

Notes from initial meeting with Science & Public representative

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This was an initial meeting for the 'Housing Experiment' project that we at CASE will do in co-operation with the association 'Vetenskap & Allmänhet' (V&A) [Science & Public]. Participated in the meeting did SI, MG, OJ and I from CASE and MB from V&A.

Initially, SI described that due to COVID-19, the project will not contain a co-operation between pupils and older people but they will both be involved in the project but work separately.

Next, I described my PhD project and what part I perceived that Bostadsförsöket and the particular study I planned to conduct within it had. explained that my doctoral project is about studying different methods or forms for conducting collaborative research or involving people who are not researchers in the research process in research on aging and health. SI filled in and gave a little more context to my story.

MB explained that citizen research has historically been about the possibility of large datasets, but also in the process to let people get a better idea of what research is. Then we went in to discuss the study structure and focus.

When it comes to previous years' mass experiments, MB said that what has been done in terms of evaluations are surveys afterwards with teachers – where they have stated what the participation possibly gave in the form of added value. MB explained that what he thought was exciting in this mass experiment was the opportunity to longitudinally follow some individuals before and after their participation and study what this participation had given them in the form of e.g. knowledge and awareness of research.

I said as a comment that a longitudinal follow-up was probably not possible within the framework of my dissertation work, but that rather out of necessity, given the time frames, it had to be about participating in the support (in the form of a Facebook group as previously mentioned) + to design and analyze some form of evaluative survey.

SI, however, thought that this with longitudinal might not be such a bad idea if it simply meant a form of pre- and post-group. Furthermore, SI stated that the focus of the study as it was intended was to examine older people's interest in and capacity to participate in this type of research. When it comes to capturing within the study what the interest in participating in this type of project looks like, SI suggested that it is easiest to report through how many people actually participate and through e.g. website statistics. When it comes to capacity, one way plausible way could be to measure the extent to

which the accessibility protocol had been filled in, as well as how many and what type of questions were filled in or left out by the participants during the process.

MG talked about that citizen science is to some extent about raising the level of awareness among the public about what research is and can be. In line with this, she suggested that the project could also be about whether we with the project have succeeded in raising awareness of research among the public. She also emphasized that she particularly thought that we should try to include some people from the disability movement and not just pensioners' associations as intended. With such a focus for the study, it would be relevant to perhaps talk to someone at Neuroförbundet or with someone who contacts support and through them get the opportunity to follow one or more groups a little closer, before and after the mass experiment itself.

MB agreed with MG and said that this was what he was referring to when he mentioned a longitudinal study. He also talked about that citizen science is about raising awareness of research and that the slightly larger perspective is about influencing society. The degree of influence, he said, is also something that an EU project is trying to develop a tool for measuring. However, MB said he had not heard from those who participated in the project for a long time.

SI mentioned that another aspect of measuring awareness could be if you look at the longer term that this type of research project can lead to, for example, PRO and their members becoming more active and taking more responsibility for their situation. She further suggested Jannike Andersson, a doctoral student who has studied the media image, ie how certain phenomena are noticed and captured by the media. MB said that V&A has tools for collecting this type of data.

Furthermore, MB told that V&A has a registration form where there are many teachers who register and their classes. Through this form, they usually receive contact information for teachers and classes already during April-May. And it is then the mailing list that they then send out the evaluation to. However, they have problems with a very low response rate.

It is extra interesting, MB emphasized, that in this case there are two different target groups, partly seniors and partly students and teachers.

OJ mentioned ABF and Vuxenskolan when it came to learning and thought about how the contacts that CASE had there could be used. He also said that, in this case, it could be said to be about two kinds of awareness, partly awareness of research as such and what it entails, but also awareness of accessibility in housing, ie the issue itself. OJ also mentioned the difference between a formative and a summative evaluation.

I emphasized that it is important that it is not just an evaluation of the app itself but that the article has a wider ambition than that.

MG suggested that SÅ's group, or Neuroförbundet, could be such a unit to work with and with them in focus, one can examine consciousness before and

after. In addition, she said that a strong thing to get people involved is to be able to use the pensioners 'unions' mailing lists.

SI added that approximately 50% of the pensioners' association's members have email addresses, and even if some people do not have email, you could send a postal survey to them because the postal addresses are also registered. In these questionnaires, things like motivation or obstacles could be included. To try to get as broad a target group as possible, it would be good to include both an SPF association and a PRO association. An alternative when it comes to PRO is Eslöv and Lena Larsson.

I mentioned the risk that many older people may have difficulty coping with using the app, when there is now no possibility of receiving support from schoolchildren as it was originally intended. MB explained that the best we can do is to produce good supporting material, which is a work in progress. SI emphasized that we always get that criticism in projects where this type of technology is included, but on the other hand, people who are 70+ have increased their use of technology.

MB mentioned that it would be good if it was possible in some way to find out the reasons why those who did not participate did not participate. He said that there is usually a drop in participants from the time people register their interest until the study itself is carried out. But capturing one or more local districts in this way can be a way to better understand why people choose not to participate.

OJ wondered if it is possible to compare with a school class, and we discussed the possibility that a chairman of PRO asks a number of questions and through a form of show of hands gets answers, in a similar way to the evaluations that teachers usually do.

As the meeting drew to a close, SI emphasized that we must first agree on what we are to do and then what this requires from an ethics review permit. She explained that for the ethics review board, it usually takes 6-8 weeks to process an ethics application, so it is important that it is completed and submitted relatively soon.

When it comes to what is justified by ethics, it is about sensitive data; as soon as data is collected on health, disability and sexual orientation, it is classified as sensitive information. And as soon as you address a particular group that is characterized by illness or disability, it in itself requires a permit for ethics testing, regardless of what questions are asked of the group.

MB said that the part with the teachers does not require ethical review. However, SI suggested that it would be interesting to try to find out if teachers had someone in their class with some form of disability, e.g. if they had a wheelchair-bound student. A hypothesis from SI that it could lead to higher awareness and interest.

What would need ethical review for my study is a before-after survey that goes to a small selection of SPF's and PRO's local associations and possibly also to one or more of Neuroförbundet's local associations. In addition,

possibly also to a qualitative data collection in the form of e.g. focus groups, where we can gather a small group and have a form of dialogue meeting to get a slightly deeper understanding of the phenomenon. An additional way to get more qualitative data is to ask some of those who contact support if they agree to participate in a short interview about how they experienced their participation.

I asked the question if it is possible to attract something to counteract that the response rate to the survey is too low. MG suggested that SI can come out and inform.

The next step is now to formulate a research plan in which I describe which questions are to be asked and how they are to be sent out. It was decided that MG, OJ and I will meet and produce one together and then MB will participate in the subsequent meeting. MG takes overall responsibility for this work in terms of time.