Exploring the unmet needs of Irish cancer patients from underserved communities: The EuCan Project

Participant Information Leaflet

Site	Trinity College Dublin
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Study Organizer/ Sponsor	Irish Cancer Society
Data Controller	Trinity College Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2

You are invited to take part in a research study that is being undertaken by Dr Martin McMahon and colleagues at the Trinity Centre for Ageing and Intellectual Disability (TCAID), Trinity College Dublin (TCD). We are recruiting people who are over the age of 65 to take part in a discussion about access to cancer services and timely diagnosis, how enablers can be replicated and sustained, and how barriers can be overcome.

This information leaflet provides contextual information on the study and explains how the information participants share will be used. It also tells you who to contact if you require more information. It is important that you take time to read and understand why this research is being conducted and what will be asked of you should you agree to participate.

This leaflet has four main parts:

Part 1 – The Study
Part 2 – Data Protection
Part 3 – Costs, Funding and Approval
Part 4 – Further Information

Part 1 – The Study

What will the study involve?

If you want to participate, you will be asked to:

- Contact the research team.
- Sign a consent form.
- Participate in an individual interview, online or in person.

The interview will discuss barriers and enablers to timely cancer diagnostics access, what does and does not work well, and how barriers can be overcome, and enablers learned from and sustained. The interview will take about 60 minutes in total, including a break.

Why is this study being done?

This study will create evidence relating to the barriers to and enablers of timely diagnosis and access to cancer care for underserved communities. Socially excluded and underserved communities face additional challenges in accessing care that result in greater imbalances across cancer care. For those over 65, research documenting the barriers and potential enablers to increase timely access is missing. Therefore, a greater understanding of these issues as planned here will help identify new solutions.
We want to find evidence relating to the barriers to and enablers of timely access to cancer care for people over 65. We will report findings on models of good practice and what reasonable adjustments should be made for underserved communities to enable a timely cancer diagnosis will be reported.

Who is eligible to take part?

One of the study's objectives is to explore cancer service provision for underserved communities, specifically relating to any barriers and enablers of timely diagnosis and access to cancer care.

You are being asked to take part in an interview because you are over the age of 65 and currently have a cancer diagnosis or have had cancer in the past. This interview will aim to understand the main barriers and enablers associated with accessing diagnostic services.

Do I have to take part in this study?

Participation in this study is entirely voluntary. A decision not to take part will not have any adverse consequences. Once the study has started participants are free to withdraw consent and stop at any time without any consequences.

Part 2 - What will happen to my data?

The interview will be recorded, and notes taken. The audio recordings will be transcribed using a transcription service. We will remove identifying information from the transcription. This written transcription can be made available to you if you wish so.

All personal data and any information we obtain from this study will be completely confidential and known only to the research team. All personal data will be handled in agreement with GDPR regulations. Personal data will be password protected and securely held on the TCD IT system or locked in a filing

cabinet. Access will be restricted to members of the research team. Personal data will be stored separately from all other data.

Consent forms will be stored for 5 years following the end of the study. Personal data will be deleted at the end of the project.

Analysis of the results will be performed within TCD. As part of this project, we will publish the results from this study in a report for the Irish Cancer Society, in academic journals and present them at scientific conferences and meetings. No participants will be identifiable from any publications arising from the study.

Are there any benefits to taking part in this research?

We do not anticipate that taking part in this study will directly benefit you as an individual, but we envisage this study will improve cancer diagnosis services for members of underserved communities.

What are the possible disadvantages and risks of taking part in the study?

The research involves a time commitment, and while we will do all we can to make the interview comfortable, we do appreciate that we are asking for your time.

What information about me (personal data) will be used as part of this study?

Personal data to be collected in this study include name and contact details. This data is required to identify the participant and to make contact related to the study. We will also collect participants' age, as well as information recorded during the interview. This data is required to address the research questions of the study.

What will happen to my personal data if I participate?

Participation in this study is completely voluntary, and you can withdraw at any time. Once recording has begun, it will not be possible to remove your comments, although you will be offered the opportunity to correct errors in the transcript. Withdrawal from the study will not negatively impact you in any way.

All personal data we obtain from our study will be completely confidential and known only to the research team. These will be pseudonymized (i.e., personal data about participants will not be stored with any data collected from them). All personal data will be handled in accordance with the GDPR regulations.

Personal data will be password protected and securely held on the TCD IT services or locked in a filing cabinet.

Who will access and use my personal data?

- The PI (Dr Martin McMahon), the research fellow (Dr Louise Lynch) and research assistant (Ms. Shauna Walsh) will have access to the participant's personal data as part of this study.

Will personal data be kept confidential? How will the data be kept safe?

Participant privacy is important to us. We take many steps to make sure that we protect confidentiality and keep the data safe. Here are some examples of how we do this:

- All paper records will be kept in a locked filing cabinet in a locked office in TCD office.
- No names will be attached to any records. Forms with names (such as consent forms) will be kept separate from all other forms.
- All data will be stored on a secure IT server in TCD. All data will be deidentified. What this means is that anyone seeing this data could not link it to the participant. We do this by giving every participant a unique ID number. This ID number is attached to all our interviews but the link between the ID number and name and personal details (address etc.) is kept separate. This list is stored very securely and only the principal investigator, research fellow and research assistant will have access to it.
- We would also like permission to be able to share the data collected from you with other researchers, as a part of this project. The data shared would only be data collected from the participant, which is deidentified, not personal details. By providing permission for the data to be used by other researchers this helps to ensure that the data can be used in the best way possible to help advance research.

We will publish our findings in scientific journals as well as present our findings at national and international conferences. However, we only present conclusions from all the interviews, and it will not be possible to identify any individual in what we present or publish publicly.

A data protection impact assessment has been carried out for this project. All researchers involved in the project have completed training in GDPR and Research Integrity.

What is the lawful basis to use my personal data if I participate?

By law, we can use the participant's personal data for scientific research in the public interest. We will also ask for explicit consent to use the data as a requirement of the Irish Health Research Regulations.

What are my rights if I participant?

Participants have the following rights and entitlements:

- The right to access to their data and receive a copy of it.
- The right to restrict or object to processing of their data.
- The right to object to any further processing of the information we hold about you (except where it is de-identified).
- The right to have inaccurate information about you corrected or deleted.
- The right to receive their data in a portable format and to have it transferred to another data controller.
- The right to request deletion of their data.

By law you can exercise the above rights in relation to your personal data unless the request would make is impossible or very difficult to conduct the research. You can exercise these rights by contacting the research fellow, Dr Louise Lynch llynch1@tcd.ie or principal investigator Dr Martin McMahon martin.mcmahon@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Part - 3 Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by Trinity College Dublin Faculty of Health Sciences Research Ethics Committee. Approval was granted on 10th April 2024.

Who is funding and organizing this research?

This research is funded by the Irish Cancer Society.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying participants to take part in the study, nor will there be any fee for participation.

Part – 4 Further Information

Who should I contact for information?

If you have any concerns or questions, you can contact:

- Research Assistant: Ms Shauna Walsh, walshs89@tcd.ie, PH: 086 1966824.
- Principal Investigator: Dr Martin McMahon, martin.mcmahon@tcd.ie

Will I be contacted again?

If you decide to take part in this study, you will be asked to sign a consent form.

- If selected for this study a researcher from the study will contact you to arrange an interview.
- We will keep your personal data until the end of the project. However, if you agree we will keep your personal data for 5 years after the end of the project for future research/ projects related to this topic.

Thank you for taking the time to read this information booklet.

Exploring the unmet needs of Irish cancer patients from underserved communities, the EuCan Study

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