[[Placeholder for University and partnering institution logos]]

A Study to Understand Privacy Concerns of the Adults Aged 60 and Above

Participant Information Sheet (Version 5.0, 21/06/2018)

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. We suggest that it may take about 5 minutes to read thoroughly. If, after reading this information sheet, you think you may be interested in taking part you will have the opportunity to ask any questions before you agree to anything.

Summary

Privacy is a basic human need and without it we are at risk of becoming mentally or physically ill. It is an ability of an individual or a group, to control access to themselves or information about themselves. If the person is unable to control it, his privacy could get violated in multiple ways and could make him/her feel very insecure. These violations generally occur in combination with each other during our daily life

activities such as using a cash machine, going to the supermarket, visiting the post office, meeting friends or using digital media like a smartphone, laptop, smart watch, home monitoring system, or any other healthcare device. Privacy is very personal and can vary depending on your upbringing or culture.

In this study we would like to understand what are your privacy and safety concerns and how do they affect you in your daily life.

What's involved?

After reading this sheet and having any questions answered, you will be asked to provide your consent to participate in the study. If you agree, we would form a small random group of 3-4 people. In the group, you will be presented with a set of questions related to daily routine, privacy and associated safety concerns. We will start a discussion and everyone will be encouraged to share his or her experience in relation to the questions. The session will be video recorded and accompanied with note taking but the research team will only use your voice and images internally. We will never publish anything that identifies you. A moderator will help run the discussion group. The first part of the study consists of questions to be answered by the participants individually and would take 30-45 minutes. The second part of the study consists of questions to be looked upon collectively and would involve moderated discussions. This part might last up to 1 hour. There will be 2 breaks.

What are the potential benefits and risks?

The immediate benefits of this study to you are limited to perhaps helping you understand your privacy concerns better.

There are no foreseeable risks arising from participation in this research and while you will not receive any payment, you will make a vital contribution to privacy research and developing useful and safe technology for adults aged 60 and above.

What will happen if I don't want to carry on with the study?

Your participation in the study is entirely **voluntary**, and you can choose to withdraw without two weeks without giving a reason. You may also ask to have your data deleted by that time, although if we have anonymised your data this may not be possible.

How will my information be kept confidential?

We strongly request all participants to respect the privacy and confidentiality of other members of the group and not to share their personal information with anyone outside the group during or after the study. However, due to nature of the research method (discussions in group), it is still possible that what you say might be disclosed outside the group and is beyond the control of the research team.

The data collected will only be accessible to the named researchers on this study. The physical notes would be stored inside the researcher's desk and locked at the XXX University. The video recordings would be stored in a password protected computer system at the XXX University. Apart form the videos; personally identifying information will not be electronically stored with your data. Instead a unique ID will be generated to record your data and we will ensure that you can never be identified by any data we publish.

The data will be retained for up to 5 years after the study. The results of this study may be published in a scientific journal. If you would like to receive the results of the study you can indicate this on the consent form by giving an email address or other contact details.

Who is organising and funding this study?

This research is being supported by a research grant from the XXX and researchers from the XXX University, University of XXX and XXX.

Who has reviewed this study?

This research has been reviewed and approved by the XXX University's Human Research Ethics Committee and has been given a favourable opinion (REF HREC/2651/XXX)

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Invitation to ask further questions

Please feel free to ask any member of the researcher team if you have any concerns or questions in relation to this study before agreeing to the Consent Form. You may also ask any questions throughout and after completion of the study. If you have any anxiety or concerns regarding the issues raised, the research team can provide practical advice as well as refer you to counsellors at XXX.

You can contact the researchers as follows:

XXX (Researcher): XXX@XXX

(phone: XXX)

XXX (Co - Investigator): XXX@XXX

XXX (Principal Investigator): XXX@XXX

In case of complaints, you can contact:

XXX (Professor of Computing)

Email: XXX@XXX

Address: XXX

Phone: XXX

Thank you for taking the time to read this information sheet and considering taking part in this study