

## Sustainable Care: Sustainability and wellbeing in our care systems

The Sustainable Care Research Programme (2017-2021), based at the University of Sheffield in collaboration with the University of Birmingham and Kings College London, is investigating how social care arrangements can be made economically and ethically sustainable and produce wellbeing outcomes for everyone involved. It has been funded by the Economic and Social Research Council.

**Why have I been contacted?** The programme is made up of a series of research projects. You are being invited to take part in the project **“The potential of technologies to support working carers”**. This project, led by Professor Luc de Witte, is looking at what parts of working carers’ lives can be supported using technology. We are contacting you as someone who provides care for someone living with dementia and also works. We would greatly appreciate it if you could read this information sheet to decide if you would like to take part, and so that you can understand what your participation would involve.

**What would the research involve?** We would like to interview you to find out about your experiences and opinions of providing care while also working, what support you receive or would need and which (if any) part technology plays in your support system. The interview will last approximately one hour and will take place at the time and place most convenient to you. We will audio-record the interview and take some written notes throughout. The recordings will be transcribed after the interview and your personal data anonymised. If you wish to terminate the session at any point, let the researcher know and the session and recording will stop.

You will be interviewed by a member of the project team, Alice Spann.

**Do I have to take part?** It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You can still withdraw at any time during the interview without there being any negative consequences and you don’t have to give a reason. If you wish to withdraw from the research, please let the researcher know either during your session or afterwards by emailing Alice Spann (aspann1@sheffield.ac.uk) or calling 07479 032945. If you want to withdraw afterwards, please ensure to let the researcher know within two weeks after the interview because after transcription your personal data will be anonymised, and it might no longer be possible to identify your contribution. If you withdraw or are withdrawn from the study for any reason, the research team will retain the personal data already collected about you for a maximum five years after the end of the project (2021), unless you request, we delete it.

**What will happen to the information you give us?** Everything you say will be kept confidential and only accessible to members of the research team unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else. Your personal information (e.g. name, contact details) will only be accessible to members of the research team at the University of Sheffield. Our conversations will be recorded, if you agree. The researcher will also take some notes during the interview. The audio recordings and transcripts will be securely stored on the University's shared networked

file store. In the transcripts any information you provide which could reveal your identity will be removed, and you will be given a pseudonym. The person with responsibility for transcribing the interviews will be subject to a confidentiality agreement. The document which notes which pseudonym you have been given will be stored in an access-restricted folder on the University's shared networked file store and will be destroyed within five years of the end of the project (2021). Excerpts from the session may be included in the projects outputs, for example in reports, web pages, and other research outputs. You will not be able to be identified in any reports or publications.

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering their research questions. You can decide whether your anonymised data can be archived at the UK Data Archive and used in future research. Only authenticated researchers will have access to this data, only if they agree to preserve the confidentiality of the information on the archive. They may use your words in publications, reports, web pages, and other research outputs but will not include any information that would identify who you are.

**Are there any risks?** As pseudonyms will be used, you will not be identifiable. In the interviews, the focus will be on your everyday experiences and opinions. You are free to decline to answer questions and can withdraw your consent to be interviewed at any time.

**How can I find out more?** If you have any questions about the study or just want to talk to someone about it, you can contact Alice Spann anytime. You can also call us, send us an email or a letter:

Alice Spann, The Innovation Centre, University of Sheffield, 217 Portobello, Sheffield, S1 4DP,

Phone: +44 (0)7479 032945

Email: [aspenn1@sheffield.ac.uk](mailto:aspenn1@sheffield.ac.uk)

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

**Note:** This study has been reviewed and given favourable opinion by the Research Ethics Committee of the School of Health and Related Research (ScHARR) at the University of Sheffield. If you wish to discuss the study with the person responsible for the research, please contact the Sustainable Care Programme leader, Professor Sue Yeandle. Address: CIRCLE (Centre for International Research on Care, Labour and Equalities), Faculty of Social Sciences, The University of Sheffield, ICOS, 219 Portobello, Sheffield S1 4DP, Tel. 0114 22 22000. If you have a complaint, please contact the Dean of ScHARR, Professor John Brazier. Address: ScHARR, The University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA, Tel. 0114 2220726.

The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'. Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not

been handled correctly), can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

If you wish to contact the Data Protection Officer at the University please write to: Anne Cutler, The University of Sheffield, Edgar Allen House, 241 Glossop Road, Sheffield, S10 2GW or e-mail her on [a.cutler@sheffield.ac.uk](mailto:a.cutler@sheffield.ac.uk). Requests to withdraw from/ remove data from the project should be addressed to the researcher in the first instance then to the Data Protection Officer. If you are not satisfied with the response you receive from the University you have the right to lodge a complaint with the Information Commissioner's Office (ICO): <https://ico.org.uk/concerns/>. Freedom of Information requests should be sent via email to [foi@sheffield.ac.uk](mailto:foi@sheffield.ac.uk).