

Participant Information Sheet: Smart Technology Research Project

This sheet contains information about the research project, to answer the type of questions people often have when deciding whether or not to take part.

Title of Research Study

Digital Clinical Safety for Older People at Home, considering accessing Adult Social Care Occupational Therapy Services: *Safe with AI at Home Co-design Workshops.*

Practical details:

The workshops will run on the 12 December 2024 and the 9 January 2025, from 10am until 2.30-3pm with lunch and refreshments provided and a voucher of £25 and any reasonable travel costs refunded. The venue will be central Leeds, at Age UK near the St John Centre.

The **expression of interest form (links below and at the end of this leaflet)** gives permission for the researcher, Alicia Ridout to email you, to offer a video call to discuss joining the research. We are looking for 8-12 people to attend both workshops.

Are you:

- ✓ **Using a smart phone, smart assistant (such as an Alexa™); devices which manage your home environment. This might include home sensors linked to a smart phone, or constantly monitoring your wellbeing and provide health advice/access to support if needed?**
- ✓ **An older person considering referral/self-referral to occupational therapy assessment in Adult Social Care services in the near future?**
- ✓ **Living in your own or rented accommodation?**
- ✓ **Able to communicate in English? (Unfortunately, we do not have funding to pay for a translator)**

If yes, we would like to invite you to take part in two, in-person Leeds workshops.

Sign up:



Link:

<https://forms.office.com/e/B0TmyqYxcc>

Or read on for more information.

Who are we?



Alicia Ridout is a Doctoral student at York St John University. Alicia is supervised by Professor Alison Laver-Fawcett, Professor in Occupational Therapy. Alicia is a registered occupational therapist, experienced in digital health and as a clinical safety officer. She works with the public, clinicians, and businesses to help develop safe and effective technology in health and care. She is studying the impact of using technology such as smart phones, internet linked systems such as Alexa™, technology that uses sensors to control for example, the lighting, heating, or safe movement around the home, and health monitoring, where artificial intelligence is making decisions or predictions. Her research looks at older peoples' and occupational therapists' conversations about digital clinical safety at assessment and how we can improve our conversations about risks and benefits of using such complex technology at home. Her research is subject to the University's ethics approval process and has been approved: Ref ETH2425-0025 on 03/10/24. It is funded by Constance Owens Trust.

This video from Surrey County Council gives an example: [Pioneering home sensors project](#).

Part 1: The research.

Introduction

This technology often has Artificial Intelligence (AI) in the software and when devices like watches, smart phones, or monitoring sensors are linked through the internet, is known as Internet of Things (IoT). It can use complex, self-learning computer software making predictions and triggering for example, a service to respond to a person's wellbeing needs or provide advice on health issues, medications and treatments.

If an older person is referred, or self-refers, to Adult Social Care occupational therapy services, they will potentially have the opportunity to use such technology.

It can be complicated to work out if this technology is safe for a person to use, owing to the way AI and IoT are created, so this research is looking at what we might need to do to make this conversation easier and help everyone look at the risks and benefits using this type of advanced technology.

Collaboration to create best practice tools, like guides, is at the heart of this research. Inclusion of older people and occupational therapists is really important.

What is the purpose of the research?

Occupational therapists' have always used technology to support people live their best lives as part of their care. For many older people facing a significant change in their daily lives, an occupational therapy assessment can be helpful.

Smart technology includes types of technology that use AI and IoT when connected (networked) using the internet, joining Apps and devices together.

These types of technology are regulated if they are used in Health and Adult Social Care. Health Professionals, such as occupational therapists, are also regulated (by the Health and Care Professions Council) and must demonstrate that they are working with people using their services to manage risk and make improvements. Some devices are also medical devices which means it is the law that health and social care services demonstrate they are of a safe standard to be used with older people.

Occupational therapists look at a persons' environment, their personal strengths and needs, goals, and way they perform day to day tasks that are important to them. They will assess factors that can influence your wellbeing and help you to balance the risks and benefits of different decisions, helping you choose the best options for you. This includes technology that is using AI or connected internet devices.

What will I need to do if I take part?

1. You will need to read this leaflet, consent to sharing your email address and some basic information about you (age bracket, use of smart technology) complete a very short online form to express your interest.
2. You will be contacted by email to ask if you would like any further information, or an online video call using Teams.
3. You will be invited to join two workshops on the dates at the top of this information leaflet. You will join a small number (8-10 older people) and similar number of occupational therapists. The workshops will be facilitated by the researcher, Alicia Ridout and two colleagues who are experts in their fields of designing information for the public, and another occupational therapist who is an expert in service improvement using technology.
4. The workshops will be using short films to get conversations flowing. The facilitators will lead and support participants. Ground rules will be agreed with everyone, such as one person speaks at a time.

5. There will be breaks throughout the day and refreshments will be available for you at all times. The toilets and venue will be fully accessible.
6. Expenses and vouchers will be given on the day. Travel costs can be refunded in cash. You will need to sign to confirm you have received the voucher and expenses. Travel expenses will need to be refunded using a paper receipt. You can email this to Alicia if you cannot print it. No bank details are required.

There are no right or wrong comments, it is your experience we are interested in. We will be sharing with you support resources/information throughout the research.

Do I have to take part?

No. It is entirely optional. We hope to share the research with you, and more widely once we have finished, via Leeds networks such as Leeds Older Peoples Forum, who are collaborators. The expression of interest form you will need to complete to join the research, has an opt out if you read this leaflet and then decide not to consent. You can change your mind at any time, even if you initially consented.

If you choose not to consent, you will not be able to join the research, as this is needed. There are no negative consequences to doing this, it is entirely your choice. We are grateful for your interest in this research.

What do you mean by digital clinical safety?

Health and care in England require services to meet a set of safety standards, for the design and use of technology that may affect peoples' safety. These standards help identify any potential risks before the technology is in use. Risk assessments identify ways to reduce any potential risks, so that people who need the technology can use it safely, fully aware of the best way to do this. This is monitored for as long as the technology is in use, including if it is changed in any way by the company that developed it, or the organisation that makes use of it. The term 'clinical' refers to the responsibilities of registered health professionals and others working under their authority. This is why it applies to occupational therapists.

An example would be a person living alone at home who has poor health and feels isolated from family and friends. Their family have bought them a smart assistant (Alexa™ for example) which uses AI for a whole range of services which can be accessed by asking it questions or giving it commands. It might link to shopping orders, a virtual assistance centre, or via a family members phone App.

Digital clinical safety looks at what might happen if this was not working properly, failed or gave the wrong information and potentially caused harm.

At home, you might use your personal smart technology, and some provided by services, making it more complex in terms of any possible risks. AI/IoT technology uses large data sets to 'train' the AI and older people may not be correctly represented in this data. We call this a bias. You may not be aware of this as you cannot 'see' what is behind its' creation.

Currently, we do not check the risks of the combined technology use. There are many benefits to using AI/IoT technology but also some risks that may not be obvious. The benefits need to outweigh the risks for you, so we need to look at ways to discuss this in an open, organised way.

What information will be collected?

You will be asked to complete *a consent form* and will be provided with information about what will happen to the information you share, and we capture during the workshop. We only need your *name and contact details* for the purpose of keeping in touch with you about the workshops. We will delete your data and email address as soon as practical after the end of the project.

The expression of interest form will *collect your age bracket*, for example 60-70, and confirm that you have and use a smart device like a mobile phone.

The researcher will be your main point of contact for practical arrangements. She will not record the video calls offered once the expression of interest form has been received as this is just an opportunity to meet the researcher and have your questions answered, before you decide if you would like to participate.

The workshops will also not be video, or audio recorded. Photos will be of the paper products from discussions (so no photos of participants) and some general, anonymised notes by the facilitators, to ensure we have a written summary of all the facilitators work. You can read these and co-write them if you would like to.

Workshops provide an opportunity for us to work as a group, to look at the benefits and risks of AI/IoT, your priorities day-to-day to keep safe and what a 'better conversation' might be like.

Between workshops we will share a visual summary. You will be able to email Alicia with any comments you would like to make before the second workshop. These will be anonymised at workshop 2 unless we have explicit permission from you.

The workshops will be quite informal, and we will provide an anonymised feedback questionnaire at the end of each session so that we can learn and improve.

You can also withdraw your contributions (captured in workshops) up to 7 days after each workshop. After this we will begin analysis.

Maintaining a safe workshop environment.

Social media: We would ask you not to use social media or share anything from the workshops with anyone outside the room and research team.

Opting out: You can opt out of the workshops at any point, even on the day, if you feel this is best for you. You will still have your expenses reimbursed and receive a voucher, even if you decide not to stay on the day.

If you realise you know one of the occupational therapists attending the workshop, you can flag this immediately to Alicia and decide what you would prefer to do. You will still have the opportunity to stay in touch via email if you would like to contribute to or hear more about the research. Alternatively, we can delete your personal information. It's up to you.

Venue: We will have carried out a health and safety risk assessment of the venue to comply with the Universities insurance and venue requirements.

Concerns: If you have any issues you would like to address via Alicia's supervisor, Professor Laver-Fawcett, her email is at the end of this leaflet. Any contact between you and Prof Laver-Fawcett is confidential unless you give permission to share this with Alicia or other University staff such as the ethics committee. Paper copies of this leaflet will be available at the workshop, along with support information for you.

Alternatively, if you feel uncomfortable at any time in the workshops, any of the facilitators can support you. You can also take a break at the venue.

What happens to the data?

The confidentiality and anonymity of the participants is of paramount importance and adhering to the University's and legal requirements; for example, the Data Protection Act 2018 and General Data Protection Regulations (GDPR), and professional/regulatory requirements. Further information on the policies can be found in the Privacy statement attached to this leaflet and included in the workshop sign up via an expression of interest online form.

The researcher and supervisors will have access to the information. The data will be stored in the University IT system and any contact details will be password protected and only seen by the researcher and her university supervisors, unless there is a concern about the wellbeing of a participant. A paper copy will be retained in a locked filing cabinet in the research supervisors' office at York St John University until

it is shredded at the end of the research in 2027. Any anonymised data will be put on to the University RaYDaR system, and information can be found here:

<https://www.yorksj.ac.uk/library/research-support/raydar/>

What will happen to the results of the study?

The results will be included in the researchers' doctoral thesis and may be included in published research articles, conference presentations, training and teaching materials for occupational therapists and occupational therapy students, information leaflets for older people and other opportunities to ensure that the learning is shared with those designing and deploying AI/IoT with older people. We will share the outcomes with you, if you give us permission to do this, via email.

Are there any risks involved in taking part in this study?

This study is considered to be low risk. Completing the expression of interest form is not linked to your health and care services in any way. We will not ask you for any sensitive personal information. You can opt out at any point. There is no pressure for you to join the research, it is up to you. If you feel you need any support, you can find services to contact here:

Ability Net AI Searches Bitesize film: https://youtu.be/4_tvqF2q_Jw

Age UK: <https://www.ageuk.org.uk/services/>

MIND: <https://www.mind.org.uk/about-us/local-minds/>

At the end of this leaflet: Privacy Notice.

Who should I speak to if I have further questions, concerns, or a complaint about this research study?

You can speak to the researcher or her lead University PhD supervisor, Prof. Alison Laver-Fawcett, Monday to Friday in office hours. Contact details are listed below. We will aim to get back to you as soon as feasible, but within a week.

Researcher and Supervisors contact details:

PhD Supervisor: Prof Alison Laver-Fawcett

E: A.LaverFawcett@yorksj.ac.uk Office phone: 01904 876419. School of Science, Technology & Health, York St John University, Lord Mayors Walk, York, YO31 7EX.

Doctoral researcher: Alicia Ridout E: Alicia.ridout@yorksj.ac.uk M: 07976785744.

Please contact Alicia with any queries about this research.

If you have any concerns or complaints about this research, you may contact:

Chair of ethics committee: Dr Charlotte Haines-Lyon, Chair Ethics Committee for the School of Education, Language and Psychology' Email: c.haineslyon@yorks.ac.uk.

Link to Expression of Interest: <https://forms.office.com/e/B0TmyqYxcc>

Thank you very much for taking time to read this information sheet.

Part 2: Privacy Notice

Part 2: Privacy Notice
All personal information gathered and held by York St John University (detailed in Part 1 of this Participant Information Sheet) is treated with the care and confidentiality required by the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. For the purposes of processing your personal information, the data controller is York St John University. The University's Data Protection Officer is the PVC Governance and Student Life.
<p>Legal basis for processing your information:</p> <p>Consent - UK GDPR Article 6 (a) - the data subject has given consent to the processing of his, her or their personal data for one or more specific purposes.</p> <p>Archiving, research and statistics (with a basis in law) - UK GDPR Article 9 (j) - processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.</p>
Additional condition for processing special category data N/A
Additional condition for processing criminal conviction/offence data N/A
<p>Your rights in relation to personal data</p> <p>Under the GDPR, you have a right to:</p> <ul style="list-style-type: none"> • be kept informed as to how we use your data. • request a copy of the data we hold about you via a Subject Access Request. • update, amend or rectify the data we hold about you. • change your communication preferences. • ask us to remove your data from our records. • object to or restrict the processing of your information. • raise a concern or complaint about the way in which your information is being used.
<p>Any questions or concerns?</p> <p>If you have any questions or concerns about the way we are collecting and using your personal data we request that you contact the University by: gov.compliance@yorks.ac.uk. You also have the right to complain to the Information Commissioner's Office (ICO) about the way in which we process your personal data. Details can be found at: https://ico.org.uk.</p>