

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

The Trinity Centre for Ageing and Intellectual Disability (TCAID)
School of Nursing and Midwifery

Steering Committee

Participant Information Leaflet – People with a Physical Disability

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 people with a physical disability to become members of a Steering Committee, to help shape a study to help shape the study on timely cancer diagnosis in underserved communities. We highly value diversity and seek members of underserved communities with lived experiences and experiences.

The EuCan Study and Steering Committee

The aim of the EuCan study is to 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 to diagnosis is absent; a greater understanding of these issues, as planned here will help identify new solutions.

This study will determine 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. This research is funded by the Irish Cancer Society.

The EuCan Steering Committee will participate and comment on the development of information leaflets, consent forms and on the reasonable adjustments necessary to fulfil the objectives of the study. The steering group will review study outputs to ensure they are accessible, and respectful, and meet the needs of underserved communities. The Steering group advise on and comment on the development of exemplars which represent good practice and what reasonable adjustments should be made for underserved communities. Members of the Steering group will be encouraged to engage in the dissemination of materials through their own networks to enhance the reach and impact of this study.

Members

The Steering Committee meetings will include individuals from various organisations that support and represent different underserved communities, along with members of the

research team, two people over the age of 65, two people with an intellectual disability and two people with a physical disability.

Roles/Responsibilities

The day-to-day management of the EuCan study is the responsibility of the Principal Investigator.

The responsibilities of the Steering Committee are to:

- 1) Participate in three steering group meetings.
- 2) Comment on the accessibility and appropriateness of information being presented to underserved communities to include information leaflets, consent forms and on the reasonable adjustments necessary to facilitate data collection.
- 3) Review study outputs to ensure they are accessible and respectful and meet the needs of the underserved community they represent.
- 4) Reflect and communicate the interests of people from underserved communities and utilise the relevant networks to ensure the research is disseminated adequately.
- 5) Support the research team where appropriate to co-develop exemplars of what good practice looks like to ensure it meets the needs of the represented underserved communities.

Meetings

Meetings will be held 3 times per year for approximately 1.5 hours virtually via Zoom. Where necessary we will use Zoom break out rooms to focus on specific underserved communities and maximise participation.

All meetings will be chaired by a member of the research team.

Meeting agenda and minutes, as well as any supporting papers and information, will be taken and provided by Ms Shauna Walsh or Dr Louise Lynch.

Members are encouraged to attend all meetings and will be consulted in the scheduling of meetings to facilitate their attendance.

Further Information

Who should I contact if I want to become a Steering Committee member?

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



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



Trinity Centre
for Ageing and
Intellectual Disability



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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This research is funded by the Irish Cancer Society



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