



Participant information sheet

Storylines of self-e-health

Principal Investigator Dr Karen Day

My name is Dr Karen Day and I am a Senior Lecturer at The University of Auckland, working in the School of Population Health. I do teaching and research about health informatics (the theory and practice of information systems and management in health care).

People with long-term health issues have to take care of themselves in many ways. They are given guidelines by their doctor and in some instances they attend workshops and participate in other learning activities to learn new skills for self-care, e.g. they are taught how to inject themselves with Insulin if they have Diabetes. Many people search the Internet for information about their health issues, and often download apps onto their phones (e.g. medication reminders) and purchase devices (e.g. pedometers) to help them track and record their progress. Many also join social media support groups (e.g. in Facebook), or follow people they admire (e.g. on Twitter and blogs) who are writing about how they handle their health issues. People like to tell stories about their health, and I am interested in hearing their stories.

My research question is therefore, 'How and why do people incorporate technologies into their self-care activities?' I would like to see if there is a difference between the stories of people who are not clinically trained, those who are clinically trained, and those who are or have been consumer representatives in hospitals or other services.

You are invited to participate in this research if you have a long-term health issue, and you use technologies for self-care, and you are 18 years or older. Your participation is voluntary (i.e. your choice).

What the study involves

You can participate in the following ways. It is your choice to participate in one, two or all three ways.

1. In an interview up to an hour long. We may need to do a follow up interview.
2. By email discussion in which you can write your stories down in response to questions, and discuss your stories with me.
3. By joining my 'Self-e-Health' Facebook group, and sharing and discussing your stories online with other people and me. Your Facebook contributions may include photos, videos, website links, and other uploads that you deem appropriate to the story you're telling.

Right to withdraw

Withdrawing from an interview: You can withdraw any time during an interview without giving a reason. Each interview will be analysed as soon as it happens in order for me to prepare for the next interview. If you want to withdraw after your interview, please let me know within three days of your interview so that I can remove your interview from my analysis before I do the next one in my schedule.

Withdrawing from an email correspondence: You can withdraw part or whole of your email correspondence until a month after your last email, without giving a reason. The parts indicated or the whole email will be deleted according to your request (by email).

Withdrawing from the Facebook group, 'Self-e-Health': Facebook allows you to delete or edit your comments. You will be able to do this in our group without giving a reason. You will be able to leave the group at any time, but all contributions you have made will be included in the data analysis unless you delete them yourself before you leave.

Privacy and confidentiality

Your contributions via the interviews and email conversations will be kept confidential and anonymous when stored in my password-protected account in the University of Auckland's computer network. Only analysed content will be shared with others, e.g. in presentations and published reports. I will do my best to mask your identity but someone who knows you may recognise a quote I use in a presentation or published report.

Your contributions in the 'Self-e-Health' group in Facebook will not be anonymous, as Facebook does not allow anonymous comments. All group members will be asked to keep the contents of the conversations confidential, and to comply with the group's etiquette rules. Group members will be able to follow the link to your Facebook profile so make sure that your privacy settings are set so that they are not able to read what you don't want to share with the public.

Possible benefits of participating in this research

Telling your stories and reflecting on them may result in your learning better ways to do self-care. Telling, reading about, and discussing your stories and those of others in the 'Self-e-Health' group in Facebook may give you new and deeper insights into your own health issues, and may result in your being able to refine your own self-care. You may find it easier to discuss your health issues with your doctors and nurses, and refine your self-care routines and activities in collaboration with them. Telling your stories in the Facebook group may benefit others. The publication of the analysed stories aims to help doctors and nurses provide advice on technologies for self-care, and to use the data coming from them in ways that are meaningful to them and you.

How we will store the data we collect from you

The digital recordings of the interviews and their transcriptions will be kept in my password protected account in the University of Auckland's computer network. Email correspondence will be done via my University email address, and will be stored in my password protected email account. The 'Self-e-Health' conversations will be collected weekly from the Facebook group and stored in Word documents in my password protected account in The University of Auckland's computer network.

All this data will be deleted after six years.

A summary report will be made available to you by email (if you indicate your email address in the consent form) and on the Self-e-Health Facebook group.

Contact Details

For further information about the study, you are welcome to contact the Principle Investigator, Dr Karen Day, by email at k.day@auckland.ac.nz, or by phone on 09 923 3870.

You can also contact Dr Day's Head of Department of Health Systems, Dr Tim Tenbenschel, by email at t.tenbenschel@auckland.ac.nz, or by phone on 09 923 9001.

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext.83711. Email: ro-ethics@auckland.ac.nz

Approved by the University Of Auckland Human Participants Ethics Committee on 18 July 2017 for three years. Reference Number 18629.