



# Informed Health Choice-Cancer (IHC-C) Programme

## Study information for the pilot randomised trial

Thank you for considering taking part in this study. Before you decide whether or not to take part, please take a moment to read through the following information carefully. It's important for you to understand why the research is being done and what it will involve for you.

## Who is organising the research?

The study is being conducted by Mengqi Li, a PhD researcher at the School of Nursing & Midwifery, University of Galway, under the supervision of Prof. Declan Devane and Dr Marie Tierney.

## What is the purpose of the study?

The Informed Health Choices-Cancer (IHC-C) programme is an online educational programme designed to help those impacted by cancer develop the skills and knowledge necessary to think critically about the reliability of health claims and make well-informed choices.

It was developed by this research team working together with current cancer patients, cancer survivors, caregivers, loved ones, oncologists, cancer nurses, cancer researchers, and educators. The development of the programme was supported by the Irish Cancer Society.

We want to find out if the programme is feasible and acceptable for use by people impacted by cancer.

## Why is this study important?

Many people now search online for cancer-related health information. While there are excellent resources available, studies show that some cancer information found online may be inaccurate or unclear. This can make it challenging for people to make well-informed decisions about their health care. Our educational programme aims to help people find and identify reliable cancer information to support their healthcare decisions.

## Why have I been invited to take part in this study?

You're being invited to consider taking part in this study because you have identified yourself as a person impacted by cancer.

## What does joining the study mean for me?

This study is completely online, allowing you to participate at times and places that work best for you. Here's what to expect:

- Getting Started





- Read this information sheet carefully.
- Sign a consent form if you wish to join.
- You'll be placed into one of two groups randomly (like flipping a coin):
  - o First group: Starts the programme right away,
  - Second group: Starts four weeks later (Which group you join is decided by chance, and we use this method to help us better understand if the programme works).

## During the Study

- Access and complete the online Informed Health Choices-Cancer programme.
- Follow the provided instructions at your own pace.
- The programme runs for four weeks.

#### – Surveys

- Complete a survey when you start.
- Complete a follow-up survey at the end of your four weeks.

Everything can be done from home or wherever you have internet access.

#### How much time will it take?

The programme has nine units, each taking about 40 minutes, so the whole programme will take around six hours. Once you start, you can go through the programme at your own speed, and you have up to four weeks to finish all the units.

### Are there reasons why I cannot take part?

You cannot take part if you:

- Are under the age of 18.
- Do not have access to the internet.
- Are not a person impacted by cancer (i.e., not a current patient, survivor, caregiver, or loved one of a person with cancer).
- Are a member of the Informed Health Choices-Cancer programme steering group.
- Are unable to read or communicate in English.

## What are the possible benefits of taking part?

- You will get free access to the Informed Health Choices-Cancer programme.
- You can help improve how people impacted by cancer think about whether health information is reliable and how they make decisions about their health.
- You will have the chance to share your experiences and help influence cancer research.

## What are the risks or disadvantages of taking part?

There is a small chance that some information might upset you; however, we consider this risk to be very small. If this happens, you can:

- Contact the research team at *ihccancer@universityofgalway.ie*,
- Reach out to the Irish Cancer Society for free advice or assistance in finding





support in your community at *supportline@irishcancer.ie* or by calling *1800 200 700*.

you can also stop taking part at any time, and there will be no problems if you choose to do so.

## Will my taking part in this study be kept confidential?

Yes, we will keep your information private. This means:

- $\sqrt{}$  Only approved researchers at University of Galway working on this project will see your information
- $\sqrt{}$  We store all data securely following data protection laws
- $\sqrt{}$  You can ask to see your data, or have it deleted any time before we start analysing it
- $\sqrt{}$  We may use the information for future research on the same topic, but only at University of Galway
- $\sqrt{}$  We will do everything possible to protect your privacy

However:

- $\sqrt{10}$  In very rare situations, we may be legally required to share certain information
- $\sqrt{1}$  If you have concerns about your data privacy, you can contact the University's Data Protection Officer at <u>dataprotection@universityofgalway.ie</u>

## What will happen to the results of the study?

The study results will be presented at conferences and reported in health journals. Your name will not be included in these publications.

## Can I stop taking part if I wish?

Yes. You do not have to take part if you don't want to. If you decide not to take part, or if you start with the study and then want to drop out, you are free to do so up until we analyse the data. It will not affect the care you receive from your medical team or the Irish Cancer Society now or in the future. It is entirely up to you whether you participate.

## How do I agree to take part in the study?

If you want to take part, you should read this information sheet carefully, and then fill out the online consent form by <u>clicking here</u>.

## Who should I contact if I'm concerned about the running of this study?

This study has been approved by University of Galway Research Ethics Committee. If you have concerns or complaints about how the study is being done, you can contact the research team at <u>ihccancer@universityofgalway.ie</u> or the Chairperson of the Research Ethics Committee of University of Galway at <u>ethics@universityofgalway.ie</u>.

#### **Further queries**





For questions or further information on the study, or if you have any concerns or complaints about any aspect of this study, please contact the research team. You may contact the team at <u>ihccancer@universityofgalway.ie</u>.

\*\*Please note that all individuals who express an interest in participating in this study may not be included. This is because we want to involve a diverse group of people to ensure we are representing the views of all people impacted by cancer.

# Thank you so much for taking the time to consider this study. This information sheet is for you to keep.