



Genetic Services survey

Genetic services survey January 2022: Information for Participants

We would like to find out more about the experience of adults and children when accessing genetic services in the Republic of Ireland, i.e., genetic testing and appointments with a Genetic Consultant or Genetic Counsellor. Please read this information to help you decide whether you would like to participate. You will also find this Information for Participants at rdi.ie/gxservices-survey/ if you would like to print a copy.

This survey is a co-operation between Rare Diseases Ireland (RDI - the national alliance for rare disease patient organisations in Ireland, www.rdi.ie) and a research team led by Prof. Sally Ann Lynch at University College Dublin/Children's Health Ireland (CHI) Crumlin, funded by the Adelaide Health Foundation. The title of the research project is "Genetic Counselling and Testing in the Irish Republic: Scoping current practice, international comparisons and recommendations for national practice".

What is the aim of this survey?

The aim of the survey is to gather experiences of people with rare diseases and undiagnosed conditions when accessing genetic services in Ireland. The findings will be used to recommend the future design of Irish genetic services. The survey should take about 15-20 minutes to complete.

Who can take part?

You can take part if you are aged 18 or over.

You can be:

- A person living with a rare condition – accessing genetic services for yourself and answering on your behalf
- A family member / carer of a person living with a rare condition accessing genetic services, and answering on their behalf
- A family member of a person living with a rare condition, accessing genetic services for yourself and answering on your behalf.

Often in a family several people access genetic services. Each of these family members is welcome to complete the survey. A separate survey should be completed by each person who wishes to take part.

What questions will the survey ask?

The survey will first check that you consent to participate in this survey. There will then be questions about:

- Background information
- Experience of accessing a genetic test
- Experiences waiting for an appointment with a Genetic Consultant or Genetic Counsellor
- Experience of being seen by a Genetic Consultant or Genetic Counsellor
- Knowledge of genetic counselling

Who will know I have taken part?

We will not ask for your name, address, or birth date in the survey. Survey responses will be securely kept by Prof. Lynch at CHI Crumlin. Only RDI and the research team will have access to the survey responses, they won't be shared with anyone else.

Because we do not ask for names, we cannot identify your survey responses. This means if later you decide that you did not want to take part, we will not be able to withdraw your responses from the study.

How will survey responses be reported?

All survey responses will be combined so that no single response can be identified. RDI and the research team will analyse the results together. A report for policy makers, healthcare providers and the public will be published. We expect that a preliminary report will be available at Rare Diseases Day (February 28th) 2022. You will be able to access the final report from RDI (www.rdi.ie) after it has been published. The results of the analysis may also be reported in scientific journals and/or conferences.

Consenting to participate

It is up to you whether you choose to complete this survey. Please read this information carefully. The first survey questions will ask you if you are happy to consent to take part in the study. If you don't want to answer the survey, that's OK too.

As part of the consent, we ask if we may quote your text answers in the study report. You may choose not to have your quotes used in the report. You can still fill out the survey if you choose 'no' – your answers are still helpful. If you say 'yes', we may use some quotes in the report. We will not use any diagnoses or any identifying information in the quotes. However, because some situations are so rare, it is not possible to guarantee that you will not be identified from the quotes.

Privacy

Please do not use your name or the names of family members or healthcare professionals in your answers.

Who is funding the survey?

This survey work is funded by Adelaide Health Foundation (www.adelaide.ie), a voluntary independent charity which seeks to advance equal access to quality healthcare. Financial support for RDI's work is provided by several industry partners who have an interest in rare conditions. No funders have any role or influence in design, analysis or reporting of this research.

Potential Risks and Benefits

It is very unlikely that you would have any harm from completing this survey. You won't benefit directly by completing this survey. Findings from this study may help to influence policy makers to develop genetic services in Ireland.

If you have questions

If you have any general questions about this survey, please contact RDI at advocacy@rdi.ie. The RDI team can also help you fill in the survey if you are not comfortable completing an online survey yourself.

If taking part in this survey has raised any issues or concerns for you, please contact the research team at GCinIreland@gmail.com. They can answer your query or point you to appropriate supports or clinical services.

This information sheet and survey has been approved by the Children's Health Ireland Research Ethics Committee and Data Protection Office in June 2021. If you have concerns about data collected or stored during this study, please contact Prof. Sally Ann Lynch at GCinIreland@gmail.com, or the Data protection Office, CHI Crumlin at dataprotection@olchc.ie.

Data Protection Notice

All data will be collected and stored in line with the Data Protection Act 2018. The data will be kept on a secure encrypted device by Prof. Sally Ann Lynch. This data will be stored for five years in line with data protection guidelines and will be destroyed afterwards.

CHI Privacy Statement

CHI understands that your privacy is important to you and that you care about how your personal data is used. We respect and value the privacy of all of our research participants and will only collect and use personal data in ways that are described here, and in a way that is consistent with our obligations and your rights under the GDPR.

Read all the information about the CHI privacy statement for research participants here: [privacy-notice-research-participant.pdf \(olchc.ie\)](#)