



Participant information sheet

Date: March 2023 Version 3

Section A: The Research Project

Title of the project: *'Exploring a Coproduction Approach to Create Learning and Teaching Materials about Hoarding for Health and Social Care Professionals'*

1. Purpose of study

Recent years have seen increasing use of technology to help teach healthcare professionals in higher education. As part of this technological shift, the use of immersive environments (e.g., virtual reality) appears promising in helping to support existing training practices.

This study aims to develop such a virtual tool to help in training social workers to work with and support people who hoard. We would like to work in partnership with you to create authentic learning tools for social work students. As part of the study we would also like to understand how such a partnership (co-production) and the process of creating immersive training environments can affect individuals who hoard.

The study has three stages. You can choose to take part in all or only some of the study stages:

Stage 1 will involve co-producing learning materials relating to hoarding in the home.

Stage 2 will involve taking images of home environments of people who hoard using a 360-degree camera and creating a virtual environment (with any personally identifying elements blurred or removed).

Stage 3 will involve an interview to understand the experiences of those taking part in the co-production and whose home environments contributed to the training tool.

2. Who are we?

Vanessa Ferguson - is a qualified social worker since 2009, specialising in adult mental health. Vanessa joined Anglia Ruskin University (ARU) to teach social work students in 2016 and is currently also completing her Doctorate in Education.

Dr Jane Scott is a lecturer in psychology and a clinical psychologist with experience in hoarding and eating disorders.

Dr Sharon Morein is an associate professor in psychology specialising in mental health conditions characterised by compulsivity, including Hoarding Disorder.

Paul Driver is the director for Simulated Learning, and an award-winning digital innovator. He is an expert in interactive virtual reality scenario development.

Dr Marques Hardin is a creative technologist and researcher. He investigates methods in which immersive and interactive mediums can support knowledge exchange and promote social impact.

3. Why have I been asked to participate?

You have been invited to take part in this study because we would like to work collaboratively with individuals who self-identify as people who hoard.

4. How many people will be asked to participate?

We are planning to recruit a maximum of 10 people and aim for a minimum of 4 to take part in the different stages of this study.

5. Do I have to take part?

You can refuse to take part without giving a reason. Your participation (or non-participation) will not generate any negative outcomes for you.

6. Has the study got ethical approval?

Yes the research project has ethical approval from the Faculty Research Ethics Panel at ARU.

7. What will happen to the results of the study?

The results of stage 1 will be used to inform stages 2 and 3.

Results from stage 2 include photographs from inside your home using a 360-degree camera. These will contribute to a 360-degree environment teaching tool. We will use software to add virtual educational learning points. We will ensure that there are no identifying elements in the material, for example by blurring out photographs on your walls. No personal images will be used, and we will be happy to show you the 360-degree environment teaching tool, once it has been created. The tool will be utilised in ARU teaching, but also on the Social Work Toolkit where it will benefit social work students in the UK.

Results from stages 1 and 3 will be made public through academic publications and conferences so that others can learn from the findings. No participants will be identified in any results.

8. Contact for further information

You can contact the lead researcher Vanessa Ferguson by email vanessa.ferguson@aru.ac.uk or phone (0845 196 5520).

Section B: Your Participation in the Research Project

1. What will I be asked to do?

Stage 1

Participants in stage 1 (research as covered by ethical approval) will be invited to 1-2 meetings to discuss what the 360-degree environment teaching tool should include to help teach social workers about hoarding. These meetings will each last 1 hour and can be in person or online.

Stage 2

Co-production of the teaching material (not research so not covered by ethics but will be covered with GDPR assurances): We would like to photograph the inside of your home using a 360-degree camera. The photography should require a single visit and this will be the minimum of two staff from the research team in person. . Dr Scott, who is a clinical psychologist, will also be available (in person or on the phone) to provide advice and support should you like this.

Stage 3

Participants in stage 3 (research as covered by ethical approval) will be invited to a semi-structured interview (in person or online) lasting up to 1 hour, where they will be asked questions about the experience of taking part in Stages 1 and/or 2. This will be recorded and transcribed and anonymised for analysis.

2. In relation to this specific research project, we need to make you aware of the following:

	We are responsible for the personal data you give to us as a:		
X	Data Controller (We are in sole control over the research)	Who are we:	Anglia Ruskin University

3. You will be asked for the following information:

Personal Data				Sensitive Personal data	
x	Name/ Contact details	X	Image (Photo or video)	<input type="checkbox"/>	Racial/ Ethnicity data
X	Age	X	Experiences	<input type="checkbox"/>	Political/ Religious beliefs
x	Address/ location data	X	Opinions	<input type="checkbox"/>	Trade Union membership

4. What will happen to my data?

Your data will be pseudoanonymised in this research. Pseudoanonymisation means that identifiable information, such as people's names, will be removed from the data and a code will be assigned. The data will, however, still be able to be linked together by research team should this be required.

ARU is committed to holding your data securely and uses information security best practice to transmit personal data. Data is held in accordance with the [Corporate Information Security Policy](#).

Your data will remain within the European Economic Area (EEA) and will not be transferred outside of it. Your data will be securely held and handled at all times, with only the research team having access to it. We are all bound by the framework for handling data within the GDPR and we take our responsibilities and your confidentiality very seriously. ARU have put in place procedures to deal with any suspected data security incident and will notify you and the regulator where we are required to do so. If you have any concerns that personal data has been compromised please contact dpo@anglia.ac.uk

After completing each stage, we will provide a date, after which we will not be able to extract your data from our set because any identifying information will be removed. The date for this is 2 weeks from data collection. Any data linking you to this project will be held for no more than 3 years from the point of collection and then will be completely removed from ARU servers.

Please find ARU's privacy policy for research participants here: <https://aru.ac.uk/privacy-and-cookies/research-participants>

5. Are there any possible disadvantages or risks to taking part?

We take your privacy and wellbeing very seriously. Anything you share will be anonymised to protect your privacy and will be handled with the protections of GDPR.

You may become distressed or upset when taking part in this research. We are acutely aware that allowing access for photographs of your home might be a difficult point in your participation. To safeguard your mental wellbeing and dignity at all times, if you do become distressed during the photograph stage, we will immediately cease the activity and will leave your home if this is what you would like. You can take breaks whenever you like throughout the process. Dr Scott is an experienced clinical psychologist who has provided support for individuals who hoard in the past and will be available to offer support should you wish it. We will also offer sign-posting to mental health charity helplines and additional support for hoarding and mental ill health (please see end of this sheet).

The agreement to participate in the study does not affect your legal rights.

6. What are the likely benefits of taking part?

Whilst there are no material or financial incentives offered you may experience benefits from participating. You may find that the process of taking part in producing materials

and tools to support the training of social workers an affirmative and empowering exercise and the structured interview may provide a chance for reflection.

7. Can I withdraw at any time, and how do I do this?

You can withdraw from the study at any time and without giving a reason, by emailing vanessa.ferguson@aru.ac.uk or calling 0845 196 5520.

8. Can I withdraw my data from the study?

You can ask for your data to be withdrawn up until 2 weeks after that data is collected. Please note it will not be possible to extract your data from the set (research material and images of your home interior) after the cut-off date. At any stage you do not have to answer any interview questions you do not wish to.

3. Are there any special precautions I must take before, during or after taking part in the study

For the photographing session, please feel free to adjust any personal items that you do not wish to be recorded (these can also be blurred). For the semi structured interview, please consider where and when you would like this to take place and we can plan this with you.

9. Will the research team pass onto anyone else what you have told us?

Individual participants' results from this research will be accessed only by the team, unless information obtained indicates possible cause for concern about your health and/or wellbeing. In this instance we will contact you in order to signpost you to appropriate forms of support. On rare occasions, for example if we become aware of a significant risk of harm to you or others, we may be required to break confidentiality and disclose information to a third party. We would aim to discuss this with you wherever possible.

10. Summary of research findings

The research team will be delighted to share a summary the research findings with you when the data has been analysed and written up.

11. Contact details for complaints

If you have any complaints about the study, you should feel free to speak to the research team in the first instance to try and reach an informal resolution. You are also entitled to make use of Anglia Ruskin University's complaints procedure:

Email address: complaints@anglia.ac.uk

Postal address: Office of the Secretary and Clerk, Anglia Ruskin University, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ.

Date March 2023

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