Genetic Alliance UK
Supporting. Campaigning. Uniting.

My Cancer, My DNA - Shaping genomic sequencing uptake in UK healthcare

Interested in how the genetic information of you and your family could be used in the NHS? Want to make sure healthcare decision makers listen to patients' views on the use of genetic data?

Thanks to a new method of genomic sequencing it is becoming faster and cheaper to sequence large amounts of genetic information. At the same time, researchers are finding out more about how our genes can affect our health, and how we can use this information to improve healthcare through better diagnosis and treatment.

But how do cancer patients and their families feel about the introduction of genomic sequencing in the NHS?

To answer this question, Genetic Alliance UK would like to invite you to participate in a series of engagement sessions that will explore the societal, ethical and practical issues raised by using genomic sequencing to collect large amounts of genetic information. The findings of this research will be fed straight back to those making decisions about how genomic sequencing could be used by the NHS in the future in the form of a 'Patient and Family Charter'.

When and where?

The sessions will begin in January. You will not have to go anywhere to take part – all of the sessions will be delivered using free online applications so that you can take part when and where is most convenient for you. None of the sessions will last longer than 45mins and there will be no more than six sessions, which will be delivered over the course of six weeks.

Project focus: how do you feel about the use of genetic information in the NHS?

This research project will help you get to grips with what genomic sequencing is, the ways it could be used in healthcare and why its use raises some important ethical, societal and practical questions. Most importantly, it gives you the chance to share your views, as a patient or family member, and have them heard by those making decisions about how genomic sequencing might be incorporated into the NHS.

What is involved?

The project would require you to take part in a series of engagement sessions that you can access using a laptop, smartphone or other device connected to the internet. Sessions will be a mixture of interactive tutorials, where you will answer survey-type questions or be asked to

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make decisions in hypothetical scenarios; and live chats, where you can pose questions and make comments.

Who can take part?

Are you 18 or over? If you or a member of your family has been diagnosed with, is suspected to have, or has an increased predisposition for cancer we would like to hear from you. Unfortunately, we will not be able to provide translators and, therefore, you will need to be able to speak and understand English.

If you are interested in taking part as an individual then please register online at this address: https://www.surveymonkey.com/r/MCancerMDNAReg Please contact Angela Wipperman either by email (Angela.Wipperman@geneticalliance.org.uk) or by phone (020 7704 3141) if you have any questions.

This research project is supported by a NIHR Biomedical Research Centre award to the Royal Marsden and ICR.

We are pleased to be collaborating with Bloodwise, Breast Cancer Now, Cancer 52 and Cancer Research UK on this project.

Bloodwise
Beating blood cancer since 1960

cancer52
the common voice for less common cancers

CANCER RESEARCH UK

The ROYAL MARSDEN NHS Foundation Trust | ICR The Institute of Cancer Research

NHS National Institute for Health Research