

INFORMATION SHEET FOR PARTICIPANTS V.1 01/12/2014



REC Reference Number: REP/13/14-47

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

An Exploration Of The Biosocial Relations And Hierarchies Present In Beyond The Clinic (Btc) And Biohacking Approaches To Personal Genomics

Invitation Paragraph

I would like to invite you to participate in this research project into personal genomics, which forms part of my PhD project at King's College London. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the study is to explore, from an end-user and researcher perspective, the relationships and hierarchies that form through the process of sequencing a person's DNA. Specifically I am interested in how users of 'beyond the clinic' companies such as 23andMe interact with the analysis process and their results compared to members of the bio hacker community who sample and sequence their own DNA.

Why have I been invited to take part?

I am inviting key users of online forums discussing personal genomics results that have been obtained through beyond the clinic companies.

Do I have to take part?

Participation is voluntary. You do not have to take part. You should read this information sheet and if you have any questions you should ask the researcher. You should not agree to take part in this research until you have had all your questions answered satisfactorily. Should you not wish to take part in the research no online communication – even that which is posted in a public forum – will be recorded for research purposes.

What will happen to me if I take part?

If you decide to take part you will be asked to read a consent form and sent a private message/email confirming you agree. The consent form will include links to further information on interview procedures and topic guides. With your consent, I will arrange to interview you either through private message/email or through group discussions on a public forum.

Private interviews will be flexible and you may take as long as you like to reply. Group discussions will move at a rate dependent on community involvement, although you should feel free to engage with points raised earlier that you may have missed out on. The interviews will be screen-captured subject to your permission. Screen-captures will be deleted after transcription, at which point all participants will be anonymised with coded initials. Even if you decide to take part, you are still free to cease your participation at any time and to have research data/information relating to you withdrawn without giving any reason up to the point of publication in Spring 2016.

What are the possible risks of taking part?

There are no foreseeable risks in participating in the study. The main disadvantage to taking part in the study is that you will be donating a small percentage of your time to take part. It is possible that you may find answering some of the questions challenging. This is unlikely but if it were to occur the interview could be terminated at any time. No specific information regarding an individual's genetic conditions or ancestry will be recorded.

What are the possible benefits of taking part?

There are no direct benefits to taking part, however the information you provide will help to influence current and future research on attitudes to personal genomics and the way we understand our own DNA. This information may also play a part in shaping policy decisions concerning future decisions on the regulation of personal genomic and genetic counselling service. Furthermore, I will provide you with a summary of a final report describing the main findings, including an analysis of the relationship between personal genomics companies and their customers.

Will my taking part be kept confidential?

What is said in the interview is regarded as strictly confidential and will be held securely until the research is finished. Your participation is entirely voluntary. If you change your mind, you are free to stop your participation and have your data withdrawn without giving any reason up to the point of publication in Spring 2016. All data for analysis will be anonymised. In reporting on the research findings, I will not reveal the names of any participants. At all times there will be no possibility of you as individuals being linked with any data sent through private messages. Please be aware that discussions on a public forum may be viewable to other members or Internet users, depending on the forum's privacy policy.

The UK Data Protection Act 1998 will apply to all information gathered within the interviews and held on password-locked computer files and locked cabinets within King's College London. No data will be accessed by anyone other than me; and anonymity of the material will be protected by using false names. No data will be able to be linked back to any individual taking part in the interview. You may withdraw your data from the project anytime up to the point of publication in Spring 2016. All screen-captured data will be

deleted after transcription. If you ask to withdraw your data at any time before Spring 2016 I will remove all traces of it from the records.

How is the project being funded?

The project is funded by the Icelandic Research Fund. The study has been approved by the King's College London Research Ethics Committee.

What will happen to the results of the study?

I will produce a final report summarising the main findings, which will be uploaded to a publicly accessible blog. I also plan to disseminate the research findings through publication and conferences in the United Kingdom and Europe.

What if something goes wrong?

If you have any questions or require more information about this study, please contact me using the following contact details:

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If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information: The Chair, Social Science and Public Policy, Humanities and Law, Research Ethics Subcommittee Chair, rec@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.