Participant information sheet – Parent and carers survey
Version 2.1: Date: 13/04/2022
IRAS: 304769
Study title: Evaluating rapid genomic sequencing for critically ill children
Principal Investigator: Dr Melissa Hill

Participant information: Survey to inform a new research study

We are inviting you to take part in a survey for a new research study. This study is being conducted so that we can find out more about parents' views on rapid exome sequencing for seriously ill babies and children and how the new test is being offered in the NHS. Before you decide whether or not to take part, we would like you to understand what the study involves. Please take time to read the following information carefully. Discuss it with your partner, relatives, friends or your doctor if you wish.

What is rapid exome sequencing?

Rapid exome sequencing is a new test that is offered by the NHS in England. This test is offered when a baby or child is seriously ill and they have symptoms which suggest they are likely to have a rare genetic condition. Rapid exome sequencing will look for a genetic cause for the child's medical condition. Those who are offered a test are usually being cared for in a newborn or children's intensive care unit. A quick diagnosis can be very important to the care and treatment they receive.

What is the purpose of the survey?

The NHS has recently started offering rapid exome sequencing to children who are seriously ill to try and find the underlying genetic cause of the child's condition. Because the technology and the service is new, it is important to look at how the test is being offered to make sure that the test is offered in a way that is beneficial to patients and supportive of parents. We are starting a new research study to look at how this test is being offered in the NHS. By answering the survey you will help us to work out the most important topics to look at in our research and how best to share our findings.

Why have I been invited to take part?

We are inviting parents and carers of children who have a genetic, rare and/or undiagnosed condition to complete the survey. Bereaved parents can also take part. We hope that around 50 people will complete the survey.

You must be 18 or over and live in the UK. You may or may not have knowledge or experience of rapid exome sequencing in the NHS.

Do I have to take part?

No. It is up to you to decide whether or not to complete the survey. If you agree, you will be asked to consent before taking part. You are free to skip any of the questions in the survey that you would prefer not to answer. You are free to stop filling in the survey at any time before you submit the completed survey. As the survey is anonymous, it may not be possible to withdraw your responses once you have completed and submitted your answers.

What will I need to do if I decide to take part?
You will need to confirm your consent to taking part and complete a survey that will take 15-20 minutes. The survey asks for your views on the test, your suggestions to guide our research and some questions about you, such as age, ethnicity and experience with genetic and genomic testing.

You can also complete the survey over the phone with a member of the research team or request a paper copy of the survey. If you complete the survey over the phone we will record your responses as an audio-file. If you request a paper copy of the survey, you will be provided with a pre-paid envelope to return the survey. If you complete a paper or phone survey your responses will be entered into the online version of the survey by a member of the research team. Translators are also available if you wish to complete the survey in a different language.

What are the possible benefits of taking part?
There is no immediate and direct benefit to you. However, by taking part in the survey you are helping to improve our evaluation of the rapid exome sequencing service which will help us make recommendations to improve the quality of care for patients and parents.

What are the possible risks and inconveniences of taking part?
You will need to take part in a survey that will take 15-20 minutes. Diagnostic tests when a baby or child has been seriously ill are a sensitive topic and it may be upsetting for you to think about this topic or to reflect on some of your own experiences with your child.

What if I find the survey upsetting?
If you find the survey upsetting you can stop at any time and not complete the survey. You can contact the research team and we can put you in touch with someone from your clinical team if you feel this would be helpful, or provide you with details of a patient support group.

How will we use information about you?
The survey is anonymous and the information collected cannot be used to identify who has taken part.

Some questions are open ended and ask you to write out your thoughts about the question. We may quote what you have written in response to these questions in an academic publication, conference or report. Quotes will be anonymous and we will make every effort to protect your identity. For example, we will not name people or include the name of any genetic conditions in the quotes.

To help us understand more about the background and experiences of the people who are completing the survey we will also ask you to share the following information, this is optional;

- Gender
- Age
- Ethnicity
- Education
- Main language spoken at home
- Number of children

- Religious affiliation
- Name of condition and experience of genetic testing (if relevant)

If you wish, you can add your email address on the last page of the survey and we will contact you at the end of the study to send you a short summary of the findings. Your email address will be kept in a different place from your survey answers.

If you give your survey responses over the phone, they will be audio recorded and then entered into the online survey by a member of the research team. We will then delete the audio recording. If you complete a paper copy of the survey, your answers will be entered into the online survey by a member of the research team. We will then destroy the paper copy securely.

We will keep any information about you safe and secure. We will write our reports in a way that no-one can work out that you took part in the study. The anonymised survey responses will be kept securely for 15 years after the study ends.

What are your choices about how your information is used?
You can choose not to answer some of the questions in the survey or you can select 'prefer not to say'. You can also stop being part of the study at any time, by not submitting your survey. Once your survey is submitted we will not be able to identify you and won't be able to delete your survey.

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

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to the lead researcher [email], or
- by contacting the Data Protection Officer at GOSH (your.data@gosh.nhs.uk)

For more information about how we keep your information safe at GOSH when we conduct research please see https://www.gosh.nhs.uk/our-research/our-research-infrastructure/joint-research-and-development-office-rd/gdpr-and-research/

What if there is a problem?
Please ask to speak to the lead researcher, Melissa Hill, who will do her best to answer your questions (contact details below). If the problems are not resolved, or if you wish to comment in any other way, please contact the Research and Development team at Great Ormond Street Hospital for Children NHS Foundation Trust; email: research.governance@gosh.nhs.uk

Who is organising and funding the research?
The survey is being led by researchers at Great Ormond Street Hospital in collaboration with Genetic Alliance UK, Breaking Down Barriers and others. The survey is funded by the National Institute for Health Research (NIHR202725).

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been given favorable opinion by West of Scotland Research Ethics Committee 3.

What will happen to the results of the research study?
The findings will be published in medical journals and presented at scientific meetings and conferences. A summary of the findings will be sent to you if you would like one.

For further information and to take part please contact Melissa Hill (GOSH).
Email: RGSevaluation@gosh.nhs.uk
Phone: 020 7405 9200 4944 (ext. 4944)