

National Public Engagement Survey on Health Information

Participant Information Leaflet

This leaflet is intended for members of the public who are taking part in the National Public Engagement Survey on Health Information. The aim of this survey is to understand your opinion about how your health information is collected, used and shared.

Taking part in this telephone survey is voluntary. Before you decide whether or not you wish to take part, you may wish to read the information provided below.

Why is this telephone survey being done?

The survey is being run by the Health Information and Quality Authority (HIQA) in partnership with the Department of Health and Health Service Executive (HSE).

We want to understand what people living in Ireland expect in relation to how their health information is collected, used and shared.

Your opinions will help to inform national policy and future developments and recommendations in the area of health information, consent and ehealth..

At the moment, Irish healthcare services operate using a mostly paper-based system. This makes the collection, use and sharing of a person's health information between different healthcare services during treatment difficult.

Ireland's 10-year healthcare plan, [Sláintecare](#), aims to address these difficulties with the introduction and use of eHealth and digital technologies. eHealth and digital technologies refers to the use of information and communication technologies for health, for example: electronic health records, patient summaries, patient portals and electronic prescriptions. These new technologies have the potential to lead to greater availability of health information, improvements in decision-making and ultimately safer care and better outcomes for patients.

The information from this survey will be used by HIQA to make recommendations on a consent model for the collection, use and sharing of health and social care information in Ireland. The Department of Health and the HSE will also use this information for informing national policy and future developments in health technology.

Who is organising and funding this survey?

HIQA is conducting this survey in partnership with the Department of Health and the HSE. The survey is funded by the partnership organisations.

The survey is being conducted by a market research company, Behaviour and Attitudes, on behalf of HIQA, the Department of Health and the HSE.

Why am I being asked to take part?

The survey will be completed by 1,200 people who live in Ireland and are aged 18 years and over. A survey recruitment method called 'random digit dialling' will be used. Both mobile phones and landlines will be called randomly. If you receive a phone call asking you to take part, this means that your phone number was generated at random. The 'random digit dialling' will allow us to ensure that the results of this survey are a true reflection of the Irish public's opinion about the collection, use and sharing of personal health information. The study is not open to volunteers.

You can change your mind about taking part any time you like, even if the survey has started, and you do not need to tell us why.

How will the survey be carried out?

The telephone survey will begin in October 2020 and will continue until 1,200 survey responses are received. If you receive the call asking you to take part in this survey, you will be asked if you are happy to complete the survey. If you cannot complete the survey when you receive the call, you can request to be called back at a date and time that suits you.

What will happen to me if I agree to take part?

If you agree to take part in this survey, you will be asked to participate in a 20-minute telephone call. An interviewer will ask you a number of questions in relation to age, gender, region, working status, ethnicity and how often you use Irish health services. These questions help us to make sure that we collect responses from a variety of people with different backgrounds. It is important to collect responses from a variety of different backgrounds to ensure that the survey results are a true reflection of the opinions of all the people living in Ireland. Other questions are designed to help us to understand your views on the collection, use and sharing of health information in Ireland. The interviewer will describe a health related scenario or situation, based on the Irish healthcare system, and will then ask you questions about how you would like your health information to be collected, used and shared in this scenario.

This is a once-off survey. You may receive a follow-up call within four weeks of taking part for quality control purposes. The interviewer will be employed by the managed service (a market research company based in Ireland) and is fully trained in conducting telephone surveys. All information collected will be kept in the strictest confidence and combined results will be reported only. It will not be possible to identify any particular individual in the results and no information that could identify you will be provided to anyone.

Will the phone call be recorded?

Telephone interviews will not be audio recorded. The interviewer will input your answers to the questions on a computer programme.

What are the benefits?

Completing this survey gives you the opportunity to have your opinion on the future of health information in Ireland heard. The survey results will 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 health information consent model.

What are the risks?

We do not foresee any risks to taking part in this survey. The survey requires your commitment to a 20-minute survey. If we call you at a time that is not suitable to you, we can reschedule the call to a time that suits you. We have taken the necessary steps to ensure your personal information is protected. Further information can be found below in 'Is this survey confidential?'

Is the survey confidential?

All information collected will be kept in the strictest confidence. The Personal information — your phone number (which has been randomly generated) and your first name, which is asked at the end of the call for quality control purposes — will be kept for four weeks after the survey closes for quality control purposes, before being deleted permanently. Access to survey answers will be restricted to selected individuals. Survey answers will be stored by the managed service and sent securely to HIQA. Survey responses will not include any personally identifiable information. It will not be possible to identify any particular individual in the survey results and combined results will be reported only. In the event that a survey participant includes personal details in their answers, the interviewer will not record, collect or store this personal information. Merged anonymous survey responses will remain on

HIQA's secure server for at least 10 years. 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 within four weeks after the survey ends. If you would like to find out more or get results, please email healthdatasurvey@hiqa.ie for more information.

Data Protection

You will be asked to give verbal consent before taking part in the survey. Participation is voluntary and you have the right to withdraw from the survey at any time. The information you provide will be used to ensure that the survey includes responses from a variety of people living in Ireland. This will allow us to ensure that the results accurately represent the Irish public's opinion about the collection, use and sharing of personal health information.

We will be processing your personal information under Section (8)(1)(j) of the Health Act 2007. Under Section (8)(1)(j), HIQA has responsibility to provide advice and make recommendations to the Minister and the Executive about deficiencies identified by the Authority.

Initially you will be identified by your telephone number through a random digit dialling process. Your first name will also be asked for at the end of the call for quality control purposes. This personal information will be stored for four weeks after the survey is completed. A file containing non-identifiable survey answers will be stored separately for at least 10 years after the completion of the project.

There will be a four-week period between the closing of the survey and the deletion of first names and telephone numbers. Within this four-week period, participants have the right, should they wish, to review, edit or delete their survey responses. After the four-week period, survey answers will no longer be linked to personal information (first name and phone number) and it will no longer be possible to make amendments or delete to survey responses. 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 survey ends.

As the data subject, you have the right to:

- request access to your personal data (first name and telephone number) and survey responses and request a copy of same (this will be available for up to four weeks after completion of the survey, after which time the survey answers are no longer linked to personal details [first name and telephone number] and therefore are no longer individually retrievable)
- restrict or object to processing
- have any inaccurate information about you corrected or deleted.
- lodge a complaint with the Data Protection Commission (DPC) if you are unhappy with how your personal data is being used.

Should you have any further queries or should you want to make a complaint you can do so by emailing healthdatasurvey@hiqa.ie. You may also contact HIQA's Data Protection Officer: dpo@hiqa.ie

Where can I get further information?

If you need any further information now or at any time in the future, please contact:

Website: www.hiqa.ie

Email: healthdatasurvey@hiqa.ie

Postal address:

National Public Engagement Survey on Health Information
c/o HIQA
Unit 1301 City Gate
Mahon
Cork
T12 Y2XT

Phone number: 021 2409300

Principal investigator's name:

Rachel Flynn
Director of Health Information and Standards, HIQA
021 2409300

Consultant co-investigator's name (1):

Niall Sinnott
Head of eHealth & Information Policy, Department of Health

Consultant co-investigator's name (2):

Fran Thompson
Chief Information Officer, HSE

Data Controller's/joint Controller's Identity:

Health Information and Quality Authority
021 2409300

Data Protection Officer:

Lydia Buckley
dpo@hiqa.ie