**PARTICIPANT INFORMATION SHEET**

**Everyday ethics of smart care: perspectives of users and their carers**

**University of Surrey Ref: SPON 2021 14 FASS**

**IRAS Ref: 301772**

**Section: Taking Part**

My name is Christine Hine. I am a Professor of Sociology at the University of Surrey. I would like to invite you to take part in this research project. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what is being asked of you. If you have any questions you can contact me using the contact details at the end of this information sheet.

**What is the purpose of the study?**

New smart technologies have been developed to care for people living with long-term conditions such as dementia in their own homes. My research aims to explore how people developing and using these technologies think about ethical issues. By ethical issues, I mean the decisions that are taken about what these technologies should do and how people should use them. I will be interviewing people who are using smart care systems and their carers as well as researchers and healthcare professionals involved in delivering these systems. The overall goal is to learn more about whether ethical issues can be predicted in advance and whether we can do more to deal with them in future.

**Who is responsible for this study?**

This study is being carried out Professor Christine Hine at the University of Surrey and also involves Professor Payam Barnaghi at Imperial College, London as Co-Investigator.

**Why have I been invited to take part?**

You are invited to participate in this study because you are someone who has been involved with a smart care system either as a user or carer.

**Do I have to take part?**

You do not have to take part. Your decision on taking part will not affect the care you receive.

**What will happen to me if I decide to take part?**

If you decide to take part, you and a carer or friend will be asked to sign consent forms to confirm your agreement to participate. I will then contact you (or your carer or friend if you prefer) to arrange a convenient time and date for me to interview you. Ideally this will be a time when both you and your carer or friend can be present. During the interview I will ask you to talk about your experiences of smart care and to reflect on any aspects that have been challenging. There are no right or wrong answers: the aim is to have an informal conversation when you can tell me about your experiences. The interview will be audio-recorded. This interview will last for about one hour. I can either visit you in your home or we can hold the interview on the video-calling service Zoom if you prefer or if restrictions at the time prevent a home visit.

At the end of the interview I will ask if you are willing for me to re-contact you after 4 weeks for a short follow-up phone call or Zoom call of approximately 15 minutes and we can decide then whether you would like me to call you or your carer. I will send a letter to remind you about the follow up call before I call. If you do complete a follow-up call I will ask you at the end of that call whether you are willing for me to re-contact you again for a further follow-up after another 4 weeks. Follow-up calls will focus on any new issues that have occurred since we first spoke, and will again be audio-recorded.

In a later phase of the research I will be conducting focus groups with some interviewees to reflect on the findings and identify next steps. You will be asked to indicate on the consent form if you are willing for me to keep your contact details so that I can invite you to a focus group. If you give consent for me to contact you in this way you are not obliged to take part when the time comes.

Audio-recordings of interviews will be sent securely to a professional transcription service to be transcribed. The transcript will then be edited to take out identifying details such as your name. After checking of the transcript the audio-recording will be deleted.

**What happens if I do not want to take part or if I change my mind?**

You are free to withdraw from the study at any time, without giving a reason. If you wish to withdraw during the interview you can ask to stop and I will delete any interview data collected up to that point. If you wish to withdraw your data after the interview has been completed you can contact me up to one month after the date of your final interview and any interview data collected up to that point will be deleted. Beyond this point I cannot guarantee to be able to withdraw interview data because it will have been anonymised and included in analysis. If you wish not to take part in a follow-up interview you can tell me at any point or simply say that you are no longer willing to take part when I re-contact you. At that point I will delete any interview data previously collected that I can if you ask me to do so.

**What are the possible benefits in taking part?**

The information we will get from the study will help us to learn more about whether ethical issues can be anticipated in advance and to develop ways to build ethical decision-making into the lifespan of a project. There will be no specific benefits to you but you may appreciate the opportunity to reflect how the system works for you.

**Are there any potential risks involved?**

There are no anticipated risks to your wellbeing. You may have concerns about your privacy: you are assured that conclusions from the research and quotations from interviews will be published without identifying you by name. I will not share the audio-recordings with anyone involved in delivering your smart care system – they will only see transcripts with names removed. However you should be aware that there may be aspects of the experiences that you discuss that could be sufficiently unique to identify you from the interview transcript.

The interview may take place online: this means that your personal data may be processed by the platform hosting the interview and will be subject to that platform’s privacy policy. The Zoom privacy policy is here: <https://zoom.us/privacy>.

**How is the project being funded?**

The research is funded under the APEX scheme, jointly awarded by the British Academy, the Royal Academy of Engineering and the Royal Society with the generous support of the Leverhulme Trust.

**Will my participation be kept confidential?**

We are responsible for making sure your participation is kept confidential and any data is kept secure and used only in the way described in this information sheet. Your information may be subject to review for monitoring and audit purposes, by individuals from the University of Surrey and/or regulators who will treat your data in confidence. In the unlikely event that I become aware of a serious risk of harm to yourself or others I will notify the team who are providing your smart care. I will inform you if this happens.

**Will my data be shared or used in future research studies?**

These interviews may prove a valuable resource for future research into the emergence and

management of ethical issues within technology research. We would like your permission to share de-identified interview transcripts with the UK Data Archive, to be made available under licence to the research community. Identifying information including names will be removed before transcripts are offered for archiving. You will have the opportunity to indicate on the consent form whether you are happy for your interview transcript to be archived in this way.

**What will happen to the results of the study?**

This research may be published in conference presentations, journal articles and monographs and summarised on social media. These publications may include anonymised quotations from interviews. You are welcome to contact me by email for a summary of the research on completion in October 2022.

**Who has reviewed this study?**

This research has been reviewed by an independent group of people, called an Ethics Committee. This study was reviewed and given a favourable ethical opinion by South Central – Oxford B Research Ethics Committee.

**Section: Your personal data**

**What is personal data?**

‘Personal Data’ means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to completing the study and this section describes what that means. The information that we will collect will include your name and contact details, which is regarded as ‘personal data’. We will use this information as explained in the ‘What is the purpose of the study’ section above*.*

**Who is handling my personal data?**

The University of Surrey, who has the legal responsibility for managing the personal data in this study, will act as the ‘Data Controller’ for this study. The research team will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly.

**What will happen to my personal data?**

As a publicly-funded organisation, we have to ensure that when we use i**dentifiable personal** information from people who have agreed to take part in research, that this data is processed fairly and lawfully. The University of Surrey processes personal data for the purposes of carrying out research in the **public interest** and special category data is processed on an additional condition necessary for **research purposes.** This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations. When acting as the data controller, the University will keep identifiable information about you for 10 years after the study has finished after which time any identifiers will be removed from the aggregated research data.

You can find out more about how we use your information <https://www.surrey.ac.uk/information-management/data-protection> and/or by contacting [dataprotection@surrey.ac.uk](mailto:dataprotection@surrey.ac.uk) .

**How will we use information about you?**

We will need to use information from youfor this research project. This information will include your name and contact details**.** People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

If you agree to take part in this study, you will have the option to permit your name and contact details to be retained on file in order that you may be contacted about a future study.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

* by visiting <https://www.surrey.ac.uk/information-management/data-protection>
* by sending an email to Christine Hine (c.hine@surrey.ac.uk), or
* by contacting our data protection officer Suzie Mereweather ([dataprotection@surrey.ac.uk](mailto:dataprotection@surrey.ac.uk))
* If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can complain to the Information Commissioner’s Office (ICO) (https://ico.org.uk/).

**Section: Further information**

**What if you have a query or something goes wrong?**

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO)

Research and Innovation Services

University of Surrey

Senate House, Guildford, Surrey, GU2 7XH

Phone: +44 (0)1483 689110

Email: rigo@surrey.ac.uk

The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study, then you should follow the instructions given above.

You can also contact the NHS complaints service if you wish to make a complaint about the way that you have been treated:

PALS and Complaints Manager

18 Mole Business Park

Leatherhead

Surrey KT22 7AD

Tel: 01372 216-202/203/204

Email: rxx.palsandcomplaintssabp@nhs.net

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Professor Christine Hine

Department of Sociology

University of Surrey

Guildford, Surrey, GU2 7XH

c.hine@surrey.ac.uk

01483 686986

**Thank you for reading this information sheet and for considering taking part in this research.**