GENROC: Improving the treatment of people with **GEN**etic **R**are disease: an **O**bservational **C**ohort study.

Working with families to increase understanding of growth and development in rare genetic conditions in order to improve clinical care.

Information leaflet for Children aged 11-15

We would like to invite you to take part in a research study.

Please read this leaflet carefully. It will explain why we are doing the study and what it will involve. You can talk about it with your family, friends, doctor, or us. Ask us if there is anything you don't understand or if you want more information.

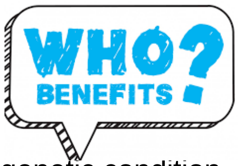
Why are we doing this study?

- We don't know enough about how genetic conditions affect children
- An example of this is that some children are smaller but we don't know if this is because of their genetic condition – which means doctors don't know whether the child needs treatment
- Families want to know more and so they join social media or online groups about the genetic condition

We want to improve everyone's understanding of these conditions.

By improving our understanding of these rare conditions and by working better with families we hope to be able to develop better treatments for patients.

What are the advantages of taking part in this study?



By taking part **you and your family will really help us** and:

- Will help doctors and scientists understand more about your rare genetic condition which will help us know the best way to care for you.
- **We hope that this study will allow us to generate charts to show how children with genetic conditions grow and other helpful information that may benefit you.** This sort of information is key to scientists being able to develop new treatments in the future.
- Will help us understand the best way of working with families and with genetic syndrome social media groups and how to get the most out of web based tools
- Will also be helping other families with these conditions now and in the future
- May also be invited to take part in other research studies that you wouldn't have known about otherwise (**you would be able to choose** if you did this)

You may also learn a bit about how research studies work.

What will I be asked to do?

1 If you **want** to take part, you and your parent/carer will be asked to fill in an online form

If you would like to hear more about the study first, we will arrange a time to talk to you over the telephone. We will explain the study to you and your parent/carer, and answer any questions you may have.

2 Your parent/carer will be asked to complete some questions online about you. This shouldn't take too long and it's **up to you** if you want to help with this.

Later in the study, your parent/carer may take part in an online discussion group – **we will make sure your information is kept private**. They will be also asked to upload some further anonymised information about you to an online portal (special secure website).

Do I have to take part? You **do not have to take part** in this study. If you want to speak to your genetics doctor or the research team, they will explain more about the study, but this will not commit you to taking part.

Are there any disadvantages to taking part?

Not really. If you take part, your parent will have to spend some time completing the online questionnaires.

You can choose whether you help them with this.

If I agree to take part, can I change my mind?

Yes. **You can leave the study at any point**. If you would like us to, we will take out some of the information we collected about you at any point before we look closely at the data. Leaving the study at any time will not affect the standard of medical care you will receive.

Further information section :How will we use information about you? In this research study we will use information (such as name, date of birth, address and NHS number) from your medical records. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it AND for future research.
We will make sure no-one can work out who you are from our reports.

This QR code will tell you more about this.

What will happen when the study stops?

Your NHS care will not change at any point. After the study stops and you want to know the study results, let us know and we can send them to you.

What will happen to the results of the study? We will share the results of the study to help people in the future get the best possible treatment for their condition.

What will happen if I feel unwell during the study?

Nothing about the study will make you unwell. If during the study you start to feel unwell, you should contact your local care providers (e.g., your GP or paediatrician).

Any medical problems you may have during the study will be handled by your usual care providers, as no medical illness will arise as a result of the study. The researchers cannot provide treatment for illnesses that you may have during the study.

Does everybody involved in the study have the right police checks? Yes. Those who are working with people within the study have had police checks to make sure they are safe to work with children and adults.

What should I do if I have a problem with the study? We think this is **very unlikely** but if you have any problems with this study, please speak to Dr Karen Low, or any member of the clinical team that you know. Dr Low’s contact information can be found below. You can also talk to the NHS in the usual way via the Patient Advice and Liaison Services (PALS) in your hospital.

Ethical approval We have the correct ethical approval from the NHS Research Ethics Committee. An independent group of people reviewed our study and agreed it was ethical.

Who can I contact for more information:

Email the study team on genroc-study@bristol.ac.uk

Research lead: Dr Karen Low Karen.low@bristol.ac.uk Please also see www.*** which will provide you with further information about the study.

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