

## AKTIVE Research Report Volume 3

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

## APPENDIX III

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*The documents in this appendix have been modified from the originals used. In many cases detailed prompts and checklists have been removed, and interviewer instructions have been shortened. The layout of the documents has also been changed from that used in the fieldwork situation.*

**FOR THE MAIN REPORT OF THE AKTIVE PROJECT'S RESEARCH METHODS SEE:**

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

## Document A1: Participant Information Sheet: example<sup>1</sup>

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

**The AKTIVE Project:** The AKTIVE project aims to explore the way telecare can be developed to help older people live a full and independent life. In particular, we are interested in addressing how telecare can help individuals who are prone to falls or have dementia. We also wish to examine how telecare can benefit those caring for older individuals, both paid and unpaid carers. Therefore, the aims are:

- a) to improve the quality of life of older individuals with dementia / susceptibility to falls and sustain their independence;
- b) to enable family caregivers to continue their care / support of older family members alongside work and other roles;
- c) to enhance and modernise social care / support in a cost-effective way.

**The Research Team:** The AKTIVE Project is led by CIRCLE at the University of Leeds, with partners OIPA at the University of Oxford, Tunstall Healthcare (UK) Ltd and Inventya Ltd. The team brings together expertise in research on care, caring and carers; telecare manufacturing; and business intelligence. The project partners will be assisted by expert consultants on technology and ergonomics, medical conditions, policy and care; and appropriate user groups.

**We are looking for....** We'd like to involve older people with mild to moderate dementia and older people who suffer from falls in this study, who use telecare in their homes. We would also like to talk to people who provide help, care or support to you.

**The Research:** AKTIVE will include a range of different research activities, including something we call 'Everyday Life Analysis'. Because we want to explore how older people and their carers use telecare on a day-to-day basis, we feel a mixture of discussion and observations will be the best way to do this. A member of the research team will either come and visit you in your home to talk about how the telecare is working for you, or may call you over the phone if that is easier. Also, we understand that things can change over time, so we would like to come back for more visits or phone calls to talk about whether the telecare is helpful and how it is affecting your life around six times over the course of a year. Every time you take part in the research, you will receive a £25 'thank you gift'.

**What will happen during the sessions?** The researcher will either visit or call you to discuss what's been happening with the telecare, such as how often it's being used, any difficulties that may have come up, what improvements you would like to see and if it is a re-visit, what's changed since the last session.

**What will happen to your data?** Some of the sessions may be sound recorded, with your consent. The researcher may also take notes during the visits. The audio recordings will be stored on a computer at the Oxford Institute of Population Ageing / CIRCLE. Only researchers involved in the AKTIVE project will have access to them. If you wish to terminate the session at any point, let the interviewer know and recording will stop. Excerpts from the session may be included in the project's outputs, for example in reports or articles. Your name will not be included and any information that may reveal your identity, or the identity of others you may refer to, will be removed. If you withdraw or are withdrawn from the study for any reason, the research team will retain the data already collected about you, unless you request that all data relating to you is withdrawn from the study.

**How can you take part?** You can either call us, send us an email or a letter so that we can contact you to arrange a convenient date and location for an interview.

**You are not able to take part, but know someone who might?** It would be great if you could still support us: please pass this leaflet to a friend, neighbour or colleague who use telecare or cares for an older person.

**Do you have any questions?** Please feel free to contact us at any time. We will be happy to give you further information.

**We look forward to hearing from you!**

<sup>1</sup> This version was used with ELA research participants; adapted versions were developed for other research participants.

## Document A2 – Consent Form: example<sup>2</sup>

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

Please circle the appropriate response:

I confirm that I have read the information sheet.	Yes	No
I have had the opportunity to ask questions about the study and have received satisfactory answers to my questions.	Yes	No
I have received any additional information I have requested.	Yes	No
I understand that I may withdraw from the study without penalty at any time by advising the researchers of this decision.	Yes	No
I understand who will have access to the personal data provided and how the data will be stored.	Yes	No
I understand that should I withdraw or be withdrawn from the study for any reason, the research team will retain the data already collected about me unless I request that all data relating to me are withdrawn from the study.	Yes	No
I agree to participate in this study.	Yes	No
I agree that this session will be audio recorded.	Yes	No
I give consent for the research team to access records about my telecare use, held by my local authority.	Yes	No

Name of Participant ..... Date .....

Signature .....

<sup>2</sup> This version was used with ELA research participants; adapted versions were developed for other research participants.

## Document A3: Stakeholder Interview Topic Guide

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

You have been asked to take part in this interview as a key expert in the area of telecare / telehealth policy, as we feel the AKTIVE project would benefit from your expertise on telecare and telehealth policy in England. The interview will also help us explore the project's research questions which relate to:

- older people's capabilities and their social environment and how these influence the uptake of telecare;
- the barriers which impede successful integration of telecare into older people's everyday lives;
- the benefits of using ALT for older people suffering from dementia or susceptible to falls, and whether the benefits vary depending on an individual's medical condition (dementia vs. falls).

We will be exploring the use of telecare by wider care networks, including formal and informal carers, and are investigating both the factors which affect older people's care-givers' ability to use ALT and what the benefits of telecare are for carers (both paid and unpaid). We are also looking at the role telecare may have in creating better / more cost-effective service delivery to older people in their homes.

With your consent, I'd like to audio-record our interview. The recordings will be transcribed, kept secure and shared only with other members of the research team. In reporting this part of the project, which is for internal circulation within the AKTIVE research consortium only, we will do everything we can to observe your confidentiality / anonymity. We will not quote you by name in any report. However, by virtue of your role you should be aware that comments you make could potentially identify you.

Are you happy for me to record the rest of our interview? Yes  No

Do you have any questions before we begin? <Turn on audio recorder to log consent>

### Your Role / Experience

Your role

Could you tell me about your role and responsibilities?

Your institution's telecare policy

Can you tell me what you consider to be distinctive about [the institution's] approach to telecare?

- History
- Key documents
- Key policies
- Investment
- Changes on the horizon

What changes have you seen since becoming [job role]?

- Were any policies abandoned? Why?
- What drove this change?
- Funding?
- Not successful?
- Change in overall telecare / social / health care agenda?
- Change at policy level?

### Policy development at the local and national levels

Now can we discuss the drivers behind these changes and how telecare policy in England is situated within the broader health and social care agenda?

## Policy development

What are the main factors driving the telecare policy agenda in England?

How does telecare policy fit within the broader health and social care policy agenda? Are there any contradictions?

- Independence?
- Costs?
- Efficiency?

## Policy Delivery and Local Authorities

I'd now like us to explore how telecare policy is implemented at the LA level - how it is interpreted, the actors involved in delivery, any significant differences between LAs and examples of best practice. I'd also like to explore any feedback you've received from LA commissioners or those in telecare service delivery roles and any knowledge you may have on the experience of individual users.

### Policy Delivery

How is the national telecare policy approach being interpreted and rolled out by LAs?

How variably is this happening between LAs? How is variability/uniformity viewed?

What groups are involved in the delivery of telecare? How are they involved?

### Telecare in LAs

Are there significant differences in telecare provision in England between LAs?

- Why does the provision differ?
- In what ways? Products? Assessment? Departmental remit (telecare service vs. OT)?

### LAs and best practice

Are there particular LAs that in your experience are successful / unsuccessful in rolling out telecare?

- For particular users?
- For particular reasons?

Do you feel there are any gaps in the current provision of telecare and telecare services at LA level?

### telecare products and services in LAs

Are there particular products that in your experience are successful / unsuccessful?

- For particular user groups?
- For design-related reasons?
- For cost-related reasons?

From your experience, does telecare contribute to better service delivery? What actually improves?

- For particular user groups?
- For carers?
- How?
- In what ways?

From your experience, does telecare contribute to a more cost-effective service delivery?

Who benefits most from cost-efficiencies?

- For particular user groups?
- For LAs?
- How?
- In what ways?

Have you received feedback on telecare from those in commissioning roles within LAs?

- Positive?
- Negative?

Have you received feedback on telecare from those in delivery roles within LAs?

- Positive?
- Negative?

Are you aware of any feedback on telecare from individual service users and their carers? From empirical research? From surveys of users?

- Positive?
- Negative?
- Variations between user groups?

*Note: Get references and ask for any documents to be sent to the research team.*

### **Policy Challenges**

Now can we turn to the challenges for telecare policy at the national / local levels, and any issues that may arise for service users. These may be challenges English telecare policy has overcome already, or is still facing.

Policy challenges - national level

What specific challenges does telecare policy in England face, at the national level?

Policy challenges - local level

Are these challenges the same, or different, at the local authority level?

Policy challenges - individual service users

What challenges does telecare policy in England face, in terms of service users and their carers?

### **Policy Solutions**

I'd now like to discuss how these challenges are being addressed at different levels, and to look to the future.

How are these challenges being addressed in national policy to extend the use of telecare by local authorities?

National policy solutions re. uptake by individual users

How are these challenges being addressed by national policy to extend the use of telecare by individuals?

Policy solutions- local authorities

How are these challenges being addressed by local authorities in England?

Policy solutions- the future

What other policy changes do you think need to be made to increase uptake by LAs?

What other policy changes do you think need to be made to increase uptake by individual users / their carers?

Where do you feel English policy on telecare and ALTs more generally will lead in the future?

## Wider Solutions

Linked to the previous section, I'd like now to explore the possibility of other solutions from outside of the policy and local authority circle, including telecare manufacturers, the voluntary sector and research and development. In particular, I'd like to discuss the areas telecare manufacturers could work on to increase the use and benefits of telecare.

### Wider solutions

How can any of the challenges we've already spoken about be addressed by those outside of policy / LA circles?

Do you feel there are any gaps in the current provision of telecare in the market?

What changes do you think need to be made by manufacturers to increase uptake by LAs?

What changes do you think need to be made by manufacturers to increase uptake by individual users and their carers?

## Final Questions

Are there any other issues concerning ALTs and telecare that we have not discussed that may be relevant to our research?

Are you aware of any key publications we may not have access to?

Do you have any further comments to make?

Thank you for your time and contribution. This interview will be included in a report which will be circulated to the project's consortium, but will also inform the design and implementation of other elements of the AKTIVE project. In the event that we may need to clarify any of the points raised in this interview, may we contact you again?      Yes  No

The main period of dissemination will be in year 3 of the project (2014). If you would like, we would be happy to notify you of the external publications the project produces.      Yes  No

## Document A4: Care Workers Focus Group Topic Guide

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

Date:  
Time:  
Location:  
Facilitator:  
Note Takers:

#### *Arrivals / Registration*

Refreshments; each person welcomed, registered, given badge; place cards distributed; consent forms.

#### *Introductory information*

Good morning / afternoon everyone. Thanks for coming here today. I'm [...] and these are my colleagues [...] and [...] who will be taking notes and helping with the session. The aim of today's session is to explore your experiences of telecare, and to get a better understanding of any ways in which telecare affects you or how you do your job. All of you here today work in home care and I think most (if not all) of you have worked in at least some homes where telecare is in place. We plan to focus today's discussion on three topics:

- A. Your experiences of telecare and your views about it.
- B. How telecare affects you when you are doing your job.
- C. The impact of telecare on the people you care for and their families.

We plan to talk about you and your job first, and then - after a short break (with refreshments) - to talk about how telecare affects the people you care for and work with. Because we want to hear everyone's views, we will try to bring everyone into the discussion. If you can't answer a question or don't have anything to add, that is absolutely fine. However we are very interested in hearing different points of view, so if you disagree with anything anyone else says or have a different experience, please say so.

Before we start, can I just say a few words about confidentiality? The research team will keep any personal details you give confidential, and when we write or speak about the research no-one will be named or individually identified. Could we also agree that, within the group, each of us will treat personal information about others here today as confidential?

Does anyone have any questions before we start? Does anyone object to the session being audio-recorded? Before we begin, would you please read and then sign the consent forms in front of you?

#### *Note to interviewer: general probes for focus group facilitator to use throughout:*

"Give us an example of ..."

"Does anyone have a different experience?"

"Could you tell us more about that?"

"Please keep talking,"

"Would someone like to summarise what we've been saying?"



## INTRODUCTION / 'ICEBREAKER'

We'd like to start with everyone briefly introducing themselves [SRT start- first name, job, organisation]. Can I ask everyone to give their name, and some background on the work they do?

### A. YOUR VIEWS AND EXPERIENCE OF TELECARE

Let's start with your experiences of working with telecare in households, and how you feel about the equipment.

<b>'EYES CLOSED' EXERCISE</b>
To get us thinking about this, please close your eyes for a moment, and think about an example of a house you work in with telecare. Could I have two volunteers to tell us about the example you were thinking of?
<p><i>Try to go round everyone before using any prompts (until nothing new is being added)</i></p> <p>Prompts:</p> <ul style="list-style-type: none"> <li>▪ What type of telecare is it?</li> <li>▪ Where is kept?</li> <li>▪ What are the care needs of the service user?</li> <li>▪ What (if anything) do you do with the telecare?</li> <li>▪ Do you work with telecare differently in any other households?</li> <li>▪ Does anyone else have a different experience of telecare?</li> </ul>
<b>USE AND UNDERSTANDING OF TELECARE</b>
<p>When you are working in a home where telecare is installed, do you (yourself) use the telecare equipment in any way?</p> <p>What do you do (with it)? How often?</p> <p>Is it part of any of your regular routines?</p>
<p>Prompts:</p> <ul style="list-style-type: none"> <li>▪ How do you feel about using the equipment?</li> <li>▪ Have you had any training in using the equipment?</li> </ul> <p>Was the training you had useful?</p>
<b>TELECARE: LIKES AND DISLIKES</b>
<p>Now I'd like us to talk about:</p> <ul style="list-style-type: none"> <li>▪ Anything you have found useful, helpful, or attractive about the telecare in place in the homes where you work?</li> <li>▪ And now can we focus on anything you perhaps find annoying, unhelpful or unattractive about telecare?</li> </ul> <p><i>[Following discussion, ask participants to write on post-it notes; separate board for things liked, disliked]</i></p>
<p>Prompts:</p> <ul style="list-style-type: none"> <li>▪ Easy / difficult to use</li> <li>▪ Positive / negative impact on the people you care for</li> <li>▪ An additional tool for providing support</li> <li>▪ Backup system</li> <li>▪ Technical problems</li> <li>▪ Anxiety about using telecare</li> <li>▪ Resistance from the service user</li> </ul>
<b>ANY CONCERNS ABOUT TELECARE</b>
When you are in a household where telecare is in place, is there anything about the telecare that worries or concerns you?

Prompts:

- Any specific difficulties you've experienced?
- Anything those you care for have complained about / found difficult?
- Any technical problems?

HOW TELECARE AFFECTS YOU WHEN YOU ARE DOING YOUR JOB

*I'd now like to find out if telecare has had any impact on how you do your job.*

#### IMPACT ON YOUR JOB

Has anyone worked in a home both before and after telecare was installed?

PROMPTS: *Ask about whether in these homes it made any difference to the work, in relation to:*

- The tasks you do
- The time you spend in the house
- The frequency of your visits
- Working alone or with a partner
- How much work there is to do
- Any contact with the client which does not involve a home visit
- The information you have about the client/ how they are feeling or getting on

*If no 'before and after', ask participants to compare the work they do in homes with / without telecare in place*

#### EXTENT OF IMPACT

To what extent has telecare affected your job in terms of ...

- The tasks you do
- The time you spend in the house
- The frequency of your visits
- Working alone or with a partner
- How much work there is to do
- Any contact with the client which does not involve a home visit
- The information you have about the client / how they are feeling or getting on

#### TELECARE AND FEELINGS ABOUT JOB

Has working in homes with telecare in place changed the way you feel about your job in any way?

Prompts:

For example, does it affect:

- How confident you feel about working with the client involved?
- What about how friendly you can be with the client?
- Do you worry less about what you might find when you go through the door?
- The amount or type of contact you have with carers /neighbours?

#### C. HOW TELECARE AFFECTS THE PEOPLE YOU CARE FOR AND THEIR CARERS / FAMILIES

For these questions we'll use cards. Each says something about telecare. Please discuss these in pairs / small groups / whole group, thinking about how the telecare affects the person you care for and their carers, neighbours or families. Please talk together about each statement and find out if you agree or disagree with it or if you have different views. (When we've collected your views we're going to discuss why you agree or disagree and find out what everyone agrees about and whether people have lots of different views.) Please use a [YELLOW] note to indicate agreement, a [BLUE] note to indicate disagreement.

IMPACT ON PERSONS CARED FOR		
Now they have telecare in place, the people I visit and care for..... <i>Show cards used:</i>		
<ul style="list-style-type: none"> <li>▪ are more independent</li> <li>▪ go out more</li> <li>▪ complain more</li> <li>▪ seem to be more worried</li> <li>▪ are more active within the home</li> </ul>	<ul style="list-style-type: none"> <li>▪ get more exercise</li> <li>▪ see more people</li> <li>▪ seem to be happier</li> <li>▪ have become more lonely</li> <li>▪ have less contact with their neighbours</li> </ul>	<ul style="list-style-type: none"> <li>▪ have fewer accidents</li> <li>▪ have more privacy</li> <li>▪ have more dignity</li> <li>▪ do more activities</li> <li>▪ say they see less of their families</li> </ul>
Prompts: <ul style="list-style-type: none"> <li>▪ What makes you say this? (details/examples)</li> <li>▪ Are the effects different if someone is prone to falls / has dementia?</li> </ul>		
DIFFERENCE TO YOU		
What difference (if any) does this impact on the people you care for make to you?		
Prompts: <ul style="list-style-type: none"> <li>▪ Easier / more difficult to work with?</li> <li>▪ Is the service you give more or less personal and individual?</li> <li>▪ Do you have more or less to record when you visit?</li> <li>▪ Do you think about them less or more when you are not with them?</li> <li>▪ Has it changed your talk or interaction with the client?</li> </ul>		
IMPACT ON FAMILIES		
How (if at all) has telecare affected the carers and families of the people you look after?		
<i>Show cards used, covering:</i>		
<ul style="list-style-type: none"> <li>▪ They seem less tired</li> <li>▪ They are getting on better together</li> <li>▪ They say they have a better quality of life</li> <li>▪ Nothing much seems to have changed</li> <li>▪ They say they are getting called to the house more often</li> </ul>	<ul style="list-style-type: none"> <li>▪ Their own health seems better</li> <li>▪ They say they have greater peace of mind</li> <li>▪ Their relationship with me has changed</li> <li>▪ There are some things they no longer need to do for the person</li> </ul>	<ul style="list-style-type: none"> <li>▪ They seem more relaxed</li> <li>▪ They seem less worried and anxious</li> <li>▪ They get a break from caring more often / more easily</li> <li>▪ They don't seem happy about the telecare</li> </ul>

#### FINAL QUESTIONS

*[Briefly summarise key themes emerging. Before we finish, let's take a few moments to share any issues we've not so far discussed and see which points you all consider important and note any differences of view between you.]*

ADDITIONAL ISSUES
<i>Would anyone like to add anything further about their experience of telecare? (Ensure everyone has the chance to speak).</i>
KEY POINTS
<i>Of the things we've discussed, which are the really important points you'd want to emphasise?</i>

Thank you very much for taking the time to participate in this session, we really appreciate it and have found the discussion very helpful. Expenses forms / thank you gifts

## Document A5: Care Worker Topic Guide

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

Preamble adapted from Document A4.

We plan to focus today's discussion on three topics:

- A. Your experiences of telecare and your views about it.
- B. How telecare affects you when you are doing your job.
- C. The impact of telecare on the people you care for and their families.

Do you have any questions before we start? Do you object to the interview being audio-recorded?

Before we begin, would you please read and sign the consent form?

#### THE CARE YOU PROVIDE

Could you tell me something about your job ...

- Who employs you? [*NHS, private*]
- How many clients do you provide care for?
- What are the characteristics of the people you care for? [*age, condition*]
- How many of your clients use telecare?

Could you tell me about the care you provide for [X]?

- How long have you provided the care?
- How often do you visit them?
- What tasks are involved?
- What (if anything) has changed in the care you provide since you began?
- Who else is involved in providing the care?

#### USE AND UNDERSTANDING OF TELECARE

- When you are working in the home of [X] do you use the telecare equipment in any way?
- What do you do with it? How often?
- Is it part of any of your regular routines?

Prompts:

- How do you feel about using the equipment?
- Have you had any training in using the equipment?
- Was the training you had useful?

#### TELECARE: LIKES AND DISLIKES

*Now I'd like us to talk about:*

Anything you have found useful, helpful, or attractive about the telecare used by [X]?

Can we focus on anything you perhaps find annoying, unhelpful or unattractive about telecare used by [X]?

Prompts:

- Easy / difficult to use
- Positive / negative impact on the people you care for
- An additional tool for providing support
- Backup system
- Technical problems
- Anxiety about using telecare
- Resistance from the service user

ANY CONCERNS ABOUT TELECARE
When you are in [X's] home, is there anything about the telecare that worries or concerns you?
Prompts: <ul style="list-style-type: none"> <li>▪ Any specific difficulties you've experienced?</li> <li>▪ Anything those you care for have complained about / found difficult?</li> <li>▪ Any technical problems?</li> </ul>

#### HOW TELECARE AFFECTS YOU WHEN YOU ARE DOING YOUR JOB

*I'd now like to find out if telecare has had any impact on how you do your job.*

IMPACT ON YOUR JOB
If the telecare was installed after you began caring for [X], what are the main differences you think it has made to the care you provide?
To what extent has telecare affected your job in terms of... <ul style="list-style-type: none"> <li>▪ The <i>tasks</i> you do</li> <li>▪ The <i>time</i> you spend in the house</li> <li>▪ The <i>frequency</i> of your visits</li> <li>▪ Working <i>alone</i> or with a partner</li> <li>▪ How <i>much work</i> there is to do</li> <li>▪ Any contact with the client which does <i>not involve a home visit</i></li> <li>▪ The <i>information</i> you have about the client / how they are feeling or getting on</li> </ul>

#### TELECARE AND FEELINGS ABOUT JOB

Has providing care for [X] now telecare is in place changed how you feel about your job at all?

Prompts: For example, does it affect: <ul style="list-style-type: none"> <li>▪ How confident you feel about working with the client involved?</li> <li>▪ What about how friendly you can be with the client?</li> <li>▪ Do you worry less about what you might find when you go through the door?</li> <li>▪ The amount or type of contact you have with carers / neighbours?</li> </ul>
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#### HOW TELECARE AFFECTS THE PERSON YOU CARE FOR AND THEIR CARERS/ FAMILIES

Now we'd like to explore how you feel [X] experiences telecare. Please rank these statements on a scale of 1-10: 1 is strongly disagree and 10 is strongly agree. Then we will discuss the reasons for your ratings.

IMPACT ON PERSON(S) CARED FOR		
Now telecare is in place, [X] ..... <i>(read statements below)</i>		
<table border="0"> <tbody> <tr> <td> <ul style="list-style-type: none"> <li>▪ is more independent</li> <li>▪ gets more exercise</li> <li>▪ has fewer accidents</li> <li>▪ sees more people</li> <li>▪ goes out more</li> <li>▪ seems to be happier</li> <li>▪ is more active within the home</li> <li>▪ has more dignity</li> </ul> </td> <td> <ul style="list-style-type: none"> <li>▪ has more privacy</li> <li>▪ has become more lonely</li> <li>▪ complains more</li> <li>▪ does more activities</li> <li>▪ says they see less of their families</li> <li>▪ has less contact with their neighbours</li> <li>▪ seems to be more worried</li> </ul> </td> </tr> </tbody> </table>	<ul style="list-style-type: none"> <li>▪ is more independent</li> <li>▪ gets more exercise</li> <li>▪ has fewer accidents</li> <li>▪ sees more people</li> <li>▪ goes out more</li> <li>▪ seems to be happier</li> <li>▪ is more active within the home</li> <li>▪ has more dignity</li> </ul>	<ul style="list-style-type: none"> <li>▪ has more privacy</li> <li>▪ has become more lonely</li> <li>▪ complains more</li> <li>▪ does more activities</li> <li>▪ says they see less of their families</li> <li>▪ has less contact with their neighbours</li> <li>▪ seems to be more worried</li> </ul>
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Prompts: What makes you say this? (details / examples)		

DIFFERENCE TO YOU	
What difference (if any) does this impact on [X] make to you?	
Prompts:	
<ul style="list-style-type: none"> <li>▪ Easier / more difficult to work with?</li> <li>▪ Is the service you give more or less personal and individual?</li> <li>▪ Do you have more or less to record when you visit?</li> <li>▪ Do you think about them less or more when you are not with them?</li> <li>▪ Has it changed your talk or interaction with the client?</li> </ul>	
IMPACT ON FAMILIES	
How (if at all) has telecare affected the carers and families of [X]? <i>Read out the following statements and get a rating from 1 to 10, with 1 strongly disagree and 10 strongly agree:</i>	
<ul style="list-style-type: none"> <li>▪ They get a break from caring more often / more easily</li> <li>▪ They seem less tired</li> <li>▪ Their own health seems better</li> <li>▪ They seem more relaxed</li> <li>▪ They say they have greater peace of mind</li> <li>▪ They seem less worried and anxious</li> <li>▪ They say they have a better quality of life</li> </ul>	<ul style="list-style-type: none"> <li>▪ Nothing much seems to have changed</li> <li>▪ They are getting on better together</li> <li>▪ Their relationship with me has changed</li> <li>▪ There are some things they no longer need to do for the person</li> <li>▪ They don't seem happy about the telecare</li> <li>▪ They say they are getting called to the house more often</li> </ul>
FINAL QUESTIONS	
<i>Would you like to add anything further about your experience of telecare?</i>	
KEY POINTS	
<i>Of the things we've discussed, which are the really important points you'd want to emphasise?</i>	

Thank you very much for taking the time to participate in this interview; we really appreciate it and have found the discussion very helpful.

## Document A6: Carer Telephone Interview Topic Guide

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

Preamble adapted from Document A4.

Thank you for agreeing to be interviewed. I plan to focus this interview on three topics:

- A. Your experiences of telecare and views about it.
- B. How telecare affects your caring role and your own well-being.
- C. The impact of telecare on the person / people you care for.

The research team will keep any personal information confidential, and when writing or speaking about the research you will not be identified.

Do you have any questions before we start? Do you object to the interview being audio-recorded?

#### A. YOUR VIEWS AND EXPERIENCE OF TELECARE

*I'd like to start by checking a few details about your caring situation before exploring your experiences of telecare and how you feel about the equipment.*

PERSON CARED FOR AND EQUIPMENT IN PLACE
<p>1. First I'd like you to tell me about the person you care for...</p> <ul style="list-style-type: none"> <li>▪ What is person's disability or care need?</li> <li>▪ Do you live in same household? If not, how close?</li> <li>▪ What's your relationship to the person you're caring for?</li> <li>▪ How long have you cared for them?</li> <li>▪ On average, how much care are you providing in a week?</li> <li>▪ Are you in employment? How many hours a week? How does this affect the care you provide?</li> <li>▪ Does (X) have any home care or use any day care services? (<i>get details</i>)</li> </ul>
<p>2. Do you care for anyone else? / Have you previously cared for anyone else?</p> <ul style="list-style-type: none"> <li>▪ What is / was that person's disability or care need?</li> <li>▪ Do / did you live in the same household? If not, how close?</li> <li>▪ What is / was your relationship to the person you're caring for?</li> <li>▪ How long have / did you care for them?</li> <li>▪ On average, how much care are / were you providing in a week?</li> <li>▪ Are / were you in employment? How many hours a week? How does / did this affect the care you provide?</li> </ul>
<p>3. ...and the telecare equipment in place</p> <ul style="list-style-type: none"> <li>▪ What type of telecare is in place?</li> <li>▪ How long has it been in place?</li> </ul> <p><i>[Repeat if caring / used to care for another person]</i></p>
INSTALLATION OF TELECARE
<p>4. Could you tell me something about the circumstances that led to telecare being installed?</p> <ul style="list-style-type: none"> <li>▪ Who suggested telecare might be useful?</li> <li>▪ Was there a particular incident that led to it being installed?</li> <li>▪ What (if any) advice/ support did you receive and from whom?</li> <li>▪ What assessment was made and by whom?</li> <li>▪ Any costs involved?</li> <li>▪ Experience of installation / training?</li> </ul>

<b>USE AND UNDERSTANDING OF TELECARE</b>
<p>5. Do you yourself use or rely on the telecare equipment when providing care?</p> <ul style="list-style-type: none"> <li>▪ How often do you use it/ find it helpful?</li> <li>▪ Does having the telecare in place affect your regular caring routine in any way?</li> <li>▪ What (if anything) do you do with it?</li> </ul>
<b>FEELINGS ABOUT AND EXPERIENCES OF TELECARE</b>
<p>6. Before it was installed, did you have any expectations about telecare?</p> <ul style="list-style-type: none"> <li>▪ Has your experience matched these expectations? In what way?</li> <li>▪ How do you feel about having / using the equipment now?</li> <li>▪ Is there anything you find particularly useful, helpful, or attractive about the telecare in place to support / assist (X)?</li> <li>▪ Is there anything you find annoying, unhelpful or unattractive about having the telecare?</li> </ul>
<b>CHANGES AND LOOKING FORWARD</b>
<p>7. Since it was first installed...</p> <ul style="list-style-type: none"> <li>▪ Has the equipment been checked or tested?</li> <li>▪ Has your (X)'s need for telecare been reviewed or reassessed?</li> <li>▪ Has the equipment been upgraded or changed?</li> </ul> <p>Has any of the original equipment been sent back or set aside? (<i>find out why</i>)</p> <p>Looking forward, are there any issues related to the telecare you think might become important for you and the person you care for?</p>

## **B. HOW TELECARE AFFECTS YOU WHILE YOU ARE CARING**

*I'd now like to find out if telecare has had any impact on how you care.*

<b>PRACTICAL IMPACT ON YOUR CARING ROLE</b>
<p>You've said you were already caring for [XX] before the telecare was installed, have there been any differences affecting you, comparing the situation before and after having the telecare?</p> <p><i>Ask about whether telecare has made any difference to the caring role, in terms of:</i></p> <ul style="list-style-type: none"> <li>▪ The <i>tasks</i> you do</li> <li>▪ The <i>time</i> you spend caring</li> <li>▪ The <i>frequency</i> of your caring tasks</li> <li>▪ How <i>many</i> caring tasks there are to do</li> <li>▪ The way you <i>interact</i> with care workers or other healthcare professionals</li> <li>▪ Your <i>financial</i> situation (+ve or -ve -e.g. cost of equipment / ability to work / welfare benefits)</li> </ul> <p><i>[if they did not care for [X] before telecare was installed]</i></p> <p>What do you think it would be like to provide care without the telecare?</p> <p>In what ways does it make a difference?</p>
<b>IMPACT ON YOU</b>
<p>I'm going to ask you now about how (if at all) the telecare has affected your own well-being and ability to care? <i>Rate each statement 1-10; 1 means you disagree strongly, and 10 that you agree strongly.</i></p>



I get a break from caring more often / more easily
feel less tired
My own health seems better
I feel more relaxed
I have greater peace of mind
I feel less worried and anxious
I have a better quality of life (including time for recreation)
Nothing much seems to have changed
I am getting on better together with the person I care for
There are some things I no longer need to do for the cared for person
<b>HOW YOU FEEL ABOUT YOUR CARING ROLE</b>
Does having the telecare in place make any difference to how you feel about the care you provide?
Prompts: <i>For example, does it affect:</i>
<ul style="list-style-type: none"> <li>▪ How confident you feel about caring?</li> <li>▪ Your personal relationship with the person you care for?</li> <li>▪ Any worries you may have about the person you care for?</li> <li>▪ The amount or type of contact you have with the person you care for?</li> </ul>

### C. HOW TELECARE AFFECTS THE PEOPLE YOU CARE FOR

Now I'd like to explore how the people you care for experience telecare and its impact on you / your caring role.

<b>HOW THE PERSON YOU CARE FOR USES/ IS SUPPORTED BY THE TELECARE</b>		
8. How does the person you care for use the telecare installed?		
Note – use the prompt below only if needed; if prompts are used this MUST be recorded		
<ul style="list-style-type: none"> <li>▪ What (if any) specific issues have they encountered? (get clear information when, circumstances, etc)</li> <li>▪ How was each specific situation dealt with?</li> <li>▪ If they don't use it / rely on it very often, why do you think this is? What could help?</li> <li>▪ If they are using it inappropriately, why do you think this is? What could help?</li> <li>▪ Has this changed over time? Why do you think this is?</li> </ul>		
<b>IMPACT ON PERSON CARED FOR</b>		
Now that telecare is in place, how would you describe its impact on the person you care for? (Use rating scale 1-10 as before; ask respondent to explain both positive and negative outcomes.)		
<table border="0"> <tr> <td> <ul style="list-style-type: none"> <li>▪ X is more independent</li> <li>▪ X gets more exercise</li> <li>▪ X has fewer accidents</li> <li>▪ X sees more people</li> <li>▪ X goes out more</li> <li>▪ X seems to be happier</li> <li>▪ X is more active within the home</li> <li>▪ X seems to be more worried</li> </ul> </td> <td> <ul style="list-style-type: none"> <li>▪ X has more dignity</li> <li>▪ X has more privacy</li> <li>▪ X has become more lonely</li> <li>▪ X complains more</li> <li>▪ X does more activities</li> <li>▪ X says they see less of family members</li> <li>▪ X has less contact with neighbours</li> </ul> </td> </tr> </table>	<ul style="list-style-type: none"> <li>▪ X is more independent</li> <li>▪ X gets more exercise</li> <li>▪ X has fewer accidents</li> <li>▪ X sees more people</li> <li>▪ X goes out more</li> <li>▪ X seems to be happier</li> <li>▪ X is more active within the home</li> <li>▪ X seems to be more worried</li> </ul>	<ul style="list-style-type: none"> <li>▪ X has more dignity</li> <li>▪ X has more privacy</li> <li>▪ X has become more lonely</li> <li>▪ X complains more</li> <li>▪ X does more activities</li> <li>▪ X says they see less of family members</li> <li>▪ X has less contact with neighbours</li> </ul>
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## FINAL QUESTIONS

*Before we finish, I'd like to a few moments to explore any issues you'd like to mention which we've not discussed.*

ADDITIONAL ISSUES
Would you like to add anything more about your experience of telecare?
KEY POINTS
Of the things we have discussed, which are the really important points you'd want to emphasise?

*Do we have your permission to contact you again, to discuss the possibility of learning more about how telecare is working for your family? YES / NO*

*This will not place you under any obligation; it would just enable us to invite you to help us further with the research if you wished to do so.*

Thank you very much for taking the time to be interviewed for this research.

We really appreciate it and have found the discussion very helpful.

## Document A7: Everyday Life Analysis Visit Topic Guide (Biography)

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

This visit will explore your biography and history as well as your experience of telecare. We want to find out more about your life, to help us learn about your everyday activities, memories and interests. This will also help us understand the way your life interacts with your experiences of telecare. We would like the session to focus on events and people that have been significant to you. We can talk about your childhood, work, family, holidays and other occasions.

#### Ethics / consent

*Confidentiality / anonymity:* we will ensure confidentiality / anonymity, and will not quote you by name in our study reports. The information you give will be stored securely and shared only with members of the research team.

*Right to withdraw:* you may withdraw from the study at any time and without giving a reason. Please also let us know if any questions arise that you do not wish to answer, or if you want to put an end to a session / interview, or take a break.

Are you still happy to participate? Do you have any questions before we begin?

*Audio recording:* Do you mind if I record the session?

#### TOPIC GUIDE

##### Telecare and recent living situation

- How are you getting on with your telecare equipment?
- What led up to you having telecare installed?
- Have you used the alarm / have there been any alerts recently / at all?
- What happened (was it a falls alarm; did someone come to see you – who? etc.)
- Have you fallen? What happened? (alarm; managed to get up on your own etc.?)
- Have you had a checking call?
- Have you been wearing the pendant alarm/ GPS tracking device? (You can tell me- this is confidential.)
- Has anyone else been talking to you about it; or have you spoken about it with someone?
- Any changes?
- Any difficulties?
- Anything that has worked well? Likes / dislikes?

##### Your life / Life events

Let's talk now about some of the events or changes that have happened in your life? *This could include getting married, having children, moving home, war, travel, retirement, etc.*

*Did you find any objects or photographs which you would like to talk to me about?*

##### People in your life

What about the people in your life? Their relationship to you and impact on your life history? Any heroes or people you particularly admire?

##### Relation to technology / telecare:

##### Work history:

- Did you use any machines or technologies as part of your work (e.g. typewriter, factory machinery, computer, sewing machine)?

Home / family:

- Which technologies or machines did you have at home when you were younger?
- Technologies to help with housework (e.g. washing machine, Hoover)?
- Technologies for leisure / communication (telephone, television, video)?
- When did you get them? Why? Who for?

Objects / photographs: *A selection of appropriate pictures was shown*

Can you tell us a bit about this picture? Who / what / when? Why did you choose this particular photo / item?

And your future plans / hopes / concerns for the future?

Key topics (*checklist for interviewer*):

Work	Change over time
Education	Later life / retirement
Family / relationships	Technology
Home / favourite places	Special occasions / holidays
Hobbies and interests	Implications of telecare: staying in own home, continuity

## **Document A8: Everyday Life Analysis Visit Topic Guide (Education, Care, Employment and Retirement)**

### **AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life**

In this session, as well as speaking some more about your telecare, we would like to talk about your schooling, work / what you did after school, your hobbies and retirement. We will start with your experiences of school, including things you enjoyed about education and things you didn't. We will follow up by discussing any jobs you have had in the past. We will also talk about your retirement and any current hobbies or interests you have.

*Edit the session to suit the participant regarding employment versus homemaking and care.*

Ethics / consent *as in Document A7*

#### TOPIC GUIDE

*General introduction / recap*

- Has anything happened since I last saw you?
- Recap from previous visit: Can I check that I understood this correctly...? Have you thought about anything else relevant about the topic of the previous visit?
- Health: How have you been since we last met?
- Diary: Have you written anything in it? Would you like to discuss it now, or should I take it with me and we can talk about it next time?

### Standard questions about telecare

- How are you getting on with your telecare equipment since our last visit?
- Have you used the alarm / have there been any alerts? What happened (falls alarm; did someone come to see you – who? etc.)
- Have you fallen? What happened? (alarm; managed to get up on your own etc.?)
- Have you had a checking call?
- Have you been wearing the pendant alarm/ GPS tracking device? You can tell me- this is confidential.
- Has anyone else been talking to you about it; or have you spoken about it with someone?
- Any changes?
- Any difficulties?
- Anything that has worked well? Likes / dislikes?

### Education, employment, caring, hobbies and retirement

#### Learning in school and youth:

- Can you tell me about learning in school?
- Did your schooling or later education have much impact on your life afterwards (*e.g. choice of employment*)?
- Did you attend further education (college / university) or work-related training?
- What did you study? How did this experience differ from school?

#### Learning during work life / adulthood

- Did you do any training at work?
- Did you learn to use any machines or equipment?
- Did you do any training at your free time
- Relation to technology / telecare:

#### Learning in later life

- What new thing(s) have you learned since retirement?
- Where / how did you learn this?
- How important has learning new things been to you?
- Was there anything you would have wanted to learn but did not have the opportunity?
- Did you use any machines or technologies during your education?

### Your experience of employment *Ask any who describe themselves as 'homemakers' about employment too*

#### Could you tell me about the first job you ever had?

- Feelings about starting work, challenges?
- What led to your choice of career?
- Did you always work in similar areas or change? What led to change of direction?
- Were you out of work at any period, could you tell me why?
- Voluntary, unemployment; feelings about this period?
- Did you enjoy work?
- Which aspects and why?
- What was your most important / enjoyable experience at work?
- What was the least enjoyable thing that ever happened at work?
- What new skills did you acquire during your working life?
- Result of experience / training? Relevance to technology? How have these skills related to everyday life?

- Could you tell me about relationships with work colleagues?
- Were they important? How were relationships with bosses? Did you work alone or as part of a team?
- How did work relate to your home life?
- Wife / husband? Children? Other commitments?
- Did you use any machines or technologies during your employment?

Caring and supporting others:

- Did you stay at home when your children were young?
- Did you work before that? How did you feel about staying at home?
- Did you have any other caring responsibilities?
- Who and what was their situation?
- How did you help / support / care for them?
- *When relevant, ask if they have had any telecare in place or any adaptations done to their home?*

Which technologies or machines did you have?

- Technologies to help with housework?
- Technologies for leisure / communication?
- When did you get them? Why; who for?

Retirement (where applicable) and hobbies:

What were your feelings prior to retirement?

- Looking forward to it or not?
- Can you tell me what the first [few months / year] was like?
- Difficulties in adjusting?
- What do you like to do in your spare time?
- Hobbies, recreational activities, travel, visiting family / friends?
- Is technology involved?
- What have been your thoughts about engaging with new technologies to pursue these interests?
- Have your leisure activities changed during your lifetime?
- What did you do when younger?
- Why have these activities changed?
- How has your state of health affected your retirement and the things you like to do?
- Presented challenges? Has telecare helped?

Relation to technology / telecare:

Retirement / leisure: Do / did you use technologies to pursue your recreational interests / hobbies (e.g. computers, cameras, TVs, transport)?

Objects / photographs: *A selection of appropriate pictures was shown*

Can you tell us a bit about this picture? Who / what / when? Why did you choose this particular photo / item?

## Document A9: Topic Guide (Health, illness and disability)

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

This session will look at your health and what you feel have been the high and low points in your life. We would like to look back over time and also explore how your health is now, and whether you have had any significant illnesses in your life. We'd also like to talk to you about the health of anyone you may care for or have cared for in the past and of course we'll want to know more about your telecare as well.

Ethics / consent *As in Document A7*

#### TOPIC GUIDE

*General introduction / recap – As in Document A8*

*Standard questions about telecare - As in Document A8*

*Own health and disability- history*

- Have you had any illness in your life?
- Can you remember any points in your life when you were particularly unwell?
- How long did it take you to get back to being healthy?
- Do you remember how you felt while you were ill or recovering?
- Who looked after you?
- Looking back, when in your life did you feel most healthy / well?
- Were there any points when you would describe yourself as disabled?

*Own health and disability- How would you say your health is now?*

*[if not good]*

- When and why did it start to change?
- Did you start to need or receive more help at that time? Who helped you?
- When your health changed, what else changed? (e.g. moved home, telecare, medicine, formal care, can't go out alone; getting telecare installed, etc.).
- If there was one thing you could change about your health, what would it be?

*[if good]*

- Where there any points in the last year when your health was not good? What helped you get better?
- What do you think has helped you keep in good health?
- When you do feel unwell, who helps you?
- Do you ask them for help?
- Would you describe yourself as disabled in any way? (If yes) for how long have you been disabled ?

*Family / friends' health*

- Were there any times in your life where members of your family / friends were particularly unwell?
- Have you ever had to look after anyone when they were ill / disabled?

*Ups and downs of life - Thinking back on your life, can you remember any points when you felt particularly low or down?*

- What made you feel low or down?
- What used to cheer you up when you felt low or down?
- Does anything make you feel low or down now?
- When you feel low or down, do you do anything to cheer yourself up? Does anyone else do anything to cheer you up?

*High points* - Thinking back again on your life, when were the times when you felt particularly happy?

- If you could go back to one point in your life, when would it be?
- When do you feel most happy now?
- Have you had any caring responsibilities during your life? Can you tell me about this? How did you feel about this; did this impact on your health and wellbeing?
- Have there been any carers in your close networks (friends/family looking after someone). What was that situation like?

*Points to follow up from previous sessions*

What do you think would have helped; what else would you have wanted / wished for?

Relation to telecare:

- Has the telecare helped you at all? How? (E.g. health / wellbeing / independence / communication / loneliness). If not, why not? (or has it made something less good?)

*Objects / photographs: A selection of appropriate pictures was shown*

Can you tell us a bit about this picture? Who / what / when? Why did you choose this particular photo / item?

## **Document A10: Topic Guide (Home, community and favourite places)**

### **AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life.**

In this session we would like to focus on the important places in your life. We will ask you about your home, favourite places and least favourite places in your neighbourhood and places you like to travel to for holidays or for work or to visit family and friends. This will help us understand how telecare fits into your home, community and mobility arrangements.

Ethics / consent - *As in Document A7*

#### TOPIC GUIDE

*General introduction / recap – As in Document A8*

*Standard questions about telecare - As in Document A8*

Your present home

Can you describe your present home?

- What is it like?
- How long have you been in the house? When did you move here?
- What did you like about it when you first visited?
- What is your favourite room in the house?
- Did plans for ageing have an impact when you were choosing to live here?
- Has the house changed at all during the time you have lived there?
- Adaptations / changes to house – e.g. did you make changes to the house in the past? What about any recent changes to do with ageing?
- Are there changes you would like to make? What would be your ideal home now?



- Are there things you are worried or fearful about in the house? (E.g. cold callers, ASBs, burglars; not being able to access all rooms, managing garden, etc.)
- What technologies (including telecare) do you have in the house?
- Has your use of these changed (e.g. using more ICTs to stay in touch with friends / family)?

*Points to follow up from previous sessions*

Where you have lived? Where did you live / who lived with you? What was the home like, can you describe it?

- What was the area like?
- Which of these have you felt most settled in, most at home? Why?
- Ideal / aspirational home
- What do you feel are key aspects of a really nice home and area?
- What would be / would have been an ideal / dream house and area for you?
- Why do you think you like that type of house / area?

Community and neighbourhood

What is your neighbourhood like?

- Has it changed while you've lived here?
- Do you know much of your neighbours? Anything you regularly do with them?
- How much engagement do you have with the local community?

Where do you go in the local area?

*Ask participant to make a 'map' of the places they go to, using relevant place cards / post-it notes.*

Card titles: Café; Pub; Library; Restaurant; Park; Garden Centre; Home of Friend / Family Member; Church; Community Centre; Golf Club; Football Club; Shopping Centre; Hairdresser / Barber.

- How do you get to this place? (*walk; drive; someone else drives; bus, etc.*)
- Who do you go there with?
- Do you go to these places regularly or only occasionally?
- Do you go there at a specific time of day (day time / evening)?
- Which of these are your favourite places?
- Why? Who do you go there with? What do you do there?
- How has this changed over time? Are there places you miss going to? Why have you stopped going?

Safety and concerns

- Do you feel comfortable / safe outside your house?
- Are there places you don't go to anymore or don't want to go to?
- Do you feel differently about the neighbourhood at different times of day?
- What about different seasons?
- Does the telecare or other technologies help with these concerns?
- What else could help you feel less worried or support you?

Favourite places, holidays

- Do you take trips or vacations? Or visit family / friends who live further away?
- What has been your favourite holiday destination?
- Can you tell me about your last / previous holiday?
- Who do you travel with?
- How do you organise your travel arrangements?
- Has your travelling changed in recent years? How?

Call list (*likely to involve checking existing information*)

*Think about changes to relationships/ possible strengthening of weak ties / building new local relationships*

- Who is on your call list? Where do they live?
- How long have you known them? How did you first get to know them?
- Why did you choose them for the list?
- Did you ask anyone else / have the people on the call list changed over time?
- How accessible is the house to them?

Objects / photographs: *A selection of appropriate pictures was shown*

Can you tell us a bit about this picture? Who / what / when? Why did you choose this particular photo / item?

## **Document A11: Topic Guide (Relationships)**

### **AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life.**

This session will look at the people in your life at the moment, as well as your relationships with them. We will consider your husband / wife / partner, friends, family members, neighbours, and health and social care professionals (such as GPs, nurses, and support workers). We are also interested in how you keep in touch, how often you see them, whereabouts you see them, and whether any provide you with assistance or support. This will help us understand how telecare fits into these relationships.

Ethics / consent - *As in Document A7*

#### TOPIC GUIDE

*General introduction / recap - As in Document A8*

*Standard questions about telecare - As in Document A8*

People in your life

*Mapping: Who are the people in your life at the moment?*

*Mark yourself on the paper, and place the people closest / most important to you nearest to you.*

Who lives nearest to you? Who do you see most?

Communication / keeping in touch

- How do you normally communicate with these people?
- Has the way you communicate with them changed over time?
- Do you ever communicate with them differently?

Socialising / going out

People you visit outside the home

- Social activities
- Outdoor activities
- Membership of societies / clubs, music / sport activities / church / religious / community groups

Visitors at home

Does anyone come to visit you at your home? Who? When / how often? Why?

### Care and support

- Does anyone help you out at home?
- Who are the people who help you / provide you with care?
- How long have you known them? Do you help anyone?
- Who would you contact first if you needed help / needed to talk to someone?

### Relationships and telecare:

- Who are the people in your responder list for telecare? How do you know them (how long; how did you get to know, if not family; where do they live)
- Did any of them suggest you have telecare? Any other services / equipment / adaptations in your home?
- Does anyone help you with your telecare equipment?
- Do any of these people have telecare themselves?
- Does telecare have any impact on these relationships?

Objects / photographs: *A selection of appropriate pictures was shown*

Can you tell us a bit about this picture? Who / what / when? Why did you choose this particular photo / item?

## Document A12: Topic Guide (Technology)

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

This session will look at your use of different technologies, including technology used in your childhood, in your work, in your family home and now (e.g. radio, domestic machines, telephone and computer). We are interested in how you started to use the technologies, your thoughts about them, who helps you with them and so on. At the end we focus on the telecare you have at the moment.

Ethics / consent - *As in Document A7*

General introduction – recap - *As in Document A8*

Standard questions about telecare - *As in Document A8*

### Technology in your childhood home

Can you tell me about any technology you had in your childhood home?

- Communication technologies, e.g. telephone. What was this used for? Who used the phone most? Did you get to use the phone, who would you call?
- Leisure technologies such as radio / wireless; television. When was the radio on, what programmes did you listen to? When did you get a television?
- Utility technologies; tools; kitchen machines; washing machine, etc.

What do you remember about any new technology coming into your home during your childhood or youth?

Questions about technology coming into the home

*Use these also in following sections, e.g. technologies in family home and retirement*

- When did your family first get this?
- Why did your family get this?
- Who decided to get this; where did you get it from?
- Where was it placed in the home?
- Who used it most?
- Roles of different family members (re using technology, making decisions)
- Did the type of use it had change over time?

- What did you / your family do if there were problems with it? Could you / they fix it? Who would you go to for help?

What opinions did your parents or other people close to you (extended family; neighbours etc.) express about (new) technology? (suspicious; eager to try, etc)

- Were there different points of view?

Points to follow up from previous sessions

In your younger days, were there specific machines you used rather than your spouse / children? Any that they used that you didn't?

For any technologies mentioned, ask questions about technology coming into the home (as above)

Using technologies at work

Did you use any technologies in your work (e.g. typewriter, adding machine, factory machinery)?

- What was it like?
- Did you like this? / were you good at it?
- Did you get some training to use it, who did you go for support?
- Did you train or support others to use them?

Technology in later life

What technologies (gadgets / machines) do you use regularly now?

- What is most useful?
- Do you have any that you don't use?
- Do you have some that were a disappointment, not working as you they would?
- What technologies do you use for keeping in touch (if any)? (e.g. mobile phone, texting, internet?)

Obtaining technologies

Are there any technologies that you have started using recently?

- When / at what age did you last buy a new gadget / machine (e.g. TV, new phone)
- Do you have any that you been given as presents, or which somebody has insisted you have?

*For any technologies mentioned, ask relevant questions about technology coming into the home*

Children's and grandchildren's use of technology, and relationship to them

- Are there things they use but you don't? Generational differences; any feelings of being left behind?
- Anyone teaching you to use them?
- Are there things about technology that worry or scare you?
- What is your favourite gadget or machine? (now or in the past)?

Telecare:

This is the last visit: what are your thoughts about telecare now? Have your views changed by taking part in the study?

Objects / photographs: *A selection of appropriate pictures was shown*

Can you tell us a bit about this picture? Who / what / when? Why did you choose this particular photo / item?

*Conclude visit sensitively, using agreed exit strategy and gift.*

## Document A13: ELA Fieldwork Notes Template

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

Name of researcher	Date of visit	Unique ID number of household
Source of referral	Pseudonym	

Age	Marital status	Family
Informal networks	Former occupation	Education

RESEARCHER'S COMMENTS AND OBSERVATIONS	
Reasons for TC	
Expectations / assumptions prior to visit	
Initial feelings about the visit	
Chronological account	
Observations on key issues	
Characteristics of user and implications for telecare	
Relationship between service user and carer / household members	
Relationship between the service user and wider care network	
When / how telecare products are used	
Positive aspects / benefits of telecare	
Any problems / difficulties in using telecare products	
Description of house and area	
Initial analysis key issues, anything surprising, striking, unexpected?	
Strategising for future fieldwork	

## Document A14: ELA Carer Interview Guide

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

*This interview can be conducted via telephone, email or in person; depending on what suits the carer.*

Thank you for agreeing to be interviewed. As you know, your [relative/friend] is participating in our research because they are an older person using telecare. We'd like to speak to you to explore how the telecare equipment has affected you as a carer. I plan to focus on three issues: your experiences of telecare and views about it; how telecare affects your caring role and your own well-being; the impact of telecare on the person / people you care for. The research team will keep personal information confidential, and when writing or speaking about the research you will not be identified. I will not discuss specific elements of your interview with your [relative / friend]. Do you have any questions before we start? Do you object to the interview being audio-recorded? I'd like to start by checking that my understanding of your caring situation is correct.

I'd like you to tell me about the person you care for...

- How long have you cared for them?
- On average, how much care are you providing in a week?
- Are you in employment? How many hours a week? How does this affect the care you provide?

Do you care for anyone else? / Have you previously cared for anyone else?

- What is / was that person's disability or care need?
- Do / did you live in the same household? If not, how close?
- What is / was your relationship to the person you're caring for?
- How long have / did you care for them?
- On average, how much care are / were you providing in a week?
- Are / were you in employment? How many hours pw? How does / did this affect the care you provide?
- Is / was telecare used in this situation?

Could you tell me something about the circumstances that led to telecare being installed?

- Who suggested telecare might be useful?
- Was there a particular incident that led to it being installed?
- What (if any) advice/ support did you receive and from whom?
- What assessment was made and by whom?
- Any costs involved?
- Experience of installation / training?
- Was the decision to install telecare a simple one or where there any disagreements?

Do you yourself use or rely on the telecare equipment when providing care?

- How often do you use it/ find it helpful?
- Does having the telecare in place affect your regular caring routine in any way?
- What (if anything) do you do with it?

Before it was installed, did you have any expectations about telecare?

- Has your experience matched these expectations? In what way?
- How do you feel about having/using the equipment now?
- Is there anything you find particularly useful, helpful, or attractive about the telecare in place?
- Is there anything you find annoying, unhelpful or unattractive about having the telecare?

Since it was first installed...

- Has the equipment been checked or tested?
- Has (X)'s need for telecare been reviewed or reassessed?
- Has the equipment been upgraded or changed?
- Has any of the original equipment been sent back or set aside (find out why)?

Looking forward, are there any issues related to the telecare you think might become important for you and the person you care for?

I'd now like to find out if telecare has had any impact on how you care. You've said you were already caring for [X] before the telecare was installed, have there been any differences affecting you, comparing the situation before and after having the telecare? For example,

- The tasks you do
- The time you spend caring
- The frequency of your caring tasks
- How many caring tasks there are to do
- The way you interact with care workers or other healthcare professionals
- Your financial situation (+ve or -ve -e.g. cost of equipment / ability to work / welfare benefits)

[if they did not care for [X] before telecare was installed]

- What do you think it would be like to provide care without the telecare?
- In what ways does it make a difference?

I'm going to ask you now about how (if at all) the telecare has affected your own well-being and your ability to care? I'd Please rate the following on a scale of 1-10, where 1 means disagree strongly, 10 agree strongly.

I get a break from caring more often / more easily	I feel less worried and anxious
I feel less tired	I have a better quality of life (including time for recreation)
My own health seems better	Nothing much seems to have changed
I feel more relaxed	I am getting on better together with the person I care for
There are some things I no longer need to do for the cared for person	I have greater peace of mind

- Does having the telecare in place make any difference to how you feel about the care you provide?
- How does the person you care for use the telecare installed?
- And now that telecare is in place, how would you describe its impact on them?

Use rating scale 1-10 as before, and ask them to explain both positive and negative outcomes.

X is more independent	X has more dignity
X gets more exercise	X has more privacy
X has fewer accidents	X has become more lonely
X sees more people	X complains more
X goes out more	X does more activities
X seems to be happier	X says they see less of family members
X is more active within the home	X has less contact with neighbours
X seems to be more worried	

Before we finish, would you like to add anything more about your experience of telecare? Of the things we have discussed, which are the really important points you'd want to emphasise?

Do we have your permission to contact you again, to discuss the possibility of learning more about how telecare is working for your family? YES / NO

## Document A15: ELA Care Worker Interview Guide

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

We plan to focus today's discussion on: your experiences of telecare and your views about it; how telecare affects you when you are doing your job; the impact of telecare on the people you care for and their families. Do you have any questions? Do you object to the interview being audio-recorded? [*Consent form*]

Could you tell me something about your job ...

- Who employs you? [NHS, private]
- How many clients do you provide care for?
- What are the characteristics of the people you care for? [age, condition]
- How many of your clients use telecare?

Could you tell me about the care you provide for [X]?

- How long have you provided the care?
- How often do you visit them?
- What tasks are involved?
- What (if anything) has changed in the care you provide since you began?
- Who else is involved in providing the care?
- When you are working in [X'S], do you use the telecare equipment in any way?
- What do you do with it? How often?
- Is it part of any of your regular routines?

Now I'd like us to talk about:

- Anything you have found useful, helpful, or attractive about the telecare used by [X]?
- And is there anything you perhaps find annoying, unhelpful or unattractive about the telecare?
- When you are in [X's] home, is there anything about the telecare that worries or concerns you?

I'd now like to find out if telecare has had any impact on how you do your job. What are the main differences you think it has made to the care you provide? For example, to:

The tasks you do	The time you spend in the house
The frequency of your visits	Working alone or with a partner
How much work there is to do	Any contact with the client which does not involve a home visit
The information you have about the client / how they are feeling or getting on	

Has providing care for [X] now telecare is in place changed how you feel about your job in any way?

Now I'd like to ask how you believe [X] experiences telecare. I'd like you to rank the following statements on a scale of 1 to 10, where 1 is strongly disagree and 10 is strong agree.

X is more independent	X has more dignity	X has more privacy
X gets more exercise	X has become more lonely	X complains more
X has fewer accidents	X does more activities	X says they see less of family members
X sees more people	X has less contact with neighbours	X is more active within the home
X goes out more	X seems to be happier	X seems to be more worried

What difference (if any) does this impact on [X] make to you? How (if at all) has telecare affected the carers and families of [X]? *Read out statements and get rating 1 to 10, with 1 strongly disagree and 10 strongly agree:*

They get a break from caring more often/more easily	Nothing much seems to have changed
They seem less tired	They are getting on better together
Their own health seems better	Their relationship with me has changed
They seem more relaxed	There are some things they no longer need to do for the person
They say they have greater peace of mind	They don't seem happy about the telecare
They seem less worried and anxious	They say they are getting called to the house more often
They say they have a better quality of life	

Would you like to add anything further about your experience of telecare? Thank you very much for taking the time to participate in this interview.



## Document A16: ELA Care Worker Questionnaire

### AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in later life

#### About you

1. Are you: Male  Female
2. How old are you? 16 – 24  25 – 34   
35 – 49  50 – 59   
60 – 64  65 or older

#### Your job role

3. How long have you been a care worker?

Up to one year  Two to five years  Six to ten years  Over ten years

4. What type of organisation employs you?

NHS  Private sector  Not-for-profit  Voluntary

Other  (please state \_\_\_\_\_)

5. How many people do you regularly care for each week? \_\_\_\_\_ person(s)

6. What kind of care do you provide? (Please tick all that apply)

<b>Personal care</b> (e.g. bathing, showering, washing/styling/cutting hair, trimming fingernails and toenails)	<input type="checkbox"/>
<b>Physical help</b> (e.g. manual handling, lifting, helping clients get in and out of bed, helping clients go to the toilet, changing dressings, catheters, colostomy bags, first aid)	<input type="checkbox"/>
<b>Practical help</b> (e.g. preparing/cooking meals, serving food and drinks, help with eating and drinking, domestic chores such as vacuuming, cleaning, washing up, ironing and laundry, shopping, help with small maintenance and repair jobs)	<input type="checkbox"/>
<b>Giving medicines</b> (e.g. administering medicines, drugs, giving injections, reminding clients about taking their tablets/medicines)	<input type="checkbox"/>
<b>Advice and emotional support</b> (e.g. giving advice about welfare benefits, providing counselling, tutoring, help with learning)	<input type="checkbox"/>
<b>Visiting / keeping him/her company / providing emotional support, motivation or supervision</b> (e.g. visiting, sitting with, reading to, talking to, playing cards or games, overnight stays)	<input type="checkbox"/>
<b>Managing or planning their other care support services</b> (e.g. helping clients contact other services, making appointments for them, chasing up services on their behalf)	<input type="checkbox"/>
<b>Other</b> (please specify)	<input type="checkbox"/>

#### Using telecare

7. Of the people you care for, approximately how many use telecare? \_\_\_\_\_ person(s)

8. How frequently do you visit those people who use telecare?

Every day  Several times a month   
Several times a week  Once a month   
Once a week  Less than once a month

Other, please specify \_\_\_\_\_

**9. What medical conditions do these telecare users have:***(please tick all that apply)*

Dementia/ memory problems <input type="checkbox"/>	Mental health problems <input type="checkbox"/>	Arthritis <input type="checkbox"/>	Falls <input type="checkbox"/>
Learning difficulties <input type="checkbox"/>	Visual impairment <input type="checkbox"/>	Hearing impairment <input type="checkbox"/>	Heart problems <input type="checkbox"/>
Breathing problems <input type="checkbox"/>	Parkinson's disease <input type="checkbox"/>	Chronic illness <input type="checkbox"/>	Cancer <input type="checkbox"/>

*If other, please specify* \_\_\_\_\_**10. What type of telecare equipment have you seen or used?** *(please tick all that apply)*

Type of telecare	I have seen this in clients' homes	I have a client who uses this	I have been trained to use this	I have used this myself	I think this equipment is useful
Personal alarm (pendant)					
Fall detector					
Flood detector					
GPS tracker					
Vibrating pillow alert					
Activity monitor					
Home Unit					
Gas sensor/cut off valve					
Carbon monoxide sensor					
Property exit sensor					
Extreme temperature sensor					
Bed occupancy sensor					
Environment controls					
Smoke detector					
Medication reminder					
Bogus caller button					
Reminder systems					

Other *(please specify)* \_\_\_\_\_

How, if at all, does telecare impact on your job? \_\_\_\_\_