**PARTICIPANT INFORMATION SHEET**

**Title of Study: Everyday ethics of smart care: perspectives of researchers and developers**

**University of Surrey Ref: FASS 20-21 028 EGA**

**PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS**

**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 participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. 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 offer great promise to improve care for people living with long-term conditions such as dementia and to enable them to live in their own homes for longer. This project aims to explore how ethical challenges arise and are managed in the everyday practice of this work. In Phase 1 of the research I will be interviewing engineers and researchers involved in development of smart technologies for care settings. I aim to identify from each participant’s perspective when and how they become aware of ethical challenges. The overall goal is to learn more about whether ethical issues can be anticipated in advance and whether we can develop ways to build ethical decision-making into the lifespan of a project.

**Who is responsible for this study?**

This study is the responsibility of Professor Christine Hine at the University of Surrey and also involves Professor Payam Barnaghi at Imperial College, London. Professor Barnaghi is Co-Investigator and in this capacity is advising and assisting with recruitment.

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

You are invited to participate in this study because you are a researcher or developer, working in a University, non-profit or commercial setting, involved in the development of smart care. You may have received an invitation because you were identified as potentially involved in this kind of work through a search of publicly available websites, or because you are a member of a relevant mailing list.

**Do I have to take part?**

Participation is voluntary and you do not have to take part. The study is described in this information sheet and you should take time to read it and decide whether you wish to take part in this study. Please contact me if there is anything that is not clear, if you have any questions, or if you would like more information.

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

If you decide to take part, please contact me by email to confirm that you wish to proceed. You will will be asked to sign a consent form to confirm your agreement to participate. You will be given a copy of this consent form to keep. We will then arrange a mutually convenient time and date for an interview. The interview will be held on Microsoft Teams. During the interview I will ask you about your involvement in projects related to development of smart care and I will ask you to reflect on the challenges and dilemmas inherent in such projects before discussing your views on ethical issues. The interview will be audio-recorded. The initial interview will last for approximately one hour. At the end of the interview I will ask if you are willing for me to re-contact you after 8 weeks for a short follow-up interview of approximately 15 minutes. If you complete a follow-up interview I will ask you at the end of that interview whether you are willing for me to re-contact you again for a further follow-up interview of approximately 15 minutes after another 8 weeks. Follow-up interviews will focus on any ethical issues of interest that you have encountered or reflected on in the intervening weeks, and will again be conducted on Microsoft Teams and audio-recorded.

In the final 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 retain your contact details for the purpose of inviting you to a focus group. Giving consent for me to contact you in this way places you under no obligation to take part when the time comes.

Audio-recordings of interviews will be transferred by secure file transfer to a professional transcription service to be transcribed. The resulting transcript will then be edited to include your chosen pseudonym and remove identifying details such as names of projects and institutions. 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 discard any data collected up to that point. If you wish to withdraw your data after the interview has been completed you can contact me by email up to one month after the date of your final interview and any data collected up to that point will be deleted. Beyond this point I cannot guarantee to be able to withdraw data because it will have been included in analysis. If you wish not to participate in a follow-up interview you can tell me by email at any point or simply indicate that you are no longer willing to participate at the point that I re-contact you. At that point I will delete any data previously collected 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 on ethical aspects of your work.

**Are there any potential risks involved?**

There are no anticipated risks to your wellbeing. You may have concerns about your professional reputation: you are assured that conclusions from the research and quotations from interviews will be published without identifying you by name. Please do not give details of any commercially confidential information during the interview. At the interview we will agree a suitable pseudonym and generic job title/role to describe you if this should be necessary in any research publications. Audio-recordings and information on the identity of participants will not be shared beyond the University of Surrey and Professor Barnaghi will not have access to audio recordings or the list of participants, 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.

**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.

**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, project titles and institutions 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 the University of Surrey 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 6years after the study has finished after which time any identifiers will be removed from the aggregated research data.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you decide to withdraw from the study, we may not be able to withdraw your data except as described above under “What happens if I do not want to take part or if I change my mind?”. We will keep and use the minimum amount of personally-identifiable information about you that we have already obtained in order to complete the study.

If you wish to make a complaint about how we have handled your personal data, you can contact our Data Protection Officer Suzie Mereweather who will investigate the matter ([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/>).

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) .

**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](mailto: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.

**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](mailto:c.hine@surrey.ac.uk)

01483 686986

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