Research Ethics Application

Please fill in the checklist first if you have not done so already. Please complete this form digitally and send it the Ethics Committee.

Date of Submission:11-12-2019

Project Title: Developing principles to support the design of eHealth interventions for people living in deprived neighbourhoods.

Name(s) of researcher(s): Jasper Faber

Name of supervisor (if applicable): Valentijn Visch

Contact Information

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Contact information of external partners (if applicable): Enter contact information here.

Summary

Please provide a brief summary of the research.

We are developing design principles that aim to support the design of eHealth interventions for people with a low socioeconomic status (SES). For the development of these guidelines, our first step is to understand how the target population perceives health, healthcare and eHealth.

We will follow a Community Based Participatory Research (CBPR) approach, which entails the involvement of a community in all phases of the research. We will approach people with a low SES through a neighborhood community center in Rotterdam (Carnisse in Charlois). In total, we will be working with the community during the entire project (lasting 4 years).

This application is for the first research phase, which entails the assessment of the community through observations and interviews. Our aim is to collect insights, stories and experiences on our target research question, i.e. the attitude on health, healthcare and eHealth in a low SES population.

We will use these results to inform the design and setup of the next research phase within the CBPR, which will entail co-creation and participatory design activities. We aim to conduct this second study after 4 months and will apply for it at the HREC when our set-up is clear.

Research

R.1. What is the research question? Please indicate what scientific contributions you expect from the research.
What is the attitude towards health, healthcare and eHealth by people with a low socio-economic status?

R.2. What will the research conducted be a part of?
☐Bachelor's thesis
☐Master's thesis
☒PhD thesis

☐Research shills training
Other, namely: Enter what the research is part of here.

R.3. What type of research is involved?
☐Questionnaire
☒Observation
☐Experiment
Other, namely: Interviews

R.4. Where will the research be conducted?
☐Online
☐At the university
☒Off-campus / non-university setting: Community Centre in Rotterdam: Carnisse
Other, namely: Enter where the research will be conducted here.

R.5. On what type of variable is the research based?
Give a general indication, such a questionnaire scores, performance on tasks, etc.
Insights, Stories and experiences

R.6. If the research is experimental, what is the nature of the experimental manipulation?
N/A

R.7. Why is the research socially important? What benefits may result from the study?
The insights that will emerge through this research will help us understand the attitude of people with a low SES towards health. These insights will help us in the subsequent stages of the research to develop design principles that improve the uptake of eHealth interventions. Improving the uptake of such interventions will contribute to reducing the health disparities between socioeconomic groups.

R.8. Are any external partners involved in the experiment? If so, please name them and describe the way they are involved in the experiment.
Erasmus MC is part of the research group. Rita van den Berg – Emons will have access to the data that is saved on the TU Delft project drive. See the DMP for further details.

Participants

Pa.1. What is the number of participants needed? Please specify a minimum and maximum.
Minimum: 15
Maximum: 30

Pa.2.a. Does the study involve participants who are particularly vulnerable or unable to give informed consent? *(e.g., children, people with learning difficulties, patients, people receiving counselling, people living in care or nursing homes, people recruited through self-help groups)*
No

Pa.2.b. If yes and unable to give informed consent, has permission been received from caretakers/parents?
N/A

Pa.3. Will the participants (or legal guardian) give written permission for the research with an 'Informed Consent' form that states the nature of the research, its duration, the risk, and any difficulties involved? If no, please explain.
Yes

Pa.4. Are the participants, outside the context of the research, in a dependent or subordinate position to the investigator (such as own children or students)? If yes, please explain.
No

Pa.5. How much time in total (maximum) will a participant have to spend on the activities of the study?

A maximum of two hours

Pa.6. Will the participants have to take part in multiple sessions? Please specify how many and how long each session will take.
The interviews will take place over a period of 6 months. During these 6 months, we intend to visit the community twice a month. During the visits, participants will participate in one or multiple interviews. The exact amount and duration of these interviews is not pre-determined and is dependent on the willing of the participants.

Pa.7. What will the participants be asked to do?
They will be asked to engage in informal conversations and/or semi-structured interviews.

Pa.8. Will participants be instructed to act differently than normal or be subject to certain actions which are not normal? *(e.g. subject to stress inducing methods)*
No

Pa.9. What are the possible (reasonably foreseeable) risks for the participants? Please list the possible harms if any.
While conducting the interview, we will touch upon several themes regarding health and experiences with health and healthcare. There is a risk that this could trigger uncomfortable thoughts, experiences or memories.

Pa.10. Will extra precautions be taken to protect the participants? If yes, please explain.
It is our intention to understand their emotions and how they are connected to past experiences. In the informed consent form, we will make clear that this is the aim of the research. We make sure that while the interviews are being conducted, a confidant is present that allows the participants to turn to in case of discomfort. This is also made clear during the informed consent. If we notice any resistance or discomfort during the interviews, we ensure not to continue on that subject. In an additional consent, which is meant for the institution, we will mention the themes we will touch upon within our interviews.

Pa.11. Are there any positive consequences for a participant by taking part in the research? If yes, please explain.
N/A

Pa.12. Will the participants (or their parents/primary caretakers) be fully informed about the nature of the study? If no, please explain why and state if they will receive all information after participating.
Before being able to conduct a research phase within the CBPR process, it is important to develop a trustworthy relationship with the community. This part of the process has taken place over the course of the past two months. It involved informal talks, observations and adopting minor organizational tasks. Prior to this process we informed the community managers about the nature of our research. The community members themselves were debriefed orally during the informal conversations. We intended to avoid using a written informed consent in these first interactions. As they were informal and not part of the research activities. We now reached the level of trust necessary to be able to ask for an informed written consent. We will move from informal conversations towards semi-structured interviews. Prior to these interviews we will take the participants through the informed consent form.

Pa.13. Will it be made clear to the participants that they can withdraw their cooperation at any time?
Yes

Pa.14. Where can participants go with their questions about the research and how are they notified of this?
Within the informed consent form, participants are informed that they can ask questions at any time to the researcher (Jasper Faber) or to the confidant at the community centre. The contact details are included within the form.

Pa.15. Will the participants receive a reward?
☐Travel expenses
☐Compensation per hour
☒Nothing
Other, namely: Enter the reward here.

Pa.16. How will participants be recruited?
The participants will be personally approached within the community centre by the researcher or by the confidant.

Privacy

Pr.1. Are the research data made anonymous? If no, please explain.
Yes. In addition, in case we want to take photos or videos for presentation purposes, we will ask permission from the participants prior to doing so.

Pr.2. Will directly identifiable data (such as name, address, telephone number, and so on) be kept longer than 6 months? If yes, will the participants give written permission to store their information for longer than 6 months?
No

Pr.3. Who will have access to the data which will be collected?
The research team (Jasper Faber, Valentijn Visch, Jos Kraal and Rita van den Berg - Emons

Pr.4. Will the participants have access to their own data? If no, please explain.
The participants can ask and retrieve their own data at any time during the research.

Pr.5. Will covert methods be used? *(e.g. participants are filmed without them knowing)*
No

Pr.6. Will any human tissue and/or biological samples be collected? *(e.g. urine)*
No

Documents

Please attach the following documents to the application:

- Text used for ads (to find participants);
- Text used for debriefings;
- Form of informed consent for participants;
- Form of consent for other agencies when the research is conducted at a location (such as a hospital or school).