

Informed Consent Form – Online Survey

Research Project Title:

The Role of Communication and Technology for Families Coping with Chronic Illnesses

Ethics Application Number: 2012s0086

Investigators:

- Carolyn Pang, SIAT, Simon Fraser University
604-319-6482, carolyn_pang@sfu.ca
- Carman Neustaedter, SIAT, Simon Fraser University
778-782-9034, carman_neustaedter@sfu.ca
- Serena Hillman, SIAT, Simon Fraser University
604-307-8793, shillman@sfu.ca
- Erick Oduor, SIAT, Simon Fraser University
604-440-0853, oduor@sfu.ca

The Simon Fraser University Research Ethics Board has approved this research study.

This consent form, a copy of which is made available to you, is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask the investigator(s). Please take the time to read this carefully and to understand the information.

Purpose:

The purpose of this research is to understand the information families coping with chronic illnesses wish to share with and receive from remote family members. This includes studying the communication patterns of patients, caregivers, and family members and the methods in which they present their availability. We will use this knowledge to inform the design of a health information sharing system that supports feelings of connectedness during a family health crisis.

Participant Recruitment and Selection:

To be recruited for this study, you should be comfortable disclosing information about your daily routine, technology usage, and thoughts about your current interactions with your remote family. Because the focus is on sharing health information, you should also be comfortable disclosing information about your current health status and/or conditions and any details related to your medical treatments.

What Will I Be Asked To Do?

Through an online survey, we will ask you questions about: your general health and family history, your communication patterns and relationships with your remote family members, your preferred methods of contacts and sense of awareness, social presence and closeness.

Your Participation

There will not be any compensation for the online survey, which will take approximately 10 minutes of your time. If you agree to participate, you will be free to withdraw at any time for any reason. However, data collected up to that withdrawal point may still be retained and used by the researchers.

Research results, such as published papers, can be obtained by contacting any of the investigators:

- Carolyn Pang 604-319-6482, carolyn_pang@sfu.ca
- Carman Neustaedter 778-782-9034, carman_neustaedter@sfu.ca
- Serena Hillman 604-307-8793, shillman@sfu.ca
- Erick Oduor 604-440-0853, eoduor@sfu.ca

What Type of Personal Information Will Be Collected?

Your anonymity will be strictly maintained. The only personally identifying information collected will be your name, which will only be used for administration of payment. Any data collected will be labeled with an anonymous participant ID.

Are There Risks or Benefits if I Participate?

The risks of participation are intended to be none or minimal. However, because we will be asking you personal questions, there is risk of feelings of emotional discomfort such as embarrassment, and/or concerns about privacy. To mitigate this, you can choose what information you are comfortable revealing.

What Happens to the Information I Provide?

No one except the researchers and their assistants will be allowed to see or hear any of the answers to the questionnaire or the interview tape. Online surveys will be conducted through a secured and encrypted SFU server housed in Canada. Confidentiality of information transmitted electronically cannot be assured. All electronic data collected as part of the study will be kept on an external hard drive and stored in a locked cabinet in the secure office of the primary investigator at the School of Interactive Arts and Technology (SFU Surrey Room 3930) until 2015.

We expect to publish reports and presentations describing this research. Public presentations of the results will primarily present the results in an aggregate form or as caricatures that are composites of one or more participants. Where individual participant data is disclosed, such as exemplar survey comments or quotes, we will ensure that the selected data does not suggest participant identities.

Acceptance of this Form:

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this research project, and 2) agree to participate as a research subject.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this

research project at any time. You should feel free to ask for clarification or new information throughout your participation.

To accept this form, please check the box below, and type your name and today's date in the following boxes as a form of digital signature.

[☐] By checking this box, I am consenting to participate in the research.

Participant's Name:

Date:

Questions/Concerns:

If you have any concerns about the way you've been treated as a participant or concerns with the research project, please contact (primary) Dr. Carman Neustaedter, Assistant Professor, School of Interactive Arts and Technology at: carman_neustaedter@sfu.ca or 778-782-9034 or (secondary) Dr. Hal Weinberg, Director, Office of Research at: hal_weinberg@sfu.ca or 778-782-6593.

[SUBMIT]

[EXIT]