also changed for some participants: examples included a son or daughter moving away from the area, obtaining a new job, leaving a job or becoming unemployed, all of which could change the amount or type of support they could give. Some participants moved during the study: into supported housing (three cases); into residential care (one case); or to live with relatives (one case); some others were considering moving to accommodation which they or their family members thought would be more suitable for them. Mobility was a significant issue for many in the study, and (as described in Fry, 2014, Paper 4) this could affect activities of various kinds, ranging from personal care to leisure pursuits outside the home.

<sup>&</sup>lt;sup>14</sup> 'Reablement' is support, usually organised or planned by health and social care professionals, designed to 'help people learn or relearn the skills necessary for daily living which may have been lost through deterioration in health or increased support needs' (Francis et al., 2011:1). In 2012-14, the Oxfordshire Reablement Service was provided by OCC in partnership with Oxfordshire Health NHS Foundation Trust, as a free reablement care service for six weeks (after which it was chargeable). During the AKTIVE study it operated alongside a separately commissioned Supported Hospital Discharge Service, available for up to 14 days, also free to users (OCC, 2012). LCC developed its reablement service in 2010, promoting it as a service which would 'also look at what else might help, (e.g. support to go out, personal alarms, home adaptations or other equipment such as bath rails), and involve your relatives and / or carers' (LCC, 2011; Care Choices, 2014).

<sup>&</sup>lt;sup>15</sup> In addition, most of the ten participants who 'dropped out' early from the study (and who were not included in the final ELA sample) did so as a result of significant deterioration in their health.

## 4 Telecare in place in the ELA study households

The telecare equipment in place in the homes of the ELA participants is shown in Table 1.2. Most participants in Leeds already had a 'package' of telecare when they joined the study, while at that stage most of those recruited in Oxfordshire had only a pendant alarm (see table footnote 1). This reflected the differences in the two telecare services outlined in Section 2.

AKTIVE aimed to study telecare use in real situations where a suitable range of telecare equipment was available to each research participant, and 'equipment upgrades' were offered during the study in appropriate cases.<sup>16</sup> About a third of all participants, and more than half of those in Oxfordshire, accepted this offer, enabling the researchers to study how they responded to the new equipment provided. By the end of the study, many of the Oxfordshire participants who initially had only a pendant alarm had a wider range of equipment in place, although two chose to return these additional items. In addition, a few participants in both sites were allocated, or chose to obtain, additional equipment including, in two cases, GPS tracking devices.

The pendant alarm (which is typically worn around the neck, but can also be worn on the wrist) is often referred to as 'first generation' telecare. It provides the wearer with an immediate means of contacting a telecare monitoring centre, usually in an emergency or when in some form of distress. This popular device, used by some 1.5 million people in the UK (Steventon et al., 2013: 1), is an effective means of summoning help in many circumstances, but its limitations include that the person needs both to be wearing the device and to be capable of pressing the button when help is needed.<sup>17</sup>

'Packages' of telecare, by contrast, provided 'second generation' telecare equipment to older people who wanted, were considered to need, or (in some Oxfordshire cases) were willing to pay the extra cost of this equipment. This supplied them with devices linked to a monitoring centre which could generate an emergency or other response as needed, without the person taking action to summon assistance. In Leeds, the telecare assessment process led to many users having equipment of this type installed as soon as telecare support was selected, but this was less usual in Oxfordshire, where initially most participants had only a pendant alarm. Among devices in the 'second generation' category, those which monitored environmental hazards or risks arising from accidents or forgetfulness in the home (gas or water left on, excessive heat or cold, carbon monoxide or smoke, etc.) were used by many ELA participants. Sensors which alerted telecare users, or those involved in their care, to take action of some kind (e.g. bed, door or gate sensors; and reminders of the time, or of actions or medications to be taken) were also in place in some households studied. Many of the devices supplied following initial local authority assessment in Leeds were 'chosen' by Oxfordshire participants as additional or upgraded equipment during the study (Table 1.2).

<sup>&</sup>lt;sup>16</sup> The 'upgrade' equipment was provided by AKTIVE partner Tunstall Healthcare (UK) Ltd as part of its contribution to the study. The company already supplied both local authorities, in Oxfordshire as the sole supplier. No charge was made to local authorities or study participants when these upgrades were provided, and participants who declined an upgrade, or who received, but later chose not to retain, the equipment, could remain in the study.

<sup>&</sup>lt;sup>17</sup> In 2008, the 'Who Uses Telecare?' study estimated that in England at least 375,000 people used personal alarms, while a further 715,000 people used 'alerting devices' (Lloyd, 2012).



## Table 1.2

## Participants' telecare equipment, by location, showing additional equipment installed

	At re	cruitment to the study	Equipment added during study			
	Pendant alarm only	<b>Telecare package<sup>1</sup> in place</b> (often including a pendant alarm)	Upgrade through AKTIVE	Other equipment change <sup>2</sup>	Pendant alarm only	
Leeds (n= 24)	2	<b>21</b> <sup>3</sup>	6	4	2	
		Packages varied: overall they included:	Equipment installed comprised:	Equipment installed comprised:		
		Bed sensor2Carbon monoxide detector5Carer alert1Chair sensor1Gas leak detector3GPS tracking device4Medication dispenser6Reminder clock2Reminder system1Smoke detector15Temp. Extreme detector2	Ivi pendant 6	Easy Press adapter 1 GPS tracking device 1 Medication dispenser 2		
Oxfordshire* (n= 36)	30	<b>4</b> <sup>3</sup>	16	5	15	
		Packages varied: overall they included: Carbon monoxide detector 1 Exit sensor 1 Flood / spillage detector 1 Medication reminder 1 Smoke detector 3	Equipment installed comprised:Bed sensor54Bogus call alert10Carbon monoxide detector5Easy Press adapter1Ivi pendant45Lifeline Vi+ unit13Pendant (1 replaced, 1 larger)2Smoke detector12Temperature extremes detector10	Equipment installed comprised: Bed sensor *1 Fall detector 1 GPS tracking device 1 Pendant alarm 2 Smoke detector 1		
<b>All ELA</b> (n=60)	32	<b>25</b> <sup>3</sup>	22	9	17	

Source: AKTIVE ELA database, CIRCLE, University of Leeds.

Notes: <sup>1</sup> A telecare package is defined here as at least two items of equipment, which may or may not include a pendant (or wrist-worn) personal alarm; <sup>2</sup> This excludes one case where the participant was allocated new equipment (a pendant and a smoke alarm) on moving to sheltered accommodation; <sup>3</sup> In Leeds one, and in Oxfordshire two participants, not included in these numbers, had single items of equipment: a GPS tracking device; a gate exit sensor and a fall detector; <sup>4</sup> Two bed sensors were removed during the study, including one installed through AKTIVE; <sup>5</sup> One Ivi Pendant was removed during the study, at the participant's request.



GPS tracking devices, more recently on the market, were in place for four Leeds participants at the start of the study. These allow a person with memory problems to travel or go out alone, without fear of becoming lost and unable to be located and assisted home; they are particularly targeted towards people with dementia. Two other participants acquired these devices during the study. The researchers were thus able to study the use of these newer devices in a limited number of cases, and to explore their impact on the lives of users and their carers (Fry, 2014, Paper 4).

Research participants' responses to specific items of telecare equipment in each of the categories just described are summarised in Table A.2 in the Appendix to the AKTIVE Working Paper Series. This table outlines specific positive responses reported in the study, as well as some negative aspects and disliked features of particular items of telecare equipment.

Telecare users in the study comprised 22 'new' users (people with telecare in place for less than 12 months when they joined the study) and 38 'established' users. As discussed in Koivunen, 2014, Paper 3, the process of identifying telecare as a desirable or necessary form of support for an older person can be varied and complex. It may, for example, involve a request made by a family member or by the older person themselves; can follow an assessment of need by a social worker or health professional, perhaps after an illness, accident, following bereavement or as a result of other concerns for an older person's welfare; or may be part of a hospital discharge process, including arrangements for 'reablement'.

In Leeds, where local policy (when the study was set up) was to offer telecare widely, and to provide a package of equipment carefully tailored to the person's needs, factors taken into account by the telecare assessor included: their identified health and social care needs; the type of accommodation they occupied; whether they lived alone or with others and the set of hazards which they might encounter, given these circumstances; their health situation; and their degree of impairment (for discussion of different types of impairment, see, Fry, 2014, Paper 4). In Oxfordshire, where charges for telecare applied during the study, and service provision was more complicated (as described in Section 2), most people initially agreed to have, or were allocated, only a pendant alarm.

In the AKTIVE study, participants were selected because they were either susceptible to falls or had memory problems. A few of those at risk of falls had been allocated fall detectors (which can detect a fall and summon assistance even if the person loses consciousness), but most relied on their pendant alarm and used this to call for help themselves if they fell (as some respondents did during the study). Those with memory problems were often supplied with memory aids, environmental sensors and activity monitoring devices and some had GPS tracker devices (Table 1.3). As discussed in Fry (2014, Paper 4), these devices 'supported' users, making them feel more secure and enabling them to continue with chosen activities, but could, for some, be (or seem to be) an 'impediment' to their preferred lifestyle or (in a few cases) somewhat irrelevant to their needs and circumstances.



## Table 1.3

## ELA research participants by health status and telecare in place at start of study

Health	Tolocaro at start	Where dat	All	
		Leeds	<b>Oxfordshire</b> <sup>1</sup>	All
Falls	Pendant alarm only	2	19	21
	Package	13	2	15
	All falls	15	21	36
Memory problems	Pendant alarm only	0	1	1
	Package	1	2	3
	Other single item	0	1	1
	GPS	1	0	1
	GPS + Package	3	0	3
	All memory problems	5	4	9
Falls AND memory problems	Pendant alarm only	0	10	10
	Package	3	0	3
	Other single item	1	1	2
	All falls & memory problems	4	11	15
	Pendant alarm only	2	30	32
ALL	Package	17	4	21
	Other single item	1	2	3
	GPS	1	0	1
	GPS+Package	3	0	3
	All ELA participants	24	36	60

Source: AKTIVE ELA database, CIRCLE, University of Leeds.

<sup>1</sup> Two cases recruited in Buckinghamshire (one person suffering from falls, one from both falls and memory problems) are included in the Oxfordshire column, as they were recruited by the researchers working there.

Other papers in this collection examine the circumstances and contexts in which older people with telecare equipment in place 'used' the equipment supplied (although many devices in place were 'passive', requiring minimal, or no, action by the user) and the extent to which they 'embraced' the equipment, found it useful, or used it as a 'bargaining counter' to enable them to remain in their own homes. Some rejected certain



types of equipment, and Papers 4 (Fry, 2014) and 5 (Hamblin, 2014) examine why that was the case; others 'ignored' it, set it aside, forgot about it, or chose not to use it, as explained in Papers 3 (Koivunen, 2014) and 4 (Fry, 2014).

Although it is well known that many older people fail to wear, or dislike wearing, their personal alarm pendants or other telecare devices, the AKTIVE study is unique in having studied over time the way a group of older people whose other circumstances, attitudes and values have also been explored, respond to this type of support. This adds new knowledge of which types of equipment were usually or regularly 'in use' once supplied (i.e. were worn, switched on, connected up, etc.), and which were not (sometimes set aside in cupboards, placed out of reach, hidden from view or forgotten about).

The study enabled the researchers to explore the extent to which the 'under-use' of telecare equipment in place in older people's homes is linked to their own characteristics, attitudes and contexts and how far it is about the equipment itself, its acceptability, design and functioning. These issues, and older people's knowledge of the equipment and its purpose and potential uses, are explored in detail in Fry, 2014, Paper 4, and in later papers forthcoming in the collection.

The telecare equipment in place changed during the study for some participants, as shown in Table 1.2. A few items were rejected: bed sensors and fall detectors proved troublesome to some, for example; but many new items were welcomed by the older people who received them. Items such as the bogus caller alert, temperature extremes sensors and smoke and carbon monoxide detectors, all linked to the monitoring centre, were often extremely well received (Table A.2, Appendix to the AKTIVE Working Paper Series).

During the study, participants built confidence in the researcher visiting them and some admitted that they were troubled or annoyed by, or unable to use, devices which, it transpired, they were using incorrectly, or did not fully understand. Examples of these are given in Koivunen, 2014, Paper 3. Learning from this, about the information older people, their carers and home care workers may benefit from or need, both in general and relating to selected items of equipment, was applied in AKTIVE workshops with key stakeholders, held in April and May 2014, and in the project's policy-focused outputs.

\* \* \* \* \* \* \* \* \* \* \* \* \*

This paper introduces the AKTIVE Working Paper Series. For full understanding of the AKTIVE Everyday Life Analysis findings, it should be read in conjunction with Working Papers 2-5, published April 2014, and Working Papers 6 onwards, forthcoming May 2014.

## References

AKTIVE Consortium (2013) *The Role of Telecare in Meeting the Care Needs of Older People: themes, debates and perspectives in the literature on ageing and technology,* AKTIVE Research Report Vol.1, online publication: <a href="http://www.aktive.org.uk/publications.html">www.aktive.org.uk/publications.html</a>, ISBN: 978-0-9570900-3-3.

Care Choices (2014) *Reablement: helping you get your confidence back'*, Care Choices online information service, <u>www.carechoices.co.uk</u>.

Francis, J., Fisher, M. and Rutter, D. (2011) *Reablement: a cost-effective route to better outcomes*, Research Briefing 36, London: Social Care Institute for Excellence, <u>www.scie.org.uk/publications</u>.

Fry, G. (2014) *Coping with Change: frail bodies and daily activities in later life,* AKTIVE Research Report Vol. 2, Working Paper 4, Leeds: CIRCLE, University of Leeds, <u>http://circle.leeds.ac.uk/</u>.

Hamblin, K. (2014). *Risk, Freedom and Control in Older People's Lives: the relevance of telecare*, AKTIVE Research Report Vol. 2, Working Paper 6, Leeds: CIRCLE, University of Leeds, <u>http://circle.leeds.ac.uk/</u>.

Koivunen, E.-R., (2014) *Telecare and Older People's Social Relations*, AKTIVE Research Report Vol. 2, Working Paper 3, Leeds: CIRCLE, University of Leeds, <u>http://circle.leeds.ac.uk/</u>.

LCC [Leeds City Council] (2011) *Reablement: helping you get your confidence back to live independently in your own home and local community*, Leeds: Leeds City Council Communications (Social Care), <u>www.leeds.gov.uk</u>.

LCC [Leeds City Council] (2012a) Leeds Community Equipment and Telecare Service Annual Report 2011-12, <u>http://www.leeds.gov.uk/docs/</u>.

LCC [Leeds City Council] (2012b) *Report to Executive Board on Telecare Equipment for the Leeds Telecare Service 2012/13,* 7 March 2012, CSR No. 21032, <u>http://democracy.leeds.gov.uk/documents/</u>

LCC [Leeds City Council] (2013) Charges for Non-Residential Adult Social Care, Executive Board Paper 22, 24 April 2013, http://democracy.leeds.gov.uk/documents/.

Lloyd, J. (2012) The Future of Who Uses Telecare, London: The Strategic Society Centre.

OCC [Oxfordshire County Council] (2012) An update report on the Re-ablement Service, Crisis Response Service and Supported Hospital Discharge Service, paper to Adult Services Scrutiny Committee, 25 September, www.mycouncil.oxfordshire.gov.uk.

OCC [Oxfordshire County Council] (2013) *Alert Service Review*, Older People's / Physical Disabilities Joint Management Group, council paper, December 2013.

Sanders, C., Rogers, A., Bowen, R., Bower, P., Hirani, S., Cartwright, M., Fitzpatrick, R., Knapp, M., Barlow, J., Hendy, J., Chrysanthaki, T., Bardsley, M. and Newman, S.P. (2012) 'Exploring barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial: a qualitative study' *BMC Health Services Research* 12: 220, http://www.biomedcentral.com/1472-6963/12/220.

Scottish Government (2009) *National Telecare Development Programme in Scotland: glossary of terms and definitions,* Edinburgh: The Scottish Government.

Steventon, A., Bardsley, M., Billings, J., Dixon, J., Doll, H., Beynon, M., Hirani, S., Cartwright, M., Rixon, L., Knapp, M., Henderson, C., Rogers, A., Hendy, J., Fitzpatrick, R. and Newman, S. (2013) 'Effect of telecare on use of health and social care services: findings from the Whole Systems Demonstrator cluster randomised trial' *Age and Ageing*, 42, 4; 501-508.

Yeandle, S. (2014) *Frail older people and their networks of support: how does telecare fit in?* AKTIVE Research Report Vol. 2, Working Paper 2, Leeds: CIRCLE, University of Leeds, <u>http://circle.leeds.ac.uk/</u>.

Yeandle, S., Buckle, P., Fry, G., Hamblin, K., Koivunen, E.-R. and McGinley, C. (2014) *The AKTIVE project's social, design and prospective hazard research: research methods*, AKTIVE Research Report Vol.3, Leeds, CIRCLE, University of Leeds, <u>http://circle.leeds.ac.uk/</u>.



phone: +44 (0) 113 343 5003 email: contact@aktive.org.uk web: www.aktive.org.uk

CIRCLE, School of Sociology and Social Policy, University of Leeds, LS2 9JT, UK



