

National Public Engagement Survey on Health Information Frequently Asked Questions

About the survey

1. What is this survey about?

This survey is about you and your health information. Health information is information that is recorded when you attend a health or social care professional such as a GP or social worker. The record can include details about your medical conditions, lists of medication you may be taking and also includes personal details such as date of birth. We want to understand what you expect in terms of how your health information is collected, used and shared by health and social care services in Ireland and your opinion on the use of digital technologies in this area. Everyone has a right to know that their personal health and social care information is safe, and is used and shared appropriately in ways that are acceptable to them. We want to understand any concerns you might have about where your information is held, who can see it, and what it is used for.

2. Who is running the survey?

The survey is being run by the Health Information and Quality Authority (HIQA) in partnership with the Department of Health and the Health Service Executive (HSE). HIQA will also be using a data processor to assist with carrying out this survey.

3. Why is it important?

The partnership organisations involved in this survey want to understand the expectations of people living in Ireland in relation to their health information. This survey will enable people living in Ireland to voice their opinion on this topic and in doing so provide a rich source of information that will inform national policy and future developments and recommendations in the area of health information, consent and health technology.

4. Why now?

At the moment, the complexity of Ireland's health and social care structures, with a predominantly paper-based system, makes the collection, use and sharing of health information difficult, particularly across organisations. Part of the aim of the [Sláintecare Implementation Strategy](#) (Ireland's 10 year healthcare plan) is to address these difficulties. This will include the introduction and use of eHealth and digital technologies. Improvements

in this area will lead to greater availability of health information, improvements in decision-making and ultimately safer care and better outcomes for patients.

5. Who will be asked to complete the survey?

The survey will be completed by 1200 people living in Ireland aged 18 and over. To ensure that we include people of all ages who broadly represent the wider population, the statistical technique of selecting a random sample of the population has been chosen. Therefore the study is not open to volunteers of the general public.

6. Does the survey comply with data protection laws?

Yes. The survey complies with all data retention and protection laws including the General Data Protection Regulation (GDPR). A Data Protection Impact Assessment has also been carried out. Further details on data protection are available here (add link to webpage).

7. Where can I find the results of the survey?

The results of the survey will be available on www.hiqa.ie. You can also sign up to receive the results by emailing healthdatasurvey@hiqa.ie.

For survey participants

1. What does taking part involve?

The survey involves answering 32 questions over the telephone with a researcher who will note your answers in an online survey form. It takes approximately 20 minutes to complete.

2. Why should I complete the survey?

Completing this survey gives you the opportunity to have your opinion heard on this topic and have a meaningful impact on future plans for health information in Ireland including the use of digital technologies and recommendations for the development of a consent model.

3. What types of questions will I be asked?

You will be asked for your opinion about the use of personal health information for both primary purposes (for your own personal health and social care including diagnosis, care and treatment by health and social care professionals) and secondary purposes (purposes beyond your own diagnosis, care and treatment such as research or service planning). You will also be asked for your opinion about new digital technologies and consent relating to how your health information is used.

4. What will you do with my answers?

All survey responses will be anonymised. The findings will be published in a report setting out people's opinions about how their health data is collected, used and shared and what changes they would like to see. Results will be made publicly available on www.hiqa.ie.

5. Will my answers be treated confidentially?

Yes, your answers will be processed in strict confidence and kept separate from your personal contact details (first name and telephone number). Your answers will be analysed for the purposes of this survey. The answers will not be given to commercial entities or used for commercial purposes. All information gathered during this survey will be managed in line with HIQA's Information Governance and Data Protection policies. For information on how HIQA uses personal data please see the HIQA Privacy Notice: <https://www.hiqa.ie/reports-and-publications/corporate-publication/hiqa-privacy-notice>

6. Who will have access to my personal information, where will it be stored and for how long?

Your personal contact information (first name and telephone number) will be collected by the telephone interviewer and stored securely for quality control purposes for 4 weeks after the completion of the survey. Access to personal information is controlled and is in line with HIQA information governance policies. Once the data quality checks are completed, your personal contact details (first name and telephone number) will be deleted and responses will no longer be linked with your personal contact information. These non-identifiable responses will be kept by HIQA indefinitely. If you request to have additional information on the survey posted to you, your name and address will be collected for this purpose and deleted four weeks after the completion of the survey. For more information on how and where your personal information will be stored, please visit (dedicated HIQA webpage link)

7. Where can I find out more?

To find out more, you can contact us by:

Email: healthdatasurvey@hiqa.ie

Postal address:

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