



Participant Information Sheet

Project: Clasp: Digital Tactile Anxiety Management for the Health Internet of Things

Researchers: Dr. Maria Angela Ferrario, Dr. Will Simm, Dr. Stephen Forshaw, Adrian Gradinar.

Principal Investigator: Prof Jon Whittle, Head of Department, School of Computing and Communications, Lancaster University. Email: j.n.whittle@lancaster.ac.uk

Project Dates: 1 February 2015 - 31 July 2016.

About the research

Clasp is an 18 month research project funded by the Engineering and Physics Research Council (EPSRC) based at Lancaster University. The project aims to prototype and evaluate a personalised digital tactile anxiety management system. The first phase of the project (Feb-Sept 2015) focused on anxiety in adults with high functioning autism. We are now in the second phase of the project that builds on lessons learned from phase-one to explore the application of the system to other domains, i.e. work-related stress, which are related to anxiety, but not necessarily to autism. Further information about Clasp can be found at www.myclasp.org

About the team

Clasp brings together staff from Lancaster University, Lancashire County Council, Autism Initiatives, and representatives from local community groups and organisations who work and live closely with people with autism.

Why have you been approached?

We are asking you to take part in the project because you have some interest and/or understanding of anxiety, personalised care, and the lives of people affected by anxiety. For this, we are inviting you to try out our system for four weeks. This will involve a first induction meeting followed by an interview in the end. There will be the opportunity to contact the researchers via email during the study and a group discussion or a practical workshop after the completion of the study if you wish to do so.

What does 'Informed Consent' mean?

Before the study commences you will be asked to sign a consent form to confirm that you have received and read this information sheet and that you are willing to take part in the research. You do not have to take part if you do not want to. You have the right to terminate the interview at any point and you are not obliged to answer questions if you do not wish to, and you may withdraw from the research without any negative consequences. If you wish to withdraw from the research, please do so within two weeks of the interview so that the interview material will be excluded from the analysis.

Recording sound and video

We would like to make audio or video recordings of interviews, group discussions and workshops. These recordings may be written out in full (transcribed). Parts of the recordings

may be used in publications such as newspapers, written reports, public presentations, and on Clasp website and its social media channels (e.g. YouTube and Twitter). We will not use your name, email or social media contact address without your explicit consent. In addition, we are committed to withhold any additional data that could be used to identify you (e.g. employer name and address, and so forth) so no one will be able to identify you.

Photographs

We would like to take photographs of workshops and discussions. If you agree, photographs may be used in publications such as newspapers, essays, reports, public presentations or websites including Clasp website and its social media channels.

Confidentiality and anonymity:

Any information collected from you will be treated with confidentiality. This means that only the research team will have access to any raw information that can be specifically associated with you. Any information that is shared beyond this team will be made anonymous. Your name and your address will be removed, and a pseudonym will be used instead. This will apply to any publications or presentations or any discussion with other colleagues in the University. Data that could be used to identify you will also be removed. We will keep personal details (such as name and contact email, if provided) and research content (e.g. interviews transcriptions) in separated encrypted and password protected files.

How will the data be used and protected:

We will treat data that you provide or that is collected from your household in accordance with the Data Protection Act 1998. This means that any personal information stored in physical format (paper, readily playable recordings) will be stored in a locked filing cabinet in a locked office on Lancaster University premises. Any personal information stored electronically will be stored on a secure, password-protected server. Any personal information that is transported electronically on a mobile device (a laptop or memory stick) will be encrypted and/or password-protected. The information collected will be used to inform the development of further research and may be included in publications, presentations and PhD theses. Only anonymised information will be retained indefinitely for on-going research purposes. We will keep the raw data till 31 December 2016, after that the data will be destroyed.

Who has reviewed the project?

This study has been reviewed by a member of the University Research Ethics Committee. If you have more questions please contact Dr. Maria Angela Ferrario, Research Fellow, School of Computing and Communications, Room C29, InfoLab21, Lancaster University, Lancaster LA1 4WA, UK Tel: ++44(0)15245 10660 or on email m.ferrario@lancaster.ac.uk

Issues or complaints

If you have any concern about this study wish to speak to someone outside the Clasp project you may contact Prof. Awais Rashid, Director of Research, School of Computing and Communications C41, InfoLab21, South Drive, Lancaster University, Lancaster LA1 4WA, UK Tel: +44 (0)1524 510316
Email: marash@comp.lancs.ac.uk