

Understanding the value of genomic tests

Participant Information Sheet

Background to the study

You are being invited to take part in a research study as part of a PhD project that aims to understand how people value information from genomic tests. We're particularly interested in understanding how people balance the health and non-health value which might come from having a genomic test. Before you decide whether to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Who will conduct the research?

Martin Eden, from the Manchester Centre for Health Economics, is conducting the research as part of a PhD project. He is supervised by Professor Katherine Payne from the Manchester Centre for Health Economics, University of Manchester.

What is the aim of the research?

This study wants to understand how people might value diagnostic information from genomic tests. The aim is to explore how people value test information in different hypothetical situations.

Why have I been chosen?

This study aims to explore the views of individuals (people from families which have been affected by inherited conditions). Anyone who is able to complete an interview in English is able to take part in this study.

What would I be asked to do if I took part?

You will be invited to complete an interview at a location convenient to you or at your home if you prefer. The interview should take no more than one hour. During the interview I will ask you about imaginary situations involving genomic tests. We might talk a little bit about your experience with genetics services and genetic testing. It is important to remember that there are no right or wrong answers; we are just trying to explore your views. I will also ask your permission to record the interview so that I do not have to take notes to remember what was said.

What happens to the data collected?

The interview will be recorded and then typed up into a written record of what was said. The answers to the survey will be used to help us understand how genomic testing can be better provided. Your name will not be recorded and each interview will be given an anonymous identification number. We might want to use some of the direct quotes from the interview in a PhD thesis and/or research paper summarising the findings but your name or any other information which could identify you will not be recorded with these quotes. Transcribed interview data will be kept secure in locked filing cabinet within a locked office in the University of Manchester. Data will be kept for a period of 5 years then destroyed.

How is confidentiality maintained?

The law called the Data Protection Act (1998) tells us how to keep your information secure. If you provide personal information (name, address, contact details) it will remain confidential and we will not give your details to anyone else.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. You can decide for the data from your interview to be withdrawn from the study at any point up until I submit my thesis in September 2018.

Will I be paid for participating in the research?

To compensate you for your time we will provide a £25 high street voucher. If you decide to travel to the University for the interview, then we can reimburse your travel expenses in line with university policy.

What is the duration of the research?

If you decide to take part, you will take part in one interview which will last no more than one hour.

Where will the research be conducted?

The interview will take place at a time and location convenient for you where it is possible to record what was said privately and clearly. A researcher can come to your home if you wanted. If you prefer, then you are free to travel to the University for the interview. The location of the interview is your choice.

Will the outcomes of the research be published?

The main outcome of this research will be a report presenting how different people might value having a genomic test. In addition, we may want to report the findings at conferences or in a published journal article and use anonymised responses in future studies.

Who has reviewed the research project?

This project has been reviewed by the University of Manchester Research Ethics Committee 5.

What if something goes wrong?

It is unlikely but possible that you could become upset during interviews. We have a procedure in place which involves stopping the interview in such an eventuality and ensuring that research participants are happy to continue when ready. We will also ensure that you have the opportunity to discuss how the interview could have affected your mood with myself, my supervisor or another relevant professional. You can contact me, Martin Eden using the contact details below at any time during the project. My supervisor, Professor Katherine Payne, can also be contacted at any time using the email address katherine.payne@manchester.ac.uk.

What if I want to make a complaint?

Minor complaints

If you have a minor complaint then you need to contact the researchers in the first instance. Martin Eden can be contacted by phone on 07748 966 951 or by email using the address: martin.eden@manchester.ac.uk. Professor Katherine Payne can be contacted by email using the address katherine.payne@manchester.ac.uk.

Formal complaints

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact the Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674 or 275 2046.

What do I do know?

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s). Please contact Martin Eden (Research Fellow in the Centre for Health Economics) on 07748 966 951 or email martin.eden@manchester.ac.uk, or Professor Katherine Payne (Katherine.payne@manchester.ac.uk).

This Project Has Been Approved by the University of Manchester's Research Ethics Committee 5