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:**21-1-2020

**Project Title:** Exploring the attitude towards health, healthcare and eHealth of people living in disadvantaged neighborhoods.

**Name(s) of researcher(s):** Jasper Faber, Msc.

**Name of supervisor (if applicable):** Dr. Valentijn Visch

Contact Information

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Summary

**Please provide a brief summary of the research.**

This application concerns the third part of our research concerning the attitude of people with a low socio-economic status (SES) towards health, healthcare and eHealth. As part of our Community-Based Participatory Research (CBPR) approach, we are working together with DOCK (institution that manages community centers throughout the Netherlands). We conducted the first parts of our research in one of their community centers: Carnisse, situated in a disadvantaged neighborhood in Rotterdam (Charlois). The first two phases have already been submitted to and accepted by HREC (see: <https://labservant.tudelft.nl/index.php/ethics/applicant_edit/953>).

The third part of our research consists of an online questionnaire and online focus groups. The online questionnaire has already been submitted to and accepted by HREC (number 1064). The goal of the focus groups is to elaborate on the answers of the questionnaire and gather more in-depth qualitative insights. The participants will be recruited through the questionnaire. In total we aim to recruit 15 participants. Each focus group session will last approximately 1 hour and consist of approximately 3 participants. In the focus group sessions we will present the fictional storyboards and ask the participants to discuss their answers with each other. We will use the online platform SURF videobellen.

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 Focus Groups

**R.4. Where will the research be conducted?**

Online

At the university

Off-campus / non-university setting: Enter which setting here.

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.*

Qualitative input as a result of discussion

**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: 10

Maximum: 15

**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?**

Approximately 1 hour

**Pa.6. Will the participants have to take part in multiple sessions? Please specify how many and how long each session will take.**

N/A

**Pa.7. What will the participants be asked to do?**

They will be asked to participate in an online focus group. In this focus group they will discuss their answers previously provided in the questionnaire.

**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.**

The platform used for online videoconferencing could pose several privacy-related risks. In addition, there is a possibility that participating in the focus group could lead to direct or indirect social pressure on the individual participants.

**Pa.10. Will extra precautions be taken to protect the participants? If yes, please explain.**

We will make use of the SURF videobellen platform which uses end-to-end encryption and is based on open-source software. The servers are situated in Utrecht. To mitigate the risk of social pressure, we will make sure the focus groups contain a small number of participants. This enables us to actively moderate the sessions, meaning we will deal with potential distress when it arises. In addition, we will ensure that codes of conduct (mutual respect, confidentiality) are established at the beginning of the session. Finally, we want to highlight that the focus of the discussion will revolve around the story elements, thereby shifting away the focus from the individual.

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

The participants will receive a free step-counter.

**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.**

The participants of the focus groups have already received an information sheet attached to the questionnaire. On top of that, they will receive a digital informed consent form that explains the full nature of the research.

**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?**

Contact details of the researcher will be included in the informed consent form.

**Pa.15. Will the participants receive a reward?**

Travel expenses

Compensation per hour

Nothing

Other, namely: Free step counter

**Pa.16. How will participants be recruited?**

The participants will be recruited through a questionnaire. At the end of the questionnaire the respondents will be asked whether they want to elaborate on their results in the form of an online focus group.

Privacy

**Pr.1. Are the research data made anonymous? If no, please explain.**

Yes.

**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).