



The Cost of Living survey – November 2022 Information Sheet

Introduction

Before you decide to take the survey, please take the time to read the information below which will explain why we are conducting this research and what it involves.

The Cost of Living survey – November 2022

What is this research about?

The purpose of this research is to understand the financial impact of a cancer diagnosis on a person and their family/household.

Core Research will carry out a survey to understand the full extent of these impacts on current and past patients, survivors and families.

What is the purpose of this research?

The findings from this research will help the Irish Cancer Society to understand

- the financial challenges associated with a cancer diagnosis during treatment and in survivorship
- if and how the current cost of living crisis impacts people who have had a cancer diagnosis

What will the outcome of this research be?

Core Research will prepare a summary analysis of the findings, which will be anonymous and non-identifiable, and provide this to the Irish Cancer Society.

Your participation in this survey will help the Irish Cancer Society to understand the extent of the financial impacts related to a cancer diagnosis, treatment and survivorship. These findings will help the Irish Cancer Society to understand the challenges and identify the need for and prioritise solutions to reduce the financial impact of a cancer diagnosis. The Irish Cancer Society will develop a policy paper, use the information in fundraising and communications campaigns, which will be publicly available.

How will this research be conducted?

People are invited to respond to a series of questions about the costs of a cancer diagnosis.

On what basis will information to be collected and processed?

Information from the survey will be collected and processed on the basis of consent. You will be asked if you have understood the information provided to you about taking part in the survey, and if you consent to take part in the research.

What types of personal information will be participants be asked about?

If you agree to take part in the research, you will be invited to respond to questions on a number of topics, including but not limited to

- Details on cancer diagnosis and limited treatment information

- Medical and non-medical related expenditure
- Treatment related travel and accommodation
- Employment status, access to financial supports, loss of income, etc.
- Demographics questions: age, geographical location, gender and marital status, etc.
- Education level
- Personal experiences
- Information relating to your family composition
- Experience of costs of utilities, subsistence, etc.

You will **not be asked** to provide your name or contact information in order to participate in the survey or at any point in the survey.

The Online Survey

Who is invited to respond to the survey?

The online survey aims to reach people who have had a cancer diagnosis between 2012-2022.

You must be 18 or older to respond to the survey.

Do I have to participate in the survey?

Your participation in the survey is voluntary.

Can I withdraw from the survey before I submit my responses?

You can withdraw from the survey at any point before you press the “Next” button at the end of the survey, simply by closing the browser.

Can I withdraw from the survey after I submit my responses?

At any point before submitting your response by pressing the “Next” button at the end of the survey, you can withdraw from the survey simply by closing the browser. There will be no penalty to you for withdrawing consent.

You will not be asked for your name or contact details in order to participate in the survey. Given that you will not provide your name within the survey, you will no longer be able to withdraw from the survey once you have pressed the “Next” button at the end of the survey to submit your responses, as the information you have provided will be anonymous and non-identifiable.

You **do not have to** provide your name or contact information in order to participate in the survey.

What will happen if I take part in the online survey?

If you take part in the online survey, you will have shared your experience as a person who was diagnosed with cancer between 2012-2022. All survey responses will be analysed by Core Research and provided to the Irish Cancer Society in a summary analysis. Learning about your experience will help the Irish Cancer Society understand if policy recommendations need to be made to policy makers. The findings will also be used in Society campaigns.

How will my information from the online survey be used?

Core Research is the data controller and will process and store responses in order to analyse them.

Limited staff in Core Research will have access to the survey responses during the time they need to analyse it. All data arising from the online survey, including quotes from your submission, will be anonymised where relevant before it is shared with or published by the Irish Cancer Society in a

summary report. Core Research may produce internal research reports that include verbatim comments, but these will not be attributed to you.

Transferring data outside the EU

The survey is run through Confirmit software. For the purposes of this research, data is being transferred between Ireland and the software supplier, Confirmit, based in the UK. Such a transfer is being completed on the basis of an adequacy agreement for GDPR.

How will my privacy be respected?

The answers you give in the online survey **will not** be attributed to you and no personally identifiable data will be shared with the Irish Cancer Society. The findings from the survey will be grouped together (aggregated) before being communicated to the Irish Cancer Society, with no reference to your personal information.

Data protection

Core Research is the data controller. If you have any queries regarding the processing of your personal data in this research or to exercise your data protection rights. ***If you have any questions about this survey, or how your data is being used, please contact Sein.Healy@onecore.ie***

If you wish to raise a complaint with the Data Protection Commission regarding any of the processing under this research please contact them at www.dataprotection.ie

Core's Privacy Policy can be found [here](#).

Confirmit's GDPR memo can be found [here](#) and their privacy notice [here](#).

Who we are

Core Research are an independent research company based in Dublin, Ireland. You can learn more about Core Research at onecore.ie

The Irish Cancer Society was founded in 1963 and is a community of patients, survivors, volunteers, researchers, etc. Through our work we seek to support people affected by cancer, and bring their voice into policy discussions. You can learn more about the Irish Cancer Society at cancer.ie

If you have any questions or concerns about cancer or any other topics covered in this research you can call the Irish Cancer Society's Support line on 1800 200 700 or log on to www.cancer.ie