

Accessing and using diabetes health services: the 'Patient Experience' survey of people living with diabetes in Ireland

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You are being invited to take part in a research study conducted by Diabetes Ireland and carried out with the support of researchers from RCSI: University of Medicine and Health Sciences in Dublin. This is an online survey focusing on the experiences of people living with type 1 and type 2 diabetes and their carers regarding accessing diabetes health services in 2022 in Ireland. The survey aims to describe the current availability and accessibility of diabetes care for people with diabetes in Ireland, provided in primary and secondary care, and to check whether people living with diabetes avail of the services, recommended screening practices or clinical annual reviews.

Before you decide whether, or not, you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or GP (doctor). Take time to ask questions – don't feel rushed and don't feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You don't have to take part in this study. If you decide not to take part it won't affect your future medical care. You can change your mind about taking part in the study any time you like. Even if you start completing the survey, you can still opt out and not submit it. You don't have to give us a reason. If you do opt out, your data will not be included in the analysis; rest assured it won't affect the quality of treatment or care you get in the future.

Why is this study being done?

The study, which you are being invited to take part in, is taking place to find out what access to and use of diabetes health services by people living with diabetes in Ireland is like. The information obtained through this online survey will be important in helping healthcare planners and policy makers to highlight the gaps in Irish diabetes care and improve and plan for future services.

Who is organising and funding this study?

This study is being conducted by Diabetes Ireland, in conjunction with the Royal College of Surgeons University of Medicine and Health Sciences. Diabetes Ireland is the only national charity in Ireland focusing on diabetes. The funding for this study is coming from Diabetes Ireland, supported by members, donors and fundraising.

Why am I being asked to take part?

You are being asked to take part because you are one of the following:

- ✓ An adult person with Type 1 diabetes.
 - ✓ An adult person with Type 2 diabetes.
 - ✓ A parent/carer of a child/adolescent with diabetes.
- and
- ✓ You live and receive diabetes care in Ireland.
 - ✓ You are aged 18 or older.

The aim of this study is to explore the experience of access and use of diabetes services in secondary and primary care.

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

If you agree to take part in the survey, you will be asked to open the link provided here: <https://www.surveymonkey.com/r/HBDDR2F> and to answer the questions. Once you open the link with the survey, you will be asked to consent to take part in the study. If you agree, the survey will begin.

You can complete the survey at any convenient time, but the data collection will take place from the 16th of January 2023 to the 5th of February 2023.

If there are any technical problems and the link to the survey does not work on your internet browser, you can try another (Google Chrome, Mozilla Firefox, Internet Explorer) or try it on another computer. If you still have problems opening the link, you can try to complete the online survey on your mobile phone. As a last

resort, if technical issues occur and you are very motivated to take part in the survey, please either e-mail or call us please, and we will arrange for you to complete it in a different format. You can find our contact details at the bottom of this information sheet.

What are the benefits?

While there may not be any immediate direct benefit to you, the study will provide an opportunity to best describe your experience (both positive and negative) of access and use of diabetes healthcare services in Ireland. As the study's aim is to inform policymakers and key stakeholders on potential areas for improvements, your participation may contribute to improving the quality of diabetes care in the future. Diabetes Ireland will benefit from the study as it will be the first time ever in Ireland, that the gap in access to health services will be explored in a structured and not anecdotal way, and the report following the findings will allow Diabetes Ireland to understand gaps in the quality of diabetes care in Ireland and to inform the policy makers on necessary improvements.

What are the risks?

There are no risks, direct or indirect, to you from taking part in the study. The only 'discomfort' you may have may be related to a time demand to complete the survey, to read e-mail reminders possibly received, or to any potential technical issues.

Is the study confidential?

The information you provide will be anonymous and will be kept confidential. All information will be kept securely in line with best practices for data security, on password protected computers and servers, and no information enabling your identification will be collected (including IP address).

There are no personal identifiers (name, surname, address etc.) and if you prefer not to answer any question regarding sensitive personal data (i.e. about ethnic background, gender, you can choose the 'I do not want to answer this question' response). You may wish to complete some of the open questions, and if you do, the research team will make sure that these will maintain your anonymity. Once the data collection is finished, all individual anonymous responses will remain anonymised and analysed together with all other completed surveys. All demographic information will be removed from the database (i.e. if you provide your

healthcare provider or address in an open question), so your individual answers will be untraceable.

What will happen to the results of the research study?

Following the completion of the study, the results will be analysed in an aggregated form, and a report summarizing the findings, and a brief summary in plain language will be produced. The findings may also be used for publication in peer-reviewed scientific journal articles. The results of this study may be presented at national and international conferences. Should you wish to have a copy of a publication arising out of this study, please let us know and we will send it to you. Please remember, that these published results will not identify you in any way: your name will not be included in the report and any quotes from the interview will be pseudonymised.

Data Protection

Your personal data such as age, gender, county of living etc will be processed as a part of this research study, but you are not obliged to answer these questions. The data will be safe and confidential. Nobody, except the main co-investigator (Dr Kate Gajewska, Diabetes Ireland), will have access to your individual responses. Other team members will only have the access to aggregated results and in the form of a report. All electronic files will be encrypted and stored on the Diabetes Ireland password protected server unless this study (including publications) is finished, for a maximum of 7 years from the data collection.

If you wish to withdraw your consent and not complete the survey, you can do so anytime before the final submission, or just not submit your responses. Due to the anonymous character of the survey, we will not be able to track and find your individual responses. But if you change your mind while completing the survey, just do not submit it. Only completed questionnaires will be analysed.

Where can I get further information?

If you have any further questions about the study or if you want to opt out of the study, you can rest assured it won't affect the quality of treatment you get in the future. If you need any further information now or at any time in the future, please contact:

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