How could technology help people who feel lonely?

A co-design project for unpaid carers of people with neurodegenerative disorders who experience loneliness

We would like to invite you to take part in a research project. This leaflet explains what the project is about and what taking part would involve. Please read it carefully and contact the research team if you have any questions.

What is this project about?

We want to co-design technology that could be used to help people who feel lonely. Co-design means working together to create something. It brings different people—like designers, users and others—into the process to share ideas and make decisions. Instead of one group being in charge, everyone works as a team. This way, the final result is more helpful, fair, and works better for everyone it's meant for. We will look at a range of technologies including familiar devices ('hardware') like telephones and less familiar things like robots, as well as 'software' – the programmes and games used on devices. We are particularly interested in working with unpaid carers of people with neurodegenerative disorders (such as dementia or Parkinson's), as research shows they may be more likely to feel lonely. With participants, we will develop ideas for new technology.

What will taking part involve?

Taking part will involve joining up to 5 workshops, each 2 hours long. Ideally, we would like you to join all 5 workshops. There will be no more than 10 participants in the workshops, plus some researchers. Workshops will be in Bristol. We would like to make sure the workshops are as comfortable for you as possible, so if you have any concerns, please let us know beforehand.

Before each workshop, we will ask you to complete a consent form. We will also ask for some background information. This will take no more than five minutes. This will help us to explore how people's experiences differ depending on their background.

During the workshops we will discuss loneliness, look at the capabilities of technology and work together to develop ideas for new technology. As well as group discussions there will be activities such as drawing and building models – researchers will be on-hand to help with these. In the later workshops, we will bring models based on your designs for you to test.

We will record what is discussed in the workshops and type it up afterwards, and photograph the materials (e.g., drawings and models). Details that directly identify you or others (such as names of people or places) will not be typed up – this is to protect your identity when we report our findings.

Who can take part?

This project is for people who provide care, in an unpaid capacity (e.g. partners, family members) for someone with a neurodegenerative disorder and who often feel lonely. Participants will need to be able to understand and communicate in English. We are running separate workshops for people with neurodegenerative disorders. The person you care for may be able to take part in these.

What are the possible benefits of taking part?

We hope that these workshops will be interesting and fun for you. This research will help us better understand the experience of loneliness for carers. We also hope to use the ideas from the workshops to develop technologies to help prevent people from feeling lonely. You will receive £50 for each workshop you attend and we will reimburse travel expenses.

What are the possible risks from taking part?

We do not believe there are any risks or disadvantages to you from taking part. If you appear uncomfortable or upset at any time during the workshops, a researcher will ask if you would like to take a break form the group. We may direct you to contact a support service.

You will be free to leave the workshops at any point, however, it will not be possible to remove from the project any information you have contributed up to that point (e.g., points you have made in discussions).

Would my participation be kept confidential?

We will keep all information about you secure. Transcripts of the workshop recordings will be made by a transcription service that complies with our Data Security standards. The transcripts will be made anonymous by removing any personal identifiable information. The audio recordings will then be destroyed.

We will write our reports in a way that no-one can work out that you took part in the study. We will delete your name and contact details from our records at the end of the study. Consent forms and the anonymised data (e.g., transcripts, photographs), will be stored securely by University of Bristol for a minimum of 10 years. The only instance in which we may need to share your details with others is if you raise a safeguarding issue in your

interview – if the researcher believes your or someone else's safety is at risk, we will let an appropriate person know.

Will the data be available for research in the future?

We will add the anonymised data to the University of Bristol's Research Data Repository (data.bris). Other researchers will be able to access the anonymised transcripts from this study to use in their research. People asking to access the data in the repository will have to show they are genuine researchers and will use the data safely and securely. It is important to note that, while every effort will be made to make transcripts anonymous (by removing names of people and places), it may still be possible for someone to identify you. For example, somebody who knows you may be able to recognise particular phrases or patterns of speech that you often use.

Who is organising and funding this project?

This project is run by a team of researchers from the Universities of Bristol and Bath, the Care Forum and an educational games company, Play Well for Life. The research is funded by the Engineering and Physical Sciences Research Council (EPSRC) LEAP Digital Health Hub.

Who has reviewed the project?

The project has been approved by the University of Bristol Health Sciences Research Ethics Committee (ref 23075).

What happens if there is a problem?

If you have a concern about any aspect of the project you should ask to speak to a member of the research team who will do their best to answer any questions. If they cannot resolve your concern or you have a complaint, you can contact the University's Research Governance Team (research-governance@bristol.ac.uk).

What will happen at the end of the project?

We will write up our findings on the LEAP website (https://leap-hub.ac.uk/) and in academic papers and present at conferences. Participants will be kept informed of the findings and plans for further work.

> ### How do I take part? Where can I find out more?
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> If you would like to take part in this project, or have some questions for the research team, please contact us either by email (info@thecareforum.org.uk) or phone (0117 965 4444).