



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








Trinity Centre
for Ageing and
Intellectual Disability





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




Participant Information Leaflet

1. What is this study about?





	<p>Irish Cancer Society wants to learn about:</p> <ul style="list-style-type: none"> • What helps to access services and detect cancer in time. • What does not help to access services and detect cancer in time.
	<p>IDS-TILDA is a study in Ireland about the lives of people with intellectual disabilities.</p>
	<p>TILDA is a study about the lives of people over the age of 50 in Ireland.</p>
	<p>IDS-TILDA and TILDA found that people with physical disabilities, intellectual disabilities and over 65 years have more difficulties to be diagnosed with cancer and access cancer services.</p>
	<p>This study wants to find out what problems you have or had to access services and detect cancer in time.</p>

	<p>This study wants to find out what can help people to access services and detect cancer in time.</p>
	<p>We want you to take part in The EuCan Steering Committee.</p>






2. Who is responsible for The EuCan Steering committee?

 <p>Trinity College Dublin Coláiste na Tríonóide, Baile Átha Cliath The University of Dublin</p>  <p>Irish Cancer Society</p>	<p>The EuCan study is being done by the Trinity Centre for Ageing and Intellectual Disabilities team in Trinity College Dublin with other professionals who work in research and practice.</p> <p>Trinity is working in partnership with the Irish Cancer Society, who is paying for the study.</p>
	<p>Dr Martin McMahon is the Principal Investigator and responsible for the study.</p>

3. What will you be asked to do?

	<p>You will take part and comment on the materials and design to help us in the study.</p>
	<p>You will help us with ideas to make the study more accessible for underserved communities.</p>
	<p>You will help us making the study more meaningful for underserved communities.</p>
	<p>You will be encouraged to help us spreading the word on the results of this study.</p>



4. How many times are we meeting?

	<p>You will be asked to take part in three steering group meetings.</p>
	<p>You will act as a voice representing people from underserved communities.</p>
	<p>The meetings will be on Zoom.</p>
	<p>Each meeting will last for approximately 90 minutes on Zoom, with breaks.</p>
	<p>Members of the research team will also be in the meetings.</p>



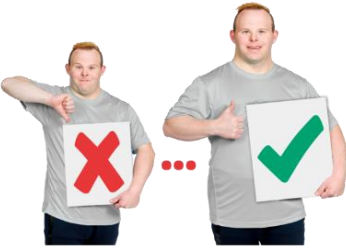





You will get a plan for the meeting before it happens.

5. Do I have to take part?

	<p>No. It is your choice to take part or not in the steering committee.</p> <p>You can also change your mind and stop taking part at any time.</p> <p>Your decision will not affect the supports you receive.</p>
	<p>You will be asked to sign a form to confirm:</p> <ol style="list-style-type: none">1. You agree to be a member of the Steering Committee.2. You agree with the contents of this information leaflet.3. You agree to keep shared information private.4. You have declared any potential conflict of interests.

6. What can I do if I take part in this study?

	<p>We do research in Trinity.</p>
 <p>Understand</p>	<p>We do it to understand things better.</p>
	<p>We do it to make things better.</p>
	<p>You can choose to take part.</p>
	<p>You can choose to say 'No' to the study.</p>
	<p>It is Ok to say 'No' to this study.</p>



If you take part in this study, we will ask you questions.



We will keep your name and contact details until the study is finished to talk to you.



If you agree we will keep your name and contact details for future research. We want to keep your details for 5 years after the study finishes.






You have a right to get a copy of any information that we have about you.





You have a right to fix any of your information so that it is correct.






You have a right to tell us to remove information we have about you until the reports are shared.

	<p>You have a right to stop us from using your information until the data and reports are released and printed by the researchers.</p>
	<p>You have a right to use any of the information we have about you.</p>
	<p>You can contact Dr Martin McMahon in Trinity College about any of these rights on Martin.mcmahon@tcd.ie.</p>

7. What do I do next?

	<p>Share this information with your family and others who support you.</p>
	<p>If you wish to take part, you should complete the expression of interest form.</p>

	<p>Return the expression of interest form in the envelope provided by <i>Insert deadline date for EOI-----</i></p>
	<p>After we receive your form, we will contact you to arrange a meeting and to get your consent.</p>
	<p>If you have any more questions about the study, you can contact Ms Shauna Walsh, Research Assistant for this study.</p> <p>Email: WALSHS89@TCD.IE Phone: 086 1966824</p>

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