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

Participant Information Leaflet

For Healthcare Professionals

Site	**Trinity College Dublin**
Principal Investigator(s) and Co-Investigator(s)	**Dr Martin McMahon, Trinity College Dublin** **Dr Louise Lynch, Research Fellow** **Ms Shauna Walsh, Research Assistant** **Associate Professor Eilish Burke, Trinity College Dublin** **Professor Maeve Lowery, Trinity College Dublin** **Dr Alyson Mahar, Queens University Canada** **Professor Philip McCallion, Temple University, USA** **Professor Mary McCarron, Trinity College Dublin** **Ms. Laura Sweeney, St. James's Hospital, Dublin** **Professor Roman Romero-Ortuno, Trinity College Dublin** **Dr Catriona Ryan, Trinity College Dublin** **Dr Mark Ward, Trinity College Dublin** **Dr Andrew Wormald, Trinity College Dublin**
Study Organiser/ 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. We are recruiting health professionals from all disciplines who play a role in the early detection of cancer, and other cancer services, to participate in a focus group, to discuss how enablers can be replicated and sustained, and how barriers can be overcome, in terms of access to cancer services and timely diagnosis for patients with a physical or intellectual disability and/or who are over 65 years old.

The following provides contextual information on the study and explains how the data will be used and 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

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 access challenges that result in greater imbalances across cancer care. For some specific groups which include people with intellectual and physical disabilities and those over 65, research documenting the barriers and potential enablers to increase timely access is missing; a greater understanding of these issues as planned here will help identify new solutions.
We want to find out evidence relating to the barriers to and enablers of timely access to cancer care for people over 65 and those with physical and intellectual disabilities. Findings on models of good practice and what reasonable adjustments should be made for underserved communities to enable a timely diagnosis will be reported.

Who is eligible to take part?
One of the study's objectives (work package 3) 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 the focus group to investigate these barriers and enablers, what does and does not work well, the impact on health professionals including, but not limited to, occupational therapists, dentists and GPs, and how barriers can be overcome, enablers replicated and sustained.

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.

What will the study involve?
You will be asked to:

- Contact the research team
- Sign a consent form.
- Participate in a focus groups, online or in person.

You will take part in this study attending a focus group that will discuss barriers and enablers to timely diagnostics access, what does and does not work well, impact on health professionals, and how barriers can be overcome, enablers replicated and sustained. The focus group will take about 90 minutes in total, including breaks.

Part 2 - What will happen to my data?

The focus groups 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 the 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.
Data and 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 these studies 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, but we envisage this study will improve cancer diagnosis services for the 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 study focus group 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 profession, current role and opinions, as well as information recorded during focus groups. This data is required to address the research questions of the study.

What will happen to participants' personal data?
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 and research assistant 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 to all other forms.
- All data will be stored on a secure IT server in TCD. All data will be de-identified. 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 very securely stored and only the principal investigator, Research fellow and research assistant will have access to it. We would also like to gain 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 de-identified, 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 the participant's personal data?

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 the rights of the participant?

Participants are entitled to:

- 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 28th March 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. An electronic version can be accessed here: https://forms.office.com/e/M4AsdjW15Z

- 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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