Impact of genetic conditions on obtaining insurance

Participant Information Sheet

You are being invited to take part in a research study looking at the experiences of people in obtaining insurance when there is a genetic condition in their family. This study will form the dissertation for an MSc Clinical Science in Genomic Counselling degree. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research study

- **What is the purpose of the research?**

Genetic testing has become more accessible over recent years. There has been a growing concern that insurance companies may use this genetic information to discriminate against people who have a genetic condition themselves, or who have a genetic condition in their family when offering insurance policies. Through this research, we aim to better understand the experiences of individuals trying to obtain insurance when there is a genetic condition in their family.

- **Am I suitable to take part?**

We would love to hear from you if you are:

  - 18 years or older
  - Have a genetic condition or genetic change in your family
  - Have life insurance, or have tried to obtain life insurance

- **What will I be asked to do if I take part?**

You will be asked to fill out an online survey. This survey will include questions about the genetic condition in your family, your health, and your experiences in obtaining insurance. The survey should take approximately 20 to 30 minutes to complete and can be completed at a time that is convenient for you. All survey responses will be anonymous. By submitting your responses to the survey, you agree to participate and understand the terms outlined in this information sheet.

- **Will I be compensated for taking part?**

No compensation will be available; however, your response would be greatly appreciated.

- **What are the possible benefits of taking part?**

It is not predicted that there will be direct benefits to yourself. However, this research should give us a greater understanding of how applying for insurance is affected by the presence of a genetic condition in the family. This may lead to additional research on the subject in the future.

- **What are the risks if I take part?**

It is not anticipated that there will be any risks to you in taking part in this study. Sometimes people find it emotional or difficult to recall their experiences. You may feel uncomfortable

sharing information about your health. You are not obligated to share any information that you do not want to. Please only provide information that you are happy to give us.

- **Who has reviewed this study?**

This study has been reviewed by **HRA and Health and Care Research Wales (HCRW) – REC reference 25/HRA/4709.**

- **What happens if I don't want to take part or change my mind?**

It is up to you to decide whether to take part. If you would like to, then please access the survey through the online link provided with this information sheet. By proceeding to the survey, you agree to participate and understand the terms outlined in this information sheet. If you do decide to take part, we encourage you to keep a copy of this information sheet.

If you decide to take part, you are still free to withdraw at any time without giving a reason and without detriment to yourself.

If you decide not to take part, you do not need to do anything further.

- **What will happen to the results of this study?**

The results of this study will form the dissertation for an MSc Clinical Science in Genomic Counselling degree at the University of Manchester. It may also be published in a medical journal.

- **Who will conduct the research?**

- Luc Van Rensburg, Trainee Genetic Counsellor at University Hospital Southampton, MSc Clinical Science in Genomic Counselling student at University of Manchester
- Jessica Williams, Principal Genetic Counsellor at University Hospital Southampton

Data Protection and Confidentiality – General Data Protection Regulation

How will we use information about you?

We will need to use information from you for this research project. This information will include your:

- Gender
- Age
- Ethnicity
- Geographical location
- Health data

People will use this information to do the research. University Hospital Southampton is the sponsor of this research. University Hospital Southampton is responsible for looking after your information. Your data will not be shared outside the UK. We will share your information related to this research project with the following types of organisations:

- NHS trusts

- University of Manchester

We will keep all information about you safe and secure:

- All data will be stored on an NHS trust sever, which is firewall protected
- Data will be accessed and processed using NHS trust computers which are password protected
- Only the study researchers will have access to the survey responses

How will we use information about you after the study ends?
Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for a maximum of 2 years. The study data will then be fully anonymised and securely archived or destroyed.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

Where can you find out more about how your information is used?
You can find out more about how we use your information:

- Our leaflet at www.hra.nhs.uk/patientdataandresearch
- By asking one of the research team
- By sending an email to Luc.VanRensburg@uhs.nhs.uk
- By sending an email to dataprotection@uhs.nhs.uk to contact the sponsor's Data Protection team

Contact details

If you have any queries about the study please contact the researchers at:
Luc.VanRensburg@uhs.nhs.uk

What do I do now?

If you have any questions, please contact the research team using the details above.

If you would like to participate in this study, you can access the questionnaire online by following the link below or using the QR code on the next page.

https://forms.office.com/e/nkRfV5LQbu

"Genetic Conditions or Changes and Insurance" Questionnaire

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