Research Report Volume 3

The AKTIVE project's social, design and prospective hazard research:
research methods

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AKT|VE

Advancing **K**nowledge of **T**elecare for **I**ndependence and **V**itality in later lif**E**

Technology Strategy Board
Driving Innovation

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Contents

Abbreviations

AKTIVE	Advancing Knowledge of Independence and Vitality in Later Life
DeNDRoN	Dementia and Neurodegenerative Diseases Research Network
ELA	Everyday Life Analysis
ESCR	Electronic Social Care Records
ESRC	Economic and Social Research Council
IRAS	Integrated Research Application System
iVi pendant	Intelligent pendant (Tunstall product)
LCC	Leeds City Council
MHRA	Medicines and Healthcare Products Regulatory Agency
NHS	National Health Service
NIHR	National Institute for Health Research
NRES	National Research Ethics Service
OCC	Oxfordshire County Council
PNC5	Monitoring centre software in use during AKTIVE
R&D	Research and Development
REC	Research Ethics Committee
SREC	Social Care Research Ethics Committee
SRT	Social Research Team
SSI	Site-Specific Information
SWIFT	Software widely used in local government information systems
TOM	Mobile communications database in use during AKTIVE
TSB	Technology Strategy Board
WP	Work package

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Chapter 1

Introduction

This volume, Research Report III of the AKTIVE (Advancing Knowledge of Telecare for Independence and Vitality in Later Life) project, presents an account of the research undertaken by the AKTIVE Social Research Team (SRT), working with the support and research contributions of some members of the AKTIVE Consortium (Appendix I). It focuses on the research design, the implementation arrangements for the study and the methods used. Copies of the research instruments developed by the team to collect data for analysis are provided in a separate online appendix (see p3). The volume complements AKTIVE Research Report I, which presented the AKTIVE project's review of relevant literature (published 2013), and AKTIVE Research Report II, comprising a set of Working Papers which present findings from the study.

1.1   Background to the study

The AKTIVE project was developed through a process initiated by the Technology Strategy Board (Section 2.1). It was conceived in a new collaboration between two academic and two industry partners (Section 1.2) and focused on older people living at home with different types of frailty. The partners' shared ambition was to develop a project which could address *challenges* arising from population ageing and *opportunities* arising from technological progress. They hoped their work would add to knowledge of the lives, needs and aspirations of older people, their families and carers and would enhance understanding of how they and the home care and other service providers who attend frail older people living at home might access, engage with and make best use of the 'telecare' equipment available to them[1]. The two academic partners, based in leading university research centres, had previously studied older people and carers and had already explored the role technology can play in supporting them. The two industry partners were England's market leader in the supply of telecare equipment and services and an SME focused on market research and commercialisation activities.

1.2   About the AKTIVE project

Commissioned through the Technology Strategy Board's 2010 competition for Social and Behavioural Studies, the AKTIVE project commenced in June 2011 and ran until the end of May 2014. Its overarching purpose was to explore how older people, particularly those susceptible to falls or who have cognitive impairments, may benefit from having access in and around their homes to various types of telecare technology and how these affect the other people and systems involved in their care.

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[1] The following definition of telecare has guided the SRT in developing the study: 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 (ICT) to trigger human responses, or shut down equipment to prevent hazards*' (Scottish Government, 2009, *National Telecare Development Programme in Scotland: glossary of terms and definitions,* Edinburgh: The Scottish Government).

The project operated through a partnership which comprised two research centres (CIRCLE[2] at the University of Leeds and OIPA[3] at the University of Oxford) and two commercial companies, the telecare manufacturer Tunstall Healthcare (UK) Ltd and the market research and commercialisation company Inventya Ltd. Throughout, the partnership had strong support from its specially established Consortium, comprising experts from a wide range of relevant professions and academic disciplines, and an Advisory Board with expert members drawn from across the UK and Europe (Appendix I).

Volume 1 of the AKTIVE Research Report[4], a literature review published online in May 2013, was released to coincide with the AKTIVE mid-project conference in London at the same time (Appendix II). This presented the literature review work undertaken by the AKTIVE Social Research Team and Consortium members in 2011-13, which was designed to harness existing knowledge and experience, ensure the new programme of research was implemented with the benefit of its Consortium's expertise, and locate the project in the existing academic and 'grey' literature on telecare.

The present volume (AKTIVE Research Report Volume 3) provides an account of the AKTIVE project's social research and related activities. It covers the study design and research methods used, including a description of the data collected, considers some of the issues the team faced in gathering this material and offers a detailed record of the procedures and research instruments used in completing the study.

1.3   Summary of AKTIVE outputs and impact

The AKTIVE project's outputs to April 2014 are listed in Appendix II to this report. They include:

- two conferences organised by the AKTIVE partners, in May 2013 and April 2014, to share and debate the project findings with an external audience; and

- 16 speeches and presentations about the work of AKTIVE given by members of the AKTIVE Social Research Team and Consortium at external events and academic meetings in the UK and overseas.

The full impact of the project is expected to emerge in the years which follow its completion in May 2014 and the dissemination of the findings of the social research study which has been its centrepiece. Impact thus cannot be fully reported at this stage. In 2014-15, some team members will undertake a new study using the AKTIVE project's Everyday Life Analysis (ELA) method (Section 6) to explore the use and effectiveness of telecare for older people with dual sensory impairment. Colleagues overseas have shown interest in the methodological approach developed for AKTIVE, and researchers at the University of Sydney, Australia, are preparing a research proposal for a project inspired by it.

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[2] CIRCLE is the Centre for International Research on Care, Labour and Equalities at the University of Leeds.
[3] OIPA is the Oxford Institute of Population Ageing at the University of Oxford.
[4] 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: www.aktive.org.uk/publications.html, ISBN: 978-0-9570900-3-3.

This volume, AKTIVE Research Report Volume 3, focuses on the AKTIVE research design and methods and is organised as follows:

- **Section 2** outlines the study's original aims and describes the research design.

- **Section 3** explains how the SRT prepared to implement the study, and covers the ethical approval processes required and the training undertaken by the team.

- **Section 4** summarises the methods used to gather initial 'stakeholder' perspectives.

- **Section 5** summarises the methods used to capture the perspectives of carers[5] and care workers on the use of telecare with older people living at home.

- **Section 6** provides an outline description of the ELA method which the team developed as part of their innovative strategy for studying the lives of frail older people living at home, designed to capture their experiences, aspirations, perspectives and feelings and to describe how telecare was used to support them. It includes the contribution made by design researcher Chris McGinley.

- **Section 7** describes the work undertaken by the SRT in collaboration with members of the Consortium, including the two Telecare Services which provided support to the project team in developing the study and recruiting suitable telecare users for it.

- **Section 8** outlines the work undertaken by Consortium member Professor Peter Buckle, in collaboration with the SRT, which explored information flows and applied prospective hazard analysis to the telecare delivery and support systems under study.

- **Appendix I** provides information about the members of the AKTIVE SRT and outlines their roles and responsibilities within the project. It also lists members of the AKTIVE Consortium and Advisory Board, and their institutional affiliations.

- **Appendix II** provides a list of the study outputs to date.

- **Appendix III**, available as a separate on-line document, provides readers with access to details of the methodological approach and includes the research instruments developed specifically for the study. The team hopes others will find these useful. Provided appropriate acknowledgement is made (of the AKTIVE project, the project funders and the SRT), the team is happy for other researchers to use or adapt these.

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[5] Throughout this volume, the term 'carer' is used to refer to people who provide their support unpaid, as a family member, neighbour or friend.

Chapter 2

Research aims and study design

2.1 The TSB Social and Behavioural Studies call

In May 2010, the Technology Strategy Board (TSB), in collaboration with the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR), launched a call for funding applications to develop projects within its Assisted Living: Economic and Business Models and Social and Behavioural Studies programme. Within the 'Social and Behavioural Studies' element of the call, the commissioners aimed to enhance 'understanding of the interactions between Assisted Living technologies and services and individuals, families and communities'[6].

The key ambition set out in the programme prospectus was to commission projects which could generate knowledge capable of helping policymakers and practitioners develop better understanding of:

- *the wide range of 'users' of assisted living technology and their varying contexts, including families and carers;*

- *the current and future nature of assistive living technologies and services;*

- *the relatively low demand for new assisted living technology at individual, family, community levels;*

- *the relatively low demand for assisted living technology at an organisational level, for example through Primary Care Trusts, Local Authorities and the Third sector.*

The proposal put forward by the AKTIVE project partners addressed these issues, aiming to explore the particular impact of the various forms of 'telecare' technology used in people's homes (for a discussion of what constitutes 'telecare', see AKTIVE Research Report Volume 1, Section 4.2).

2.2 Aims of the AKTIVE project

To plan and develop the project, the partners brought together an informal group of potential collaborators to discuss the design for the funding proposal. This included: industry and commercial partners; care commissioners; policymakers and practitioners in health and social care; voluntary agencies representing older people and carers; leading technical and medical experts; and other academics. Through this process the partners, led by Dr Andreas Hoff[7] (then at the University of Oxford) and Professor Sue Yeandle (at the University of Leeds), identified the initial study design, invited selected collaborators to join the planned Consortium and agreed initial objectives, which were to investigate:

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[6] http://webarchive.nationalarchives.gov.uk/20130221185318/http://www.innovateuk.org/_assets/pdf/competition-documents/briefs/assistedlivingmodelscomp.pdf

[7] Dr Hoff was appointed Professor of Social Gerontology at the University of Zittau-Goerlitz, Germany in autumn 2011 and was consequently unable to act as co-Director of AKTIVE, as originally intended. He remained involved in AKTIVE as a member of its Advisory Board and continued to offer support and guidance to the Social Research Team, which gratefully acknowledges his role in conceptualising and designing the project.

- the circumstances and characteristics of selected groups of telecare users and the contexts in which telecare[8] was being used (via comparison of older people with a recent or existing diagnosis of dementia and who were susceptible to falls, in northern and southern England);

- how telecare was being used in private homes, and its significance for the users, carers, agencies and workers living and operating within those homes;

- how, when and in what ways carers were (or were not) benefitting from the use of telecare in older peoples' homes, and whether this affected their capacity to remain in employment;

- what barriers to the adoption of telecare existed, at the levels of the individual, the family, the local community or local services, and what innovations were needed to overcome them;

- what opportunities telecare offers to improve job design, job quality and care outcomes: for care workers; for home care and other service providers; for care commissioners; for other health and related workers who attend older people at home; and for older people themselves and their carers;

- the state of the current and future market for telecare (and other forms of Assistive Living Technology) and how best to enhance innovation and increase take-up of technical developments.

2.3   Research questions

To achieve the study aims, the team developed the following main research questions around which its research design and methods were subsequently planned.

- How do older people's capabilities and their social environment influence their uptake of telecare and what barriers impede the successful integration of telecare into older people's everyday lives?

- What are the benefits of using telecare for older people suffering from dementia or susceptible to falls? To what extent do their telecare needs, and any benefits they may derive from telecare, vary according to their medical condition(s) (*focusing on dementia vs. susceptibility to falls*)?

- What factors affect older people's care-givers' ability to use telecare, and what are the key benefits to them? (*Here 'care-givers' were conceptualised to include both carers and care workers*.)

- How does telecare contribute to better and / or more cost-effective service delivery to older people in their homes, through adjustments to the design or content of their jobs, or produce benefits for care workers through changes to the way their jobs and work are organised?

2.4   Study design and methods

The AKTIVE project was approved for funding, in principle, in autumn 2010. In the early part of 2011 the partners agreed a detailed plan for the implementation of all aspects of the project (set out in a series of 'Work Packages') and agreed a formal partnership agreement. Arrangements were also made during this time to agree sub-contracts with members of the Consortium which set out their roles in the overall project.

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[8] The original application used the term 'Assisted Living Technologies', which was used in the TSB prospectus. As the AKTIVE project focused from the outset on 'telecare', this term is substituted here, for clarity about its focus (see also Section 1, footnote 1).

The AKTIVE project work packages (WPs) relevant to the social research study within it, whose development is described in this methodological report, were:

- WP1 'State of the art' review of literature and evidence

- WP2 Interviews with stakeholders

- WP3 Focus groups with care workers

- WP4 Secondary analysis of telecare monitoring data

- WP5 Everyday Life Analysis

- WP6 Focus groups with carers

- WP7 Prospective Hazard Analysis

The Social Research Team (SRT), with members of the Consortium, commenced WP1 in 2011 and published the main output from this work in May 2013 (Section 1 and AKTIVE Research Report Volume 1).

WP2 was undertaken in 2011-12, and produced interviews with 15 stakeholders. It was used to inform the subsequent development of WPs 3 to 6 (Section 4).

WPs 3 and 6 were undertaken by members of the SRT and in 2012-13 produced data based on interviews with 24 carers and 35 care workers respectively (Section 5).

WP4 involved close working with the two local authorities and their partners throughout the lifetime of the project. Although it proved impossible to achieve some planned analysis because of problems with the way these data were collected and stored, this WP enabled the team to develop a good understanding of the issues involved, and to produce recommendations about telecare monitoring data (Section 7).

WP5, the centrepiece of the AKTIVE social research activities, comprised a detailed study of the everyday lives of a sample of older people who were users of telecare. A total of 70 older people were recruited to the ELA element of the study, and 60 participated in sufficient interviews, over a long enough period of time, to be included in the final sample for ELA analysis (Section 6).

WP7, led by Consortium member Professor Peter Buckle, also involved workshops, visits to telecare monitoring centres and other activities (Section 8).

This report presents a full account of the methods and techniques used in implementing the study, with further detailed material available in Appendix III.

2.5   Development and implementation of the study

The AKTIVE project was planned with the full co-operation of the local authorities responsible for providing services to adults with social care needs in Leeds and Oxfordshire. Both LCC and OCC agreed sub-contracts with the project partners at the outset, and received agreed resources to support their involvement. Under the terms of these agreements, they were to provide research access, support the SRT in implementing the study, and contribute to the activities of the AKTIVE consortium.

Throughout the project the SRT was in regular contact with both authorities, whose staff supported the implementation of the research by: providing the team with detailed information about the local telecare service; identifying telecare clients who met the inclusion criteria for the study and assisting the team to contact them[9]; and supporting the team to access and analyse available telecare monitoring data.

The support provided by the two local authorities was affected by the local arrangements in place for providing and delivering the telecare service. These were rather different in the two research sites; the main features of the telecare services for which LCC and OCC were responsible during the lifetime of the AKTIVE project, are set out below:

Leeds City Council

- Most aspects of the telecare service in Leeds were provided by LCC's own organisation, the Leeds Telecare Service, whose role included: researching and testing the equipment used, sourcing this from a range of different suppliers; training staff involved in assessing clients' telecare needs; and installing and maintaining the equipment in clients' homes following referral for telecare.

- Where appropriate, adults aged 65+ resident in Leeds were assessed for telecare variously by LCC Adult Services Department social workers, local health professionals and local voluntary agencies subcontracted to LCC, who referred suitable clients to the Telecare Service, which was then available without charges to telecare users. To be eligible for telecare, clients did not need to meet FACS[10] criteria and no means-test was applied.

- Monitoring of telecare use and calls was also undertaken within LCC, by its Care Ring response centre. Clients were asked to provide details of two people who held keys to their homes and agreed to be contacted in an emergency. Where this was not possible, LCC provided a back-up emergency response.

Oxfordshire County Council

- Client telecare assessments in Oxfordshire, and the installation of pendant alarms, were outsourced to a not-for-profit company, Community Voice, which also provided the emergency response service to telecare clients where this was not provided by clients' own choice of named 'emergency telecare responder'.

- The contract for equipment supply was held by a single commercial company, Tunstall Healthcare (UK) Ltd, which also installed the telecare equipment in clients' homes where equipment beyond a simple pendant alarm was provided.

- The telecare monitoring service was 'contracted out' to a separate company, Eldercare.

- The service was offered to residents living in the Oxfordshire area as a means-tested service, but (as in Leeds) FACS criteria were not applied in assessing a client's need for telecare.

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[9] This included contact with organisations providing outsourced elements of the telecare service in Oxfordshire.
[10] 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 http://www.scie.org.uk/publications/guides/guide33/).

Chapter 3

Preparing the ground

Once work on the AKTIVE project began in June 2011, the team undertook the preparatory work needed to begin implementation of the study. This included obtaining approval for the study from a number of research ethics committees, arranging bespoke training for the Social Research Team (SRT) in undertaking research with people with dementia or memory problems, and (once the literature review and preliminary research with stakeholders, carers and care workers had been completed) reviewing and refining the aims of the study, making adjustments as necessary to the study research questions. This section describes how this work was carried out.

3.1   Research ethics: approvals and implementation

Prior to implementation of the social research elements of AKTIVE, the research team obtained ethical approval for the study from relevant committees within the Universities of Leeds and Oxford, research governance approval from Leeds City Council[11] and national Social Care Research Ethics Committee (SREC) approval. Later, to support participant recruitment, ethical approval was also obtained from the Oxford Health NHS Foundation Trust. Together, these approvals covered: the participant recruitment strategy; methods for enrolling study participants, including approved participant information sheets (Appendix III, Document A1) and consent forms (Appendix III, Document A2); the research instruments used to collect data from study participants; and the arrangements for data protection, managing confidentiality and storage of the data collected.

The team's participant recruitment strategy for the ELA element of AKTIVE involved working with the telecare services of AKTIVE Consortium members, Leeds City Council and Oxfordshire County Council. Both services agreed to approach new and existing telecare users during their routine assessment and reassessment processes, to identify clients who were willing to be contacted about joining the study[12]. The team applied to SREC for ethical approval (submitting documentation[13] through the SREC Committee's Integrated Research Application System [IRAS] and attending a Committee meeting to respond to questions about the study), which was given in February 2012, once minor amendments to the supporting documentation had been made[14].

As the project progressed, recruitment of study participants with dementia and / or memory problems proved slower than expected in Oxfordshire, and the team sought advice about this from AKTIVE Consortium member Dr Rupert McShane (a clinician specialising in dementia). With his support, the team approached the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) to assist with this aspect of recruitment[15]. This proved a successful strategy, but required additional ethical approval (as

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[11] As SREC approval was sought / awarded, Oxfordshire County Council did not require local ethical approval.

[12] These clients were Adult Social Care service users, so SREC approval was needed prior to implementation of this approach.

[13] The project proposal, the principal investigator's CV, participant information sheets, consent forms, proof of indemnity and a letter confirming receipt of funding.

[14] In the study, compliance with ethical approval was an ongoing process; amendments to project plans and additional research materials were submitted to the SREC for approval, and the team submitted annual reports to SREC (and will provide a final report to SREC when the project ends).

[15] DeNDRoN is an NHS body, funded by the National Institute for Health Research (NIHR), which supports research by facilitating the recruitment of research participants for research on neurodegenerative diseases.

respondents would be NHS patients). The study's existing SREC approval eliminated the need to apply for National Research Ethics Service (NRES) approval, but applications to the Oxford Health NHS Foundation Trust for Research and Development (R&D) and Site-Specific approvals were required[16].

All the team's applications for ethical approval were successful, and the team adhered to the agreed processes during the implementation of the study.

3.2   Bespoke training in researching people with dementia

As the project included research participants who were older people with dementia or memory problems (a group with whom the research staff had not previously worked), the team sought specialist advice on working with these participants, to help them develop relevant skills and ensure they had adequate awareness of the conditions involved.

Bespoke training was arranged with the Bradford Dementia Group (BDG) at Bradford University, led by Professor Murna Downs. This included two one-day sessions with BDG specialists which ensured the research team understood the different types of dementia and how these can affect memory, behaviour and social interaction, and helped the team consider how to approach the fieldwork with these study participants. The sessions also helped the team apply the knowledge gained through Rupert McShane's contribution to the initial literature review (AKTIVE Research Report Volume 1, Chapter 1).

Following the sessions with the BDG, the team adapted three aspects of the planned arrangements for implementing the study:

- Research instruments: a photograph of the researcher was included in the materials left with the research participant, to help him / her remember the researcher, and to give family members more information. Some additional supporting materials and techniques were also developed for use in the research visits and interviews with participants with memory problems.

- Preparation for interviewing: the dementia training sessions ensured the team felt confident about adjusting and adapting the research instruments and memory aids used to suit each research participant. This could be done, as the ELA methodology encourages researchers to be flexible and responsive in fieldwork interactions, interviews and observations. The training sessions also prepared the researchers to observe, listen and 'think on their feet', and to gather the data accessible to them rather than to feel constrained by the need for rigid adherence to every detail of each topic guide.

- Preparation for interacting with participants with dementia and their family carers: the discussions about how to observe and respond to the interactions between research participants with dementia and their family members increased the team's awareness of the need to allow family members to contribute their views and perspectives. They also helped the team recognise that while family members' 'corrections' to the 'factual' information supplied by the person with dementia were relevant parts of the data collected, it was also important to ensure that the voice, point of view and perspectives of the person with dementia were also heard, responded to and recorded in the team's fieldwork notes.

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[16] This involved some amendments to the earlier IRAS and NIHR Portfolio applications, accompanied by supporting documentation.

3.3   Refinement of the research aims

The initial literature review, *The role of telecare in meeting the care needs of older people: themes, debates and perspectives in the literature on ageing and technology* (http://www.aktive.org.uk/publications.html) familiarised the research team with different disciplinary perspectives on ageing, design, and telecare policy and helped them reflect on and refine the original research aims and questions (Sections 2.2 and 2.3).

This clarified the study's focus on telecare as a specific sub-set of assisted living technologies (ALTs), and highlighted the need to study the service-related elements of telecare (including the monitoring and response arrangements in place). It also alerted the team to the importance of design features and to how older people's previous experience of other types of technology was likely to affect how they approached, used and could benefit from telecare.

The team's subsequent detailed work on planning the implementation of the study led to a decision to adjust two of the original research questions (Section 2.3), to ensure the ELA fieldwork took an holistic approach in the interactions with older people and created opportunities to explore how their perspectives and circumstances in old age related to their experiences throughout the life course. (These changes are reflected in research questions 1 and 2 below.)

The literature review also drew attention to the need for a proactive strategy to ensure the team was able to collect data about how carers, care workers or others involved in an older person's care viewed, engaged with and responded to the telecare in place. This led the team to split the original research question 3 (Section 2.3) into two questions, to ensure its approach could capture the particular challenges and benefits of telecare relevant to different members of the 'caring network' which was in place (in some cases) to support the older people being studied (research questions 3 to 5 below)[17].

The revised 'main' research questions, which guided subsequent development of the study, were thus:

1. What are the characteristics of older people who use telecare, and in what context are they doing so? (*With a focus on older people with dementia and / or susceptibility to falls*.)

2. How is telecare equipment used in private homes, and what is its significance for the users, carers, agencies and workers operating there?

3. How, when and in what ways can (unpaid family) carers benefit from the use of telecare in older peoples' homes (and does this affect carers' capacity to remain in paid employment)?

4. What are the barriers to the adoption of telecare for individuals, families, local communities and service providers (and what innovations are needed to overcome them)?

5. Does telecare offer opportunities to improve job design and job quality for care workers, providers and commissioners, or for other health and related workers who attend older people at home, and does it improve outcomes for older people and their carers?

6. What are the main features of the current / future market for telecare, and what can be done to enhance innovation and improve take-up of appropriate technical developments?

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[17] The way the concept of a 'caring network' was developed and operationalised within the AKTIVE project is discussed in Yeandle, 2014, Paper 2 in AKTIVE Research Report Volume 2.

Chapter 4

Stakeholder interviews

Prior to commencing collection of new empirical data, the team conducted a series of 'stakeholder' interviews, designed to ensure that the main elements of the data collection outlined in Section 2.4 were informed by understanding of current thinking among key experts, practitioners and policy-makers. AKTIVE Consortium and Advisory Board members gave advice on the selection of these interviewees.

4.1   Sample selection and data collection

Four categories of potential interviewees with relevant knowledge or expertise were identified: academics; care professionals; care commissioners; and policy makers. Twenty-four people were approached and interviews were secured within the agreed time-frame with fifteen: three academics; three care professionals; four care commissioners; and five policymakers. Tailored topic guides were produced (Appendix III, Document A3), covering the following issues: *telecare and policy*, including how telecare fits in with broader national / local authority policies and what drives this agenda; *challenges in implementing telecare policies,* at the macro (national), meso (local authorities) and micro levels (individual users and their carers); *the impact of telecare on service users and their carers*, including the use and uptake of telecare by these groups; and *the benefits and limitations of current telecare products and services*, including how these technologies can be improved / changed in the future.

4.2   Data analysis and influence of stakeholder interviews on the study

Analysis of the stakeholder interviews helped the team refine some of the themes AKTIVE would explore, influenced detailed planning of the study, and brought the following issues into sharper focus:

- *Variations in how telecare services have been developed and implemented in different localities:* as two local authorities were Consortium members, AKTIVE could explore their different approaches and consider how different delivery models may affect use of telecare and how older people and carers become aware of and respond to it.

- *Nationally, telecare training and awareness-raising for health and social care staff had been inconsistent:* AKTIVE could explore telecare assessment arrangements, and ask: are assessments holistic and person-centred?; which professionals deliver support that older people and carers value; what training do staff get, and does it affect how telecare is received?

- *Past attempts to demonstrate the cost effectiveness of telecare had overlooked some issues:* within AKTIVE, the team could collect information on how using telecare affects the financial circumstances of older people and carers, and review evidence available in the two local authorities about cost-savings arising from telecare.

- *Historically, some people working in social care had viewed telecare with concern:* AKTIVE could add new evidence about whether older people, carers and care workers using telecare view it as an intrusive form of surveillance, fear it may replace face-to-face care, or feel it increases isolation among older people. The study could explore: if perceptions change over time, with experience of using telecare; and whether older people and those involved in supporting them hold conflicting views about telecare.

- *When working with people with dementia, memory problems or susceptible to falls, some professionals lack the skill, knowledge, sensitivity or creativity needed to tailor social care and telecare packages:* the study's longitudinal aspect meant it could examine: how professionals working with older people with these conditions select the support and telecare they offer; how they adjust support as older people's needs change; whether telecare is a suitable way of supporting people with these conditions; and how any benefits from telecare are distributed between older people, carers, care workers and the wider system of support.

- *When telecare is provided, why are specific items chosen, and how do they interact with other support?* AKTIVE could examine older people's understanding of: why specific items of telecare equipment were recommended; if these sustained their abilities or enhanced their lives; whether they felt involved in choosing this form of support; and how their experiences affected how they used, accepted or rejected the equipment.

- *Some telecare services have focused on managing risk rather than enabling users to live as they wish:* the study could investigate whether telecare equipment was installed with older people's existing abilities in mind, and whether older people found the equipment enabling and supportive of their own choices in later life.

- *Conflict over the use of telecare can arise between older people and their carers:* the ELA elements of AKTIVE would enable the team to explore any differences between older people's desire to be independent and their carers' concerns about their safety. It could identify whether these changed over time, and could deepen understanding of what the term 'peace of mind', used by older people and carers, means in practice.

- *Telecare technology is continually evolving, and future integration with mobile phones, TVs, etc., is likely*: AKTIVE could consider new developments during the project and could seek to explore the suitability and usefulness of some new products by upgrading the equipment in place in some of the homes studied.

Preliminary interviews with carers and care workers

In line with the original research design, the team planned focus group interviews with carers and care workers as a way of gaining insight into their perspectives on the use of telecare by people with social care needs and to help in designing the research instruments and methods for the ELA fieldwork.

5.1   Sample selection and data collection

To recruit participants for the focus groups with carers, advertisements were placed (in local carers' centres and in the newsletters of local carers' organisations). Eight carers volunteered to participate in Leeds and sixteen in Oxford. The team felt these numbers were too small to run the focus group interviews as planned, and instead offered these volunteers individual telephone interviews, which took place in July-October 2012. Among the 24 interviewees, most carers were women, people of working age (aged 16-64 years) and caring for older relatives[18].

To recruit participants for the focus groups with care workers, the research team approached local authority-registered care agencies in the two localities, speaking with managers and providing flyers for distribution among staff. The response to this was modest; some managers felt many care workers had 'nothing to do with telecare' and that few would volunteer; some felt the £20 'gift' was inadequate to compensate staff for their time away from work attending a focus group. The team set up two focus groups in March-April 2012, but attendance was low: in Leeds five female care workers attended and in Oxford two female care workers. The team subsequently altered the approach, arranging to attend staff meetings at care agencies agreeable to this, where shorter discussions with care workers took place. Six agencies (three each in Leeds and Oxfordshire) were visited in May-June 2012. These sessions were attended by 28 care workers (26 women and two men; 11 in Leeds and 17 in Oxfordshire) and thus 35 care workers in total participated in the discussions about telecare.

The topic guides developed by the team for the carer and care worker interviews are included in Appendix III (Documents A4 to A6). They focused on: carers' and care workers' experiences of telecare and their views about it; how telecare was affecting or had affected them in their caring and professional roles; and the impact of telecare on the person or people they cared for.

5.2   Data analysis, outputs and contribution to the study

The team undertook thematic analysis of the data collected and produced two internal reports which were used in developing the ELA topic guides, recruiting participants and conducting the ELA fieldwork. Points which informed the team's approach related to carers' and care workers': knowledge about and understanding of telecare; concerns about the implementation of telecare arrangements and services; perceptions of how the telecare service they were familiar with affected users and carers; and barriers to the use of telecare by organisations and professionals providing social care support.

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[18] Each carer interviewed received a £20 thank you 'gift' after taking part, as this incentive had been offered in the original focus group recruitment advertisements.

Chapter 6

Everyday Life Analysis

The Everyday Life Analysis (ELA) method chosen to address the AKTIVE project's main research questions was initially conceived by Andreas Hoff and Sue Yeandle and developed during the study by members of the SRT. Based on established principles and practices used in qualitative sociological research and ethnographic studies, it was innovative in: its longitudinal aspect; its holistic but person-centred approach; its use of creative data collection techniques; and its use of expertise from disciplines outside conventional social science, which included close working with design and prospective hazard experts[19], who among other research activities, visited, and collected research data, in a sub-sample of the households included in the ELA element of the study (Sections 6.8 and 8).

6.1   Design of the ELA methodology

The ELA method was designed to include specific features which would enable it to address the study research questions. These included its:

Longitudinal aspect: this involved repeat household visits, over up to a year, to frail older people. This enabled a single researcher to get to know and build research rapport with each and to observe and discuss with them the changes they were experiencing in later life. These included changes in their physical, and in some cases mental, capabilities; shifting risks in their home and external environments; changes in their relationships (which for some included dealing with loss and grief); and changes in their routines and activities, often as a consequence of limitations imposed by illness or disability.

Holistic but person-centred approach: each set of ELA visits focused on a specific older person living at home who had been supplied with telecare equipment. The aim was, over time, to paint a holistic picture, placing the older person in the context of their whole life, identifying their full set of relationships and sources of support, and paying attention to their preferences, chosen activities, values and aspirations. Treating this person as the 'central character' in the data gathered, the researcher sought to explore their perceptions, values and attitudes. The visits were also used to identify and understand how others in their lives were responding to these changes and were affected by the technology in place. This led to development, using sociological 'ideal type' analysis, of the concept of 'caring networks', enabling the team's work to inform understanding of what a 'caring network' looks like; how and why it works; how 'tools' such as telecare equipment affect its functioning; and what needs to be in place for it to offer an older person with significant mental or physical frailty the support they need to live independently and at home.

The study's creative data collection techniques: these were designed with the needs of frail older people in mind. As described in Sections 6.3 to 6.6, during the ELA visits these used talk (interviews and informal conversations), observation, joint activities and exercises; and, between visits, encouraged research participants to reflect on, record and consider their changing circumstances and how the telecare equipment in place was assisting or affecting them, using diaries, photographs and other techniques.

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[19] Chris McGinley and Professor Peter Buckle (see Appendix II).

The study's use of expertise from disciplines outside conventional social science: the AKTIVE project set out to work collaboratively across disciplinary boundaries and to draw on the knowledge and experience of a range of experts. The SRT comprised expertise in sociology, gerontology, social psychology, social policy and social anthropology, but its supporting Consortium brought additional capabilities of particular value in developing and implementing the ELA. Thus the clinicians helped the SRT understand the conditions experienced by study participants and advised on research access; the social care practitioners helped the team access different players in the delivery of telecare support and understand their roles; and the experts on design and on prospective hazard analysis brought a unique and different perspective, yielding insights not conventionally available in social studies of older people and, through this, the potential for significant additional influence and impact (see Sections 6.8 and 8).

6.2   ELA fieldwork

The ELA fieldwork commenced in June 2012 with clear recruitment criteria established in advance to guide the selection of participants. In compliance with these, all the older people recruited met the following criteria by:

- having memory problems / a dementia diagnosis and / or being susceptible to falls[20];

- living in the community;

- being aged 65 years or older;

- being telecare users in one of two categories:

  - new users (due to receive telecare equipment for the first time);

  - established users (with telecare equipment in place for about 12 months or longer).

The study design also enabled any family members, friends, neighbours, carers or care workers who provided support to the older person participating in the study to be included as ELA informants (subject to the agreement of the main research participant).

Recruitment was arranged in partnership with the telecare services of LCC and OCC. Staff in each service agreed to approach clients (new and existing) when assessing or reassessing their needs, and to ask if they were willing to be contacted by the Social Research Team. Where applicable, the SRT approached these potential participants and sent them the participant information sheet (Appendix III, Document A1). A week later, the team re-contacted the person to see if they wished to take part in the study. As indicated in Section 3.1, in Oxfordshire, DeNDRoN also assisted with this process.

The team originally aimed to recruit up to 20 people with dementia or memory problems and 20 people susceptible to falls in each research site (total n=80). As expected, there was overlap between these categories, as people with dementia or memory problems are often also susceptible to falls and in many cases participants' health status changed during the research contact. The composition of the sample by health condition at recruitment is shown in Table 6.1 (although by the end of their involvement in the study, some participants' health conditions had changed).

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[20] 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.

Table 6.1

Research participants, by location and selected health condition at recruitment

Condition	Leeds	Oxford	Total
Falls	15	21	36
Memory problems / dementia	5	4	9
Both falls and memory problems / dementia	4	11	15
TOTAL 'AKTIVE ELA' cases (individuals)	24	36	60

Source: AKTIVE ELA Database, University of Leeds.

Note: Data relate only to AKTIVE participants whose extended participation in the study made them eligible as ELA cases (Section 6.2).

A total of 70 people were recruited to the ELA element of study (33 in Leeds and 37 in Oxfordshire). Of these, 10 (nine in Leeds and one in Oxfordshire) withdrew from the study prematurely because of significant deterioration in health (affecting the research participant or his / her spouse) and in two cases a research participant died before completing the study. By the end of fieldwork, 60 participants had been visited by the researcher at least four times, or had remained in the study for at least six months, and at this stage the SRT decided that only these cases should be analysed as participants in the longitudinal study[21].

The participants recruited by the Oxford researchers included people living in both rural and urban settings and people living in a range of different kinds of accommodation[22]. In Leeds, participants were recruited throughout the city; most lived in urban or semi-urban settings, but a few lived in small villages on the city's outskirts. These participants also lived in a range of different kinds of accommodation, and (as in Oxfordshire) included both owner-occupiers and renters (some in social housing), and people living in houses, flats and supported housing.

Table 6.2

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

Numbers

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
TOTAL 'AKTIVE ELA' cases		39	21	33	8	2	17	41	19

Source: AKTIVE ELA Database, University of Leeds.

Note: Data relate only to AKTIVE participants whose extended participation in the study made them eligible as ELA cases (Section 6.2).

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[21] The ELA design was for six household visits over 6-9 months.

[22] Arising from the additional recruitment via DeNDRoN (Section 3.1), two participants recruited by the SRT in Oxford lived in Buckinghamshire. The relevant local health authority covered both counties.

Selected characteristics of the 'full ELA' research participants (as defined above) are presented in Table 6.2. In four cases (two each in both Leeds and Oxfordshire) the household contained a couple where both spouses used telecare. In these, both were included in the study. Both spouses were included as separate ELA participants if they had their own telecare equipment and took part in the interviews at each visit, making contributions relevant to how they used and responded to their telecare equipment.

In three cases (one in Leeds and two in Oxfordshire) the person for whom the telecare was supplied was a person whose ability to participate in interviews was very limited because of their health. In one case the spouse participated and during the study began to use the telecare equipment present in the home for themselves. In some cases, one or more relatives (the spouse, or an adult child and / or his or her spouse) were present to help a participant take part. This was usually because the participant had dementia and, while they had the capacity to consent, communicated mainly through brief comments and nods and could not engage in prolonged discussion. Some of these relatives were present at every ELA visit made, others at one or more, but not all.

Table 6.3
Research participants by care support available / in place at recruitment

Locality	Carer(s)		Care Worker(s)		Day service or similar support	
	Yes	No	Yes	No	Yes	No
Leeds (n=24)	23	1	11	13	2	22
Oxfordshire (n=36)	33	3	13	23	10	26
TOTAL 'AKTIVE ELA' cases	56	4	24	36	12	48

Source: AKTIVE ELA Database, University of Leeds.
Note: Data relate only to AKTIVE participants whose extended participation in the study made them eligible as ELA cases (Section 6.2).

As discussed in Research Report 2 (Chapter 1), the telecare in place in respondents' homes varied, and differences in how the telecare services operated in the two sites contributed to this. In Leeds, most participants had a mix of equipment, usually including 1st and 2nd generation telecare, and a few had 3rd generation equipment; however in Oxfordshire many participants had only a (1st generation) pendant alarm (for details of the telecare equipment in place in ELA households, see Yeandle, 2014, Paper 2, AKTIVE Working Paper Series Volume 2)[23].

All ELA participants were offered, as part of the study, an additional review of their telecare equipment. In 20 households this led to installation of additional equipment, or upgrading of existing equipment, provided without charge as part of their contribution, by AKTIVE industrial partner Tunstall Healthcare (UK) Ltd. In Leeds, where most participants already had a good range of 2nd generation equipment, the 'upgrades' consisted mainly of replacing the existing pendant alarm with a newly available device, Tunstall's

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[23] 1st generation telecare: user-activated pendant (etc.) alarm equipment; 2nd generation telecare: sensors which monitor home environments, vital signs, physiological measures and lifestyle and transmit information within / outside the home; 3rd generation telecare: broadband, wireless or audio-visual technology for virtual or tele-consultations and to maintain contact with others. For details see Scottish Government (2009) *National Telecare Development Programme in Scotland: glossary of terms and definitions,* Edinburgh: The Scottish Government.

iVi 'intelligent pendant' (which was just coming on to the market and incorporates a fall detector). These were installed in seven Leeds households, together with a newer model of the alarm unit, Lifeline plus. In Oxfordshire, owing to the more limited equipment in place at recruitment, a much wider range of additional equipment was installed as part of the 'upgrading' process, in 13 households (containing 15 research participants)[24].

6.3   ELA visits and Interviews

To sustain the interest and commitment of research participants in this longitudinal study, the researchers developed topic guides for the research visit interviews designed to make participation an enjoyable and engaging experience (Appendix III, Documents A7 to A12). The team hoped this approach would yield good research material and reduce the risk of sample attrition.

To ensure researchers and participants maintained a focus on telecare throughout, each visit and interview included specific questions about how the older person concerned was using and responding to the telecare installed for their use. At the first visit, the researcher clarified the background to the initial installation of telecare; this information was updated at each subsequent visit. This approach enabled research participants to tell the researchers about any events or situations which occurred between visits in which the telecare equipment was used (or could have been used), and provided an opportunity to discuss the older person's feelings about this and their experiences of it. This focus on concrete examples proved valuable in helping the team to record changes in how the telecare equipment was used or experienced, and often yielded opportunities to capture the perceptions of others involved in their care. This material fed into the team's subsequent thematic analysis of older people's changing (in some cases enhanced, in others diminished) acceptance of the technology, and helped them to record the frequency of incidents and crises (with or without telecare use) affecting their everyday lives and the impact which these, and the telecare equipment, had on those involved in their care.

The focus of the six topic guides provided a good stimulus for exploring the lives of the older people in the study, and covered: life course and biographical events; social networks; homes and environments; education and employment histories; health and well-being; and attitudes towards technology. Many participants welcomed the opportunity to reflect on these different aspects of their lives.

The conversations which took place, along with respondents' diary entries (Section 6.4) and photographs (Section 6.5) helped participants recall significant past events and articulate their thoughts, feelings and attitudes about their current circumstances. Participants often said they had greatly enjoyed exploring their personal histories with the researcher, some pointing out that they had very few other opportunities to do so. Their enthusiastic engagement produced very rich, 'thick' data[25] and helped the SRT gain insights into many different features of their lives.

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[24] Details of these arrangements are presented as part of the study findings in AKTIVE Research Report Volume 2. Information about the telecare equipment available to support older people in the study can be found at: http://www.tunstall.co.uk/solutions/products; http://www.leeds.gov.uk/residents/Pages/Telecare-services.aspx; and http://www.jitscotland.org.uk/downloads/1208770184-telecare-glossary-of-terms-and-definitions.doc.

[25] Denzin, N.K (1989) *Interpretive Biography,* Newbury Park, California: Sage.

Because of the age and health circumstances of the older people taking part, the team expected to lose some research participants during the course of the study and, as explained in Section 6.2, a number of participants were unable to complete their planned participation. To minimise sample attrition, the researchers aimed to build a good rapport with each older person and where applicable with members of their caring networks. This strategy proved successful and after the first meeting many respondents looked forward to each subsequent ELA visit. Participants were invited to contact 'their' researcher between visits (by telephone, letter or email) if they wished to discuss any concerns and / or thoughts relating to the project. Some did so, variously to speak about changes affecting their telecare equipment or service, to rearrange a planned visit (to accommodate ill health or unforeseen commitments), or to talk through some aspect of the conversation they had had and about which they had been thinking since the previous visit.
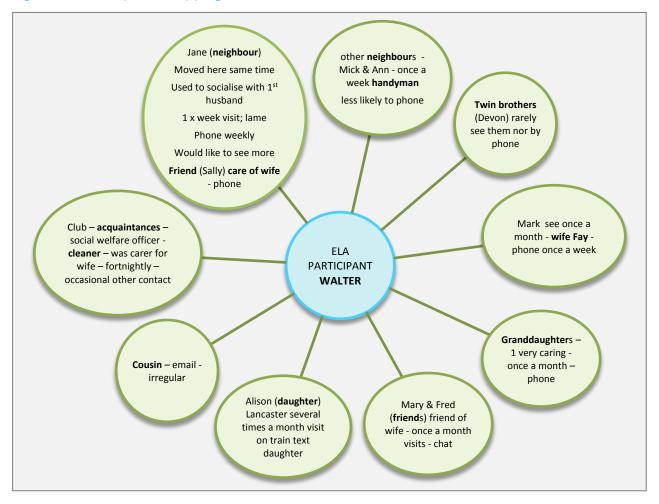
Respondents' family members or carers also sometimes contacted the researcher who had visited, sometimes to speak about aspects of the older person's situation which they had not been able to mention or explore during the visit. These exchanges sometimes included sensitive matters relating to the research participant (for example one carer wanted to explain why the older person had not been told she was suffering from a dementia-related condition); information about how the older person's care needs were affecting the carer; and changes in circumstances relevant to the care situation (such as care services being offered or withdrawn).

Researchers, as expected, sometimes found it challenging to keep participants 'on topic'. The flexibility of the ELA topic guides typically produced, as intended, an open, 'chatty' style of interview, and participants were encouraged to discuss issues they found relevant and meaningful. Some participants were lonely or felt socially isolated and some of them treated the repeat research visits as social events. The researchers encouraged this, considering it a good context in which to collect the research data. Some of the research relationships took on aspects of friendship and researchers developed very good relationships with some participants. SRT members discussed the ethical issues arising from this and the team's strategy for exiting the field was carefully planned.

The team used the topic guides to keep visits focused on exploring the study research questions. They also used additional techniques, including various 'mapping' exercises and the use of images to help respondents focus on appropriate topics. In the exercise used in the visits focused on 'social networks', a laminated card marked with a grid was used to help participants map their social contacts, including their close family and friends, neighbours, health and social care professionals and others performing tasks in or around their homes (such as gardeners, cleaners or hairdressers) (Figure 6.1). Another exercise (used in the 'homes and environments' visit) explored participants' neighbourhoods and communities. Small printed cards, each with a sketch of a common local venue (such as a pub, restaurant or church) were shown to the person and used as a trigger to help them discuss which types of venue they visited, with whom and how frequently, and to articulate their thoughts and feelings about doing so, and about which, in different circumstances, they might like to visit.

Figure 6.1 Example of mapping exercise

Jane (**neighbour**)
Moved here same time
Used to socialise with 1st husband
1 x week visit; lame
Phone weekly
Would like to see more
Friend (Sally) **care of wife** - phone

other **neighbour**s - Mick & Ann - once a week **handyman**
less likely to phone

Twin brothers (Devon) rarely see them nor by phone

Club – **acquaintances** – social welfare officer - **cleaner** – was carer for wife – fortnightly – occasional other contact

ELA PARTICIPANT **WALTER**

Mark see once a month - **wife Fay** - phone once a week

Cousin – email - irregular

Granddaughters – 1 very caring - once a month – phone

Alison (**daughter**) Lancaster several times a month visit on train text daughter

Mary & Fred (**friend**s) friend of wife - once a month visits - chat

Source: AKTIVE ELA Database, University of Leeds.

Note: wording in Fig. 6.1 replicates research respondent's own words; all names are changed.

Most research visits were conducted when the older person was alone, but some took place when a carer or relative was present. While this was often helpful, such visits could be challenging if this person was especially vocal or if the carer tried to 'take over' the conversation, especially when communication was affected by a participant's condition (particularly where this included memory problems), or if the older person found a question hard to respond to.

Some carers were helpful in re-wording questions or comments in ways that the older person was able to understand, but this could become difficult if they 'spoke over' or answered on behalf of the older person. These situations were handled by the researcher directing their remarks and questions more directly to the older person and asking them to clarify or expand on information provided by the carer. The team felt it was important to gain participants' own perspectives on issues and events, wherever possible, even if this took some time or resulted in some ambiguity about what had actually happened.

Overall, the topic guides used worked well in enabling the researchers to explore older people's lives in ways which were enjoyable for both parties and which produced material relevant to the study. Most visits worked extremely well, some lasting over two hours and the shortest ones, where communication was more difficult, about 45 minutes.

6.4   ELA respondents' diaries

Where appropriate, participants were offered an 'Everyday Life Analysis box' which contained a flexible range of materials, selected to suit the individual participant, and a readily visible photograph of the researcher and his / her contact information. Contents could include: a notebook with guidance on its potential to be used as a diary; a disposable camera; writing paper and stamped addressed envelopes (for sending to the researcher); and writing materials - pens, paper and adhesive notes. A few participants were also offered a voice recorder to enable them to record an audio diary.

In total, 21 participants kept diaries (11 in Leeds and 10 in Oxfordshire). Participants varied in how they approached keeping the diaries. Some used the diary to list their activities, while others used the diary more reflectively, recording feelings and experiences, sometimes about events long past. The diaries proved to be an extremely interesting source of data and a useful resource for the study. In particular, they helped some participants record 'minor' events, such as interactions with their telecare equipment or monitoring centre, which they might otherwise have forgotten about between visits (Figure 6.2).

Figure 6.2   Extract from participant diary – use of telecare

11.15 pm All my electrics went off.

Pressed my pendant - spoke to lady telling me someone would be with me shortly.

"John" warden came he put things to right, changed my living room bulb – all OK – he went.

Source: Mrs Cash's diary, 76, Oxfordshire

The diaries also helped the researchers to triangulate the data. Often, participants (especially those unable to leave home alone) said that 'nothing' had happened since the last visit. However the diaries helped spark memories, clarified points which had become confused and provided an insight into participants' perceptions of aspects of their lives. One participant told the researcher that while her daughter had been on holiday, her neighbour had been her only visitor. Her diary revealed a number of visitors (including a hairdresser and her son-in-law's parents who had brought her fresh supplies). As these visits had a purpose other than socialising, she did not initially include them, but it was important for the research to have the broader understanding this made possible, both about what had happened, and about what she felt about it.

The diaries could also help a participant 'say' something they perhaps felt uncomfortable speaking about with the researcher. Thus one, who had spoken at length about her osteoporosis and a broken bone, never mentioned in conversation that she suffered from depression, but used her diary to express this (Figure 6.3).

Figure 6.3 Extract from participant diary – mental health problems

I wear a pendant.

I have high blood pressure, clinical depression. Sometimes breathing problems - and – osteoporosis.

I have broken quite a few bones over the last few years and thought that when I broke my heel it was a minor break, but it was NOT.

Source: Mrs Davent's diary, 82, Oxfordshire

The diaries had other benefits, including benefits for some participants. Several said it provided them with a useful reminder of events, such as falls they had experienced, or a means of reflecting on how much they were able to do in a day or week, which encouraged them. One participant found writing the diary reinforced a bond with his son who lived several hours away. The son asked to read his entries and learned much that he did not know, about his father's early life and his feelings about his health problems. Some participants said they planned to continue keeping a diary after their involvement in the AKTIVE project.

6.5 ELA respondents' photographs

The disposable camera given to some participants in their ELA box offered an alternative to keeping a written diary. Participants were given guidance about what to photograph: 'anything you like that you feel tells us about your experiences that day'. Suggestions included places visited, friends or family members, and how the telecare affected their daily life.

The cameras were used less widely than the written diaries; in all, eight participants took photographs (four in Leeds and four in Oxford).The main themes of the photographs were:

- *Things that help me:* these photographs included pictures of telecare and other assistive technology in the home (such as a stair lift or adapted bathroom).They included some technologies which support everyday life activities, such as an iPad. One participant photographed his wife's 'hospital' table with her medications and her fall detector, showing things she needed close by to support her.

- *People:* these pictures included persons close to the research participant. One took his camera with him to a family Christmas to show interactions with family members he did not regularly meet. In two cases, the photographs were taken by the spouse who cared for the research participant. In these, the focus could be on the care given by the spouse, or on the care workers who came to the home.

- *The home and environment:* the garden was an important topic for some participants. One photographed his garden in different seasons; another showed the raised flower beds which enabled him to continue gardening. Another photographed his staircase, showing the steep stairs which were a source of worry for him, as they were too narrow for the stairlift he feels he really needs. One took pictures while out walking with his dog, an activity which his GPS tracker had made safer.

Photographs taken by participants were printed and discussed with them at the following ELA visit.

6.6   Observational data

At each ELA visit the interview which (in most cases) took place was audio-recorded and (if appropriate, as in the large majority of cases) subsequently transcribed by an external agency. These transcripts provided a main source of data for analysis, and were coded thematically using NVivo software[26].

During the ELA visits, the researchers used ethnographic observation techniques to capture information and perceptions which the transcripts could not convey. Observations were made using a template to ensure fieldworkers recorded their observations in a standardised way (Appendix III, Document A13) which was structured to include: the researcher's thoughts prior to the interview; what happened during the interview; key issues emerging from the interview; the researcher's reflections on how the telecare was being used (its location in the home, any usage problems, how it affected others involved in the person's care); and initial analytic themes (for further exploration at subsequent visits to participants' homes).

The researchers also wrote fieldnotes during their visits, covering: points they noted but which were not apparent from the recorded conversation (such as the participant's physical disabilities or sensory limitations); features of their homes relevant to the study (for example those which constrained mobility or made it risky); attitudes and emotions expressed by the participant when discussing particular issues or events (such as tearfulness or evident anger); and dynamics between those present in the home (for example, when a carer was present, non-verbal cues indicating frustration or disagreement).

The field notes proved invaluable during analysis of the research data, and assisted the team in identifying some of the detailed themes brought out in their accounts of the study findings (detailed in Research Report Volume 2). They also helped orient the researchers to participants they had not visited (each participant was visited by only one member of the research team), and helped them manage a large volume of data by highlighting important features of each case, some of which were not readily evident in the transcribed interview data (for the field notes template see Appendix III, Document A13).

6.7   Interviews with family members, carers and care workers

As well as collecting data from the older people participating in the study, the research design included interviews with any family members, carers, care workers or other health and social care staff attending them at home. The study revealed the complexity and variability of some older people's networks of support as well as the lack of support available to some others. The team interviewed only people identified by the older person (usually identified during the research visit on relationships) and contacted them only when the older person gave explicit permission for this (Table 6.4).

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[26] NVivo is a qualitative data analysis computer software package, widely used by qualitative social researchers.

Table 6.4

Data collected from others involved in research participants' care

Numbers

Research site	Carers and family members			Care workers or other health and social care workers		
	Joint interview	Individual interview	Observation or informal discussion	Individual interview	Observation or informal discussion	Structured questionnaire
Leeds	15	6	4	2	7	5
Oxfordshire	13	5	11	3	11	3
Total	**28**	**11**	**15**	**5**	**18**	**8**

Source: AKTIVE ELA Database, University of Leeds.

Note: Data relate only to AKTIVE participants whose extended participation in the study made them eligible as ELA cases (Section 6.2).

Accessing these informants involved a range of different arrangements: some were present during the ELA visits to the older person's home; some were interviewed in other settings, face-to-face or by phone; some observations were made when the person was attending or interacting with the older person.

Building on the topic guides used in the earlier interviews with carers (Section 5), additional topic guides were developed for these interviews, one for carers (Appendix III, Document A14) and one for care workers (Appendix III, Document A15). In addition, and because recruiting care workers for interviews was difficult (given their work schedules), a short, structured questionnaire was also developed (Appendix III, Document A16).This was left in households with care workers, with a note asking those visiting the household to complete and return it. These methods were used to gain an understanding of how (if at all) telecare affects carers and care workers to support older people living independently, and to explore any changes to their caring roles or experiences related to the telecare in place. These interviews also provided opportunities to triangulate the data and for carers and care workers to express their views.

6.8   Bringing in design perspectives

To make best use of the design expertise available within the AKTIVE Consortium, it was agreed in 2012 that designers from Consortium member the Helen Hamlyn Centre for Design would work with the SRT to plan and undertake additional research with a sub-sample of the ELA research participants[27]. This section describes the approach used to implement this element of the study.

It was decided that additional 'design' visits would be made to the homes of six research participants who would be carefully selected to ensure they were fully informed about the purpose of these visits, would not feel over-burdened by this additional research contact, and would have the capacity to participate in the planned design research activities. Additional permission was sought from SREC to include this element in the study. Relevant documentation was sent to the committee as a non-substantial amendment, and the CVs of the design researchers were provided, following which approval was given for this element of the study to proceed.

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[27] The Helen Hamlyn designers involved in these visits were Amanda Buckley and Chris McGinley.

Conscious that engaging with groups, particularly those among whom some members may be considered vulnerable, requires careful consideration and planning to ensure the process works for both the project and the individuals recruited, the designers met with the SRT to review the characteristics of participants taking part in the ELA research and to identify participants who might be comfortable engaging in a creative design ethnography process. The research participants identified were then approached by the researcher conducting their ELA visits, to ask if they were interested in taking part, and inviting them to do so. About half of those approached agreed to this, and six visits were arranged, taking place between August and October 2013.

The designers planned their research visits as a variation and extension on 'cultural probe'[28]. Based on issues identified from the literature analysis and in preparatory team discussions, a participant 'probe' booklet was created for use in the ELA design visits[29]. These were timed to take place during an ELA session, where possible just prior to the final 'technology' session.

The 'probe' booklets were designed to engage participants creatively, and to present an interview framework that broached issues that might otherwise have been difficult to discuss. They encouraged reflection, and produced textured insights into each older person's life, linking back to the pre-identified themes (used in the prior ELA visits) of people, technology and health. The material collected was then subjected to thematic analysis to draw out areas of interest and to further unpick these to identify key design questions, future possibilities and potential opportunities.

To address concerns about introductions, receiving and returning packs, developing pictures (etc.), it was agreed that the booklet would be introduced by the SRT researcher conducting the ELA visits with the selected participant, who could then decide if they wished to engage with this part of the study. During this discussion, an introduction sheet prepared by the design researcher was shared, giving the participant an overview of the design research aims and details of the design researcher who would visit.

The 'probe' booklet was developed around selected themes of interest. This provided a structure which 'primed' those taking part and helped them consider the themes ahead of the visit. The tasks were 'open-ended', as a way of drawing genuine responses from them and challenging them to think creatively.

As planned, six participants were selected, chosen to ensure a varied sample in terms of the other care support available to them and their attitudes to technology. The ELA team provided descriptions of suitable participants, which were used by the design researchers to shortlist candidates for inclusion. Where the circumstances of a person selected changed, affecting their ability to participate further, discussions were held to identify appropriate alternatives. The characteristics used to determine selection included prospective participants': age; health; gender; available care support; attitudes to technology; home type; abilities; and relationship status. Participants were selected in both the main research sites (Leeds and Oxfordshire). Interviews lasted between one and two hours and the design research on technology engagement was limited in all cases to one booklet and one interview, supported by the use of a disposable digital camera and a voice recorder.

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[28] Gavers, B, Dunne, T. and Pacenti, E. (1999) 'Cultural Probes', pp21-29 in *Interactions,* Jan-Feb.
[29] This booklet is available from the Age and Ability Research Lab at the Helen Hamlyn Centre for Design, Royal College of Art, www.hhc.rca.ac.uk/.

6.9   Reflections on the ELA fieldwork

The ELA approach, comprising the longitudinal, holistic, creative and multi-disciplinary aspects described in this section, offered researchers a sophisticated and flexible means of exploring the personal lives, experiences and attitudes of older people, whose complex circumstances created significant methodological challenges. Reflecting on the study visits, researchers felt the combination of open, 'conversational' questions and the additional ELA exercises and techniques enabled most participants (sometimes with the assistance of their carers) to discuss past and present events and to voice their opinions about telecare as well as their more general concerns and aspirations.

The ELA topic guides helped the team explore a wide range of issues with participants, even those experiencing communication difficulties, for whom the visual aids could be especially important. In these cases the team's observational work and additional research contact with carers and care workers produced especially useful additional data. The team succeeded in sustaining a focus on use of, and response to, telecare but found the ELA approach yielded much additional information, revealing a range of overlapping themes in older people's lives. Topics included: their use of and attitudes to technology; their thoughts and feelings about ageing; the role of other people in their lives; and how social care, including telecare support, is organised. Through the use of photographs and diaries, some participants felt able to disclose aspects of their lives which they did not speak about in conversation or interviews.

The complexity of the fieldwork approach proved valuable. The observational notes helped the researchers capture their impressions and thoughts following each visit, and proved useful in later analysis. The interviews with carers, care workers and others assisting the older person at home produced a holistic understanding of the care situation. They were especially helpful in cases where older people with dementia struggled to articulate their experiences. Here the team's dementia awareness training helped them elicit 'framing' memories to help participants recall relevant information or details.

One person's interpretation of events often differed from that of others, with often no 'objective' way of 'resolving' conflicting accounts. These differences of opinion or perception often highlighted tensions in a caring situation and could generate useful theoretical reflection and, via 'triangulation' of the data, a deeper understanding of the issues involved.

Visiting participants six times, over an extended period, enabled researchers to record how older people responded as telecare equipment was installed, came into use and was (or was not) integrated into daily routines or shaped emergency or one-off events. The repeat visits also built trust and rapport. In later visits, participants often raised issues not mentioned earlier. Some shared a wide range of thoughts and emotions with the researcher and disclosed ways of maintaining independence, dignity or behaviours which, they said, few, if any, others knew about or had been told.

The 'connection' established with some participants meant the team needed a careful, and ethical, 'exit strategy'. At the final ELA visit, which sometimes involved emotional farewells, participants were given a certificate of appreciation (in recognition of their contribution to the study) and a small memento, and reminded that the team planned to share the study findings with them (in a suitable format).

Some visits, particularly to participants with serious health problems or care needs, were emotionally draining: a few disclosed that they wished their lives were over, and communication became increasingly difficult with some participants with memory problems. Researcher debriefings in regular team meetings and with the principal investigator or BDG dementia experts helped support the team in handling these.

The ELA method produced a large volume of data comprising approximately 400 transcripts. This was managed using an analytical strategy which relied on initial identification of themes (cross-checked by all researchers), computer-aided techniques for data mark-up and retrieval, and various indexing and summarising techniques to help the whole team acquire and retain a 'picture' of each participant, even those they had not personally met.

Chapter 7

Telecare monitoring data

7.1   Data sources and availability

Both LCC and OCC routinely collected data about their clients and monitored the data generated by telecare users, LCC in-house and OCC by outsourcing this work (Box 7.1). The team aimed to use the data as contextual information on these populations of telecare users, to guide ELA recruitment and benchmark the characteristics of the ELA sample, but this proved more difficult than expected (Box 7.2).

Box 7.1

Telecare data collection arrangements in the two local authorities

Data available on telecare use: Leeds

- The Leeds Telecare Service (LTS) used the TOM database to record client data for all its telecare clients (past and current) and to keep stock of equipment.

- LCC's Care Ring monitoring centre used the PNC5 system to record details of all current clients. This recorded equipment activations, monitoring / checking calls to or from the client, and any responder alert calls.

- LCC used its ESCR database for social care client data. This recorded the allocation of homecare or other services, but was not routinely used by LTS.

Data available on telecare use: Oxfordshire

- OCC's Social and Care Services used SWIFT, an electronic database, to manage its client information.

- SWIFT includes both demographic data and information on the social and care services clients receive.

- Eldercare (the external organisation contracted by OCC to provide its telecare monitoring service) used the PNC5 system, which had details of all current telecare clients and was used when telecare equipment was activated.

Notes: ESCR = Electronic Social Care Records; PNC5 = monitoring centre software in use during AKTIVE; SWIFT = software widely used in local government information systems: TOM = mobile communications database in use during AKTIVE.

The initial aim was to analyse telecare use by the inclusion criteria for AKTIVE and gain insight into the characteristics of the general populations in Leeds and Oxfordshire using telecare (Section 6.2). Data on gender and ethnicity were often missing, however, and sometimes the health conditions selected were recorded only as 'secondary conditions', which could not be selected for analysis in the PNC5 reports.

Other developments added further complexity; in both LCC and OCC telecare services and data recording were changing. OCC ceased adding some data to its system after July 2012 (Box 7.2) and LCC made changes including merging its 'Care Ring' (pendant alarm only without assessment) and telecare services, leading to changes in the volume of data and in the staff involved in data monitoring and recording.

7.2   Data analysis

Analysis of the data was affected by the data quality and management issues highlighted in Section 7.1 and summarised in Box 7.2. The following steps were taken in each location to make best use of the data collected within the resources available for this part of the AKTIVE study.

In Leeds, records were available from LCC's TOM database (for April 2012) on 19,240 telecare clients (including those with a pendant alarm only, through self-assessment). Anonymised telecare client data drawn from these records were analysed by available client characteristics. The usage data for Leeds telecare clients (from the PNC5 database) were also analysed for a single month (October 2012), revealing that the monitoring system was activated, with a monitoring call recorded, 20,020 times in the period. The team subjected this data to secondary analysis, by the cause recorded for the alert or call. This was a complex task because of the large number of reasons recorded (including some 'free text' 'write in' responses). The SRT team in Leeds also had access to LCC's own internal monthly reports on telecare monitoring data, for the period July 2011 to March 2013, which provided additional contextual information for the study.

Box 7.2	
Telecare data analysis issues in the two local authorities	
Leeds	**Oxfordshire**
Most aspects of the telecare service (assessment, installation and monitoring) were provided in-house, but the databases were not linked.	No new data on OCC clients was added to the SWIFT database after July 2012.
The large volume of data in Leeds created challenges in manually linking these databases.	Eldercare's monthly reports to OCC (based on a PNC5 database) reported overall telecare use, but did not analyse individual client data.
	The PNC5 data were not linked to the client data stored on the SWIFT system[30].

In Oxfordshire, OCC staff agreed to match client data from SWIFT with the available usage data from the PCN5 database (which showed the number of alerts, although it was not possible to include the reasons for them or their outcomes in this analysis). This produced 1,833 matched records for the year July 2011 to June 2012, which were subjected to analysis. Among other things, this showed that the system was activated, with a monitoring call recorded, 16,474 times during the year. Macro-level telecare usage data (from Eldercare's monitoring records and Community Voice's data on installations and assessments) were also analysed for the year 2013 (January to December).

Results of these analyses, and the team's recommendations about telecare monitoring data recording and analysis, will be discussed at workshops due to take place as AKTIVE concludes in April and May 2014.

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[30] Linkage of these two data sets could only be done manually and (for data protection reasons) by OCC. Working with Eldercare, OCC staff linked the PNC5 and SWIFT datasets for July 2011 to June 2012. Some relevant categories (e.g. 'secondary client type', which included 'dementia') were affected by missing data and certain records, including classification of some telecare alert data ('client feeling unwell', 'response team sent'), were not available for linkage, although OCC provided separate macro-level data on these issues.

Chapter 8

Telecare systems analysis

In collaboration with AKTIVE Consortium member Professor Peter Buckle, the SRT undertook analysis of the telecare systems in place in Leeds and Oxfordshire, gathering information on flows of information and exploring risks and hazards within these systems and the mechanisms for guarding against and managing these.

8.1   Interviews and observations with stakeholders

In Oxfordshire, members of the research team attended telecare assessment and installation visits, making observations on all aspects of the process. This included the information provided to older people using telecare, including how specific items of equipment worked and what they were for, and the financial and other arrangements which were made. The team's focus on information flows also highlighted various points of interest about how some equipment functioned.

In Leeds, the team also visited different parts of the telecare service as part of the study. Interviews were conducted with LCC's telecare service managers and the team maintained regular informal contact with these staff. Relevant local authority reports and documents were identified and included in the data collected, enabling the SRT to obtain a good understanding of how the service was run. The researchers also observed work procedures in the telecare team offices and attended installation and upgrade visits in research participants' homes with a LCC telecare technician, where they observed how procedures worked in practice and could record the technician's interactions with older people and responses to the issues they raised.

Further observations were made when SRT members: (i) attended telecare training sessions for health and social care workers and voluntary sector agencies (which were organised to give them information about telecare and to enable them to assess and refer clients for telecare); and (ii) visited telecare monitoring centres in Leeds (run by LCC), Lancashire (run by Eldercare Ltd and Community Voice Ltd) and a joint telecare and telehealth monitoring centre in Yorkshire (run by Tunstall Healthcare (UK) Ltd), observing calls and work practices and speaking with responders in informal interviews.

8.2   Prospective hazard analysis

Systems mapping workshops, which have been applied to a number of problems in health care[31] had not previously been used to explore the complex socio-technical systems that link people with dementia and / or at a risk of falling with telecare and other social care needs. Such workshops are designed using experiential group work principles and involve stakeholders from across the whole provider system, including designers who may be able to enhance the safety of the products and systems used. The method encourages stakeholder participation, provides robust results within a limited time and enhances understanding across specialist interest groups. The final 'map' provides a high level, but full, description of the system and can be used for specific applications or to inform further field data collection. It enhances

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[31] Buckle, P, Clarkson, PJ, Coleman, R, Bound, J, Ward, J and Brown, J (2010) 'Systems mapping workshops and their role in understanding medication errors in healthcare' *Applied Ergonomics* 41, 645-656.

understanding of the complex relationships between stakeholders and enables gaps in the system to be identified.

In AKTIVE, the team created workshops which, while operational, acted as miniature, self-reflecting societies that could understand themselves as a subset of the entire system, and explore the reality and consequences of interactions between elements of that system. The goals of the AKTIVE systems mapping workshops were:

- to map the care system and the relationship / interactions between major stakeholders;

- to map the regulatory and manufacturing sectors, and specialist services and professions;

- to understand the system from the user perspective and to recognise both its strengths and its potential for failure;

- to rapidly capture data on currently perceived problems and errors within the system; and

- to identify the strengths in the system and where resilience is located.

The workshops took place in Leeds, Oxford, at a telecare R&D design headquarters and at a telecare conference. The map developed was built over this series of workshops. The first began with a simplified map of the social care system, produced by the research team and based on earlier desk-based investigations. Participants completed a short personal profile, gave some details about their reasons for attending, and positioned themselves on the map. Additional elements of the system and relationships were added to the map as requested by the workshop participants.

The map was based on concentric rings, with the older person and their carer placed at the centre (Figure 8.1). In the first ring, professionals and others with direct contact and responsibilities to the older person (doctors; nurses; social services; assessors; carers; relatives; and technical support) were located. Procurement, purchasing and stock holders were located in the next ring, while stakeholders such as equipment suppliers, designers, trade associations, regulators, distributors and government agencies, (e.g. MHRA[32]) were placed in the outer ring. Over the course of four further workshops, with participants drawn from most stakeholder groups, the map was developed and additional stakeholders were added as appropriate and as agreed by the workshop participants.

This method allowed for all participants to understand relationships between individual system elements, and aided their discussions regarding potential failure modes.

Capturing problems and sources of error

Workshop participants followed several basic steps used in Prospective Hazard Analysis (PHA) to identify potential hazards and risks inherent in complex systems, using a predictive and proactive approach which is standard practice in many high hazard industries, including chemical engineering, aerospace and nuclear power. The approach is capable of identifying problems in existing systems and opportunities for improving them. Here AKTIVE was breaking new ground, as although these methods are increasingly used in health care settings, they have previously been very little used in telecare. The approach, particularly useful in developing systematic thinking about risk and the design of systems, demands a different mind-set and an organisational culture that understands risk in a new way.

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[32] The Medicines and Healthcare Products Regulatory Agency.

PHA is not a single method, but an approach and a range of tools. Its methods are systemic, systematic and structured processes that support the identification of hazards, their potential consequences and hence risk. PHA draws on existing system performance and failure data, but also relies on subjective sources of risk information, drawn from those with experience of the system(s) being assessed. It is characterised as being: *systemic* (it takes account of the interaction of the part of the system being examined and the wider system within which it sits); *systematic* (it has specific aims and scope, and is methodical); *structured* (there is a logical approach, which should be followed consistently, and which supports consistency and repeatability); *documentable* (the approach allows detailed records to be kept, not only of the hazards and risks identified but also of the reasoning behind their evaluation); and *informative* (the output can be used to support improvement and redesign processes).

The following steps were considered:

- *Describing the socio-technical system*

- *Generating a process description*

- *Identifying hazards prospectively – i.e. where is the potential harm, where might the system fail?*

- *Analysing, prioritising and / or quantifying the risk arising from the hazards*

- *Recommending mitigation and risk reduction or hazard elimination strategies*

Step 1 was achieved through the workshops described above; the process descriptions (step 2) were derived from the same source. Participants, stakeholders and researchers assisted in identifying hazards (step 3) to list actual or potential problems, errors and difficulties with the systems they had experienced. Potential causes were also identified, enabling 'hot spots' to be identified on the system map.

These observations were supplemented with researcher observations (described in previous sections) obtained during ELA visits to telecare users, attendance at installer training days, observations of installation visits and assessor training, visits to monitoring centres, and issues identified by the research team through the overall ELA approach. The highly complex nature of the socio-technical systems found, and the extensive variations that existed within them, made it impossible to complete step 4. Recommendations about risk reduction and risk mitigation were made and prioritisation of attention to these advised.

APPENDIX I

AKTIVE Social Research Team (at CIRCLE, University of Leeds and OIPA, University of Oxford)

Professor Sue Yeandle was AKTIVE's Principal Investigator and Project Director throughout the AKTIVE project. Her role included leading the Social Research Team and providing guidance and quality assurance on: research design; research ethics; methodological decision-making; fieldwork practices; data storage and analysis; and dissemination strategy. Sue is Professor of Sociology and Director of CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Leeds and a sociologist specialising in the study of care, work and family life. Her portfolio includes recent work evaluating large government programmes of carer support in England and other studies on telecare and ICT-based support for carers. She has published widely on carers and social care policy and on employment and equality issues, most recently *Combining Paid Work and Family Care: policies and experiences in international perspective* (Policy Press, ed. with T. Kröger), in 2013.

Dr Kate Hamblin was responsible for the AKTIVE: fieldwork planning, management and activities in the Oxfordshire site; managing ethical approval processes for the study; and liaison with OCC's telecare service and partner organisations involved in delivering telecare in Oxfordshire. She undertook most of the data collection in Oxfordshire with older people participating in the study and their carers and care workers. Kate is Research Fellow at the Oxford Institute of Population Ageing (OIPA), University of Oxford. Her previous research has included the 'Carers@Work Combining Job and Care: conflict or opportunity' project, funded by the Volkswagen Foundation, and the Dulwich Picture Gallery project, with Professor Sarah Harper, which evaluated community outreach programmes for older people. Kate's PhD was awarded by the University of Bath in 2010 for her thesis on changes in policies on work and retirement transitions in EU15 nations. Her book based on this was published by Palgrave in 2013.

Dr Emma-Reetta Koivunen was responsible, from September 2012, for the AKTIVE: fieldwork planning, management and activities in the Leeds research site and liaison with LCC's telecare service. She undertook much of the data collection in Leeds with older people participating in the study and their carers and care workers, building on Dr Christina Buse's earlier contribution. Emma-Reetta is Research Fellow at CIRCLE, University of Leeds. Her PhD was awarded by Manchester Metropolitan University in 2012 and her Master of Social Studies in Social Anthropology (2006) by the University of Helsinki, Finland. Her research interests include social studies of technology; technology use in everyday life; the domestication of technology; tourism anthropology and anthropology of the Shetland Islands. She has research experience in health and wellbeing and housing, internet use and e-commerce in rural Finland.

Dr Gary Fry worked part-time on AKTIVE 2011-14 and contributed to all aspects of the research in the Leeds site, including data collection with older people participating in the study and their carers and care workers, and work on the analysis of the Leeds telecare monitoring data. Gary is Research Fellow at CIRCLE, University of Leeds. He has a first degree in psychology and a PhD from the University of Huddersfield. His previous work includes research for the Carers, Services and Employment study, evaluations of national carer support programmes and studies of the use of technology in social care.

Dr Emanuela Bianchera worked part-time on the AKTIVE project from June 2012 to August 2013, contributing to all aspects of the work in the Oxfordshire site, including data collection with older people participating in the study and their carers and care workers. Emanuela is Research Fellow at the Oxford Institute of Population Ageing, which she joined in 2010 to work on the 'Grandparenthood within Bilingual Families' study of intergenerational care, transnationalism and heritage transmission among Italian migrant families in Wales, and previously held an EU Marie Curie Fellowship at the University of Surrey's Centre for Research on Ageing and Gender. Her doctoral thesis examined the impact of family care on the health, sleep and work-life balance of midlife and older women in Italy. Emanuela has also worked as a consultant for Italian NGOs in the fields of social exclusion and gender inequalities.

Throughout the AKTIVE project, the SRT was supported by Deborah Alder, administrator at OIPA, University of Oxford, and Rebecca Wilding, AKTIVE Project Officer, at CIRCLE, University of Leeds. It also had the support and advice of the AKTIVE project's Industry Partners, Consortium and Advisory Board.

AKTIVE INDUSTRY PARTNERS

Inventya Ltd, represented by Valerie de Leonibus, Chief Executive, Radka Bartosova, Healthcare Innovation Consultant and Fiona Barker, Marketing and Communications Manager.

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Carers UK, represented by Madeleine Starr MBE, Director of Business Development and Innovation.

Helen Hamlyn Centre, Royal College of Art, represented by Rama Gheerawo, Deputy Director and Chris McGinley, Senior Associate.

Leeds City Council (Leeds Telecare Service), represented by Katie Cunningham, Service Manager, and by Marianne Howard and Donna Whitelock, Telecare Technical Advisors.

Oxfordshire County Council, represented by Alison Fishpool, Service Development and Policy Manager and Natalia Lachkou, Supporting People Programme Manager.

Skills for Care, represented by Diane Buddery, Project Manager (Carers Strategy).

Individuals

Professor Peter Buckle, Director, The Robens Institute.

Dr Adam Darowski, Consultant Physician, Oxfordshire Falls Prevention Service.

Dr Rupert McShane, Consultant Physician, Thames Valley Dementias and Neurodegenerative Diseases Research Network.

Professor Alan Roulstone, Professor in Disability Studies, University of Leeds (formerly Professor of Applied Social Sciences, Northumbria University).

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Dr Verina Waights, Senior Lecturer in Professional Health Care Education, Open University

Simon Williams, National Lead on Dementia, Association of Directors of Adult Social Services and Director of Community and Housing, London Borough of Merton.

Stephen Johnson (until 2013), Head of Long Term Conditions, Department of Health.

AKTIVE project outputs (to April 2014)

Conferences hosted by the AKTIVE project

Telecare and Independent Ageing: marketing, distribution, product development and user perspectives
the AKTIVE mid-project conference, held in London, UK, 17.5.13. Presentations from this event are available at: http://www.aktive.org.uk/conference2013-presentations.html and the conference report can be found at: http://www.aktive.org.uk/downloads/AKTIVE_Newsletter_June2013.pdf

Technology, Care and Ageing: enhancing independence
AKTIVE final conference, University of Leeds, UK, 8-9.4.14, the launch event for AKTIVE Research Report II. A conference report and presentations will be made available on the AKTIVE website in May 2014.

External Conferences and Events

Conference	Presentation title	Date and Place	Presenter(s)
'Better Connected: Strengthening networks in later life': Senior Network Support Project	Ageing, loneliness and technology: findings from the AKTIVE project and international examples	Leeds, UK 13.2.14	Emma-Reetta Koivunen
Patient and Healthcare Provider Safety	The Design of Health and Social Care Technology for Ageing Populations: the use of socio-technical systems approaches	NCVO, London 25.11.13	Peter Buckle
Gerontological Society of America Annual Conference 2013	Telecare in the Everyday Life of People with Dementia and their Caring Networks: barriers and facilitators	New Orleans, Louisiana, USA 20-24 .11.13	Emma-Reetta Koivunen & Murna Downs
	Are you asking me that? I don't even remember what I did tomorrow! Qualitative interviewing with people who have dementia		Emma-Reetta Koivunen
Workplace Ergonomics and Productivity	Ergonomics, Health and Social Care: improving telecare for older people	1-2.10.13 Ibis Earls Court, London	Peter Buckle
British Society of Gerontology Annual Conference 2013	The Role of Technology in Promoting Wellbeing and Independence in Later Life (session title)	University of Oxford, UK 11.9.13	Sue Yeandle (Chair)
	Design, Technology and Ageing: the use of socio-technical systems approaches		Peter Buckle
	Telecare to support independent living: experiences from Leeds City Council		Katie Cunningham
	Exploring Telecare Use in Everyday Life: a longitudinal and ethnographical methodology		Emma-Reetta Koivunen & Emanuela Bianchera
	The AKTIVE Project: how telecare can improve the lives of older people prone to falls or who suffer memory problems		Gary Fry & Kate Hamblin

External Conferences and Events (continued)

Conference	Presentation title	Date and Place	Presenter(s)
European Sociological Association Biennial Conference	Telecare Use in Everyday Life: benefits and challenges; early findings from the AKTIVE project	Turin, Italy 29.9.13	Emanuela Bianchera & Kate Hamblin
Innovation, Integration, Implementation: 3rd International Congress on Telehealth and Telecare	The AKTIVE project: how telecare can improve the lives of older people prone to falls or who suffer memory problems	King's Fund, London 01-03.7.13	Gary Fry
International Association of Gerontology and Geriatrics, 20th World Congress of Gerontology	What Does Telecare Contribute to Ageing-Environment Interactions? Early findings from a study of older people and their caring networks in two localities in England	Seoul, Korea 24.6.13	Sue Yeandle
Gerontologia: Eighth Finnish Gerontology Conference	Telecare and everyday life of older people prone to falls or with dementia and their carers	Helsinki, Finland 05-07.6.13	Emma-Reetta Koivunen
Designing for People: Ergonomics & Human Factors	Telecare Design: the importance of socio-technical system analysis	Cambridge 15-18.4.13	Peter Buckle
Engaging Sociology: British Sociological Association Annual Conference 2013	Domesticating telecare into the everyday life of older people. [poster]	Grand Connaught Rooms, London 03-05.4.13	Emma-Reetta Koivunen & Sue Yeandle
Assisted Living Platform Conference 2013	Mapping the Telecare System	Liverpool 5-6.3.13	Peter Buckle
Telemedicine in Action, Oxford Telemedicine Institute Seminar Day	Introducing the AKTIVE Project	Green Templeton College Oxford 29.11.12	Kate Hamblin
Assisted Living Platform Conference 2012	AKTIVE: Advancing knowledge of telecare for independence and vitality in later life (poster)	Coventry 08.2.12	AKTIVE SRT

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