**Interview guide: carers and people living with dementia**

The aim of this interview is to explore the various kinds of dilemmas and challenges that arise around innovations in smart technologies for dementia care, and to understand those from the perspective of the various professionals and lay people involved. In the interview I’d like to explore your experiences of smart care for dementia and understand more about how it looks from your perspective. We will be talking specifically about ethics later in the interview, but I’d like to start by getting a better idea of your experience.

**Introduction**

Could you start by telling me about the smart care that you (your relative etc) have? What kind of sensors/devices do you have in the house, and what do they do? How long have you had them? Could you talk me through a typical day with smart care? How does it fit into your daily routine?

**Challenges**

Have there been any challenges, hitches or dilemmas in getting smart care to work, in your experience? Are there instances where the smart care hasn’t run as smoothly as you’d like? *I’d like to focus on this issue of challenges in some detail - can you tell me about some examples of those difficult challenges – (for each challenge that the interviewee identifies) how did you realise there was a problem, how did you get through it and who was involved in that? What would you say are the sources of the challenges? (If the interviewee finds it difficult to answer, offer the possibilities that you might say that it was difficulties getting technologies to work as required, or lack of knowledge or expertise, or challenges of collaboration, or various kinds of human problem error or misunderstandings). Did any of the challenges that you have faced make any fundamental difference to getting smart care to work for you? Have any of the challenges been unexpected, or unexpectedly difficult?*

Was there anything that worried or concerned you about smart care? Maybe when you were first deciding whether to take part? Or something that came to mind at a later stage? What sort of concerns did you have, and how did you get over them?

Has anything turned out to be unexpectedly straightforward or easy, despite concerns you might have had? Why do you think that might be?

**Ethical frameworks**

Many new innovations have to go through a process of ethical review, to consider not just whether the technology works, but whether it is doing things that we are comfortable are the right things that we should do. Can you think of any issues that you feel an ethical review of smart care should focus on?

**Ethics of AI and care ethics**

Smart care involves using artificial intelligence – that is, computers that learn to analyze patterns in the various kinds of information that are collected about you and then highlight issues that the doctors looking after you think might raise concerns. Experts have suggested that when we develop artificial intelligence we need to think particularly carefully to make sure that what we are doing is ethical. They have identified five key areas that we need to think about. I’d like to tell you about each of those in turn, and ask you to reflect on how you think it applies to the smart care technologies that you have experienced, if at all. This isn’t a test, there’s no right or wrong answer.

Promoting human good – it should be a benefit to the people who receive it

Not doing harm – nobody should be at risk. *Prompts – this might include checking that the technology can’t be mis-used, doesn’t intrude on anyone’s privacy*.

Humans and not machines should have ultimate right to make decisions (and to decide whether or not to take part)

Fairness – people should be treated equally without discrimination

Understandable – we should be able to explain how and why decisions are made by artificial intelligence

Can we pause and reflect on these now – who should do this kind of evaluation, and when? Do you think it’s possible to meet these ethical standards?

Does smart care raise particular ethical challenges because of the use of artificial intelligence? *Why might that be? Do you have any thoughts on how we might deal with those ethical challenges?*

Does smart care raise particular ethical challenges because it takes place in the context of dementia care? *Why might that be? Do you have any thoughts on how we might deal with those ethical challenges?*

**Futures**

How do you see the future of smart care for people living with dementia?

Who might want to use it and who might not? *How widely do you see it being used? Will there be any challenges as it rolls out more broadly? Do you think there is anything that we can do to anticipate and mitigate or avoid these ethical challenges?*

What would your advice be to someone considering becoming a user of smart technology for dementia care? What should they think about and is there anything you would want to warn them about?

**Follow-up interview invitation**

I’m keen that this research get a sense of the ways that our ideas about smart care develop and change over time. Would you be willing for me to contact you in about 4 weeks time to ask if you’d be available for a short (15 minute) catch-up on any new issues that you have encountered in that time? This would mean that I’d need to keep your contact details until then in order to send you an invitation. Of course, if you’ve changed your mind at that point there is no obligation to go ahead.

**Closing thanks**

Thank you very much for your time and your thoughtful consideration of my questions. I just want to remind you that you have the participant information sheet giving all of the information about me and the project and my contact details. I’m happy to answer any questions you may have about that at any point. Is there anything you’d like to ask now, about that, or about my research more broadly?

**Interview guide for follow-up interview**

We last spoke x weeks ago, talking about your experiences of smart care for dementia. This follow-up interview is intended as a quick catch-up to explore any issues that you may have thought about or encountered since we last spoke.

Has the smart care gone smoothly since we last spoke? Have there been any challenges, hitches or dilemmas? If so, how did you realise there was a problem, how did you get through it and who was involved in that? What would you say was the reason for the challenges? (*If the interviewee finds it difficult to answer, offer the possibilities that you might say that it was difficulties getting technologies to work as required, or lack of knowledge or expertise, or challenges of collaboration, or various kinds of human problem error or misunderstandings).* Did any of the challenges that you have faced make any fundamental difference to whether smart care was working for you? Have any of the challenges been unexpected, or unexpectedly difficult?

Has anything that you would consider an ethical dilemma arisen? Is there anything that would relate to the ethical principles that we spoke about last time – I’ll remind you of them, they were that these technologies should work for human good, not do any harm, allow humans to be the decision-makers, be fair and be understandable.

Finally, have you had any other further thoughts about what we discussed last time? (*Prompt if needed – we talked about whether there are particular ethical challenges posed by smart care for dementia and we discussed how you saw the future for this technology*).