Irish Cancer Society

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

Participant Information Leaflet

1. What is this study about?

	Irish Cancer Society wants to learn about: • What helps to access services and detect cancer in time. • What does not help to access services and detect cancer in time.
	IDS-TILDA is a study in Ireland about the lives of people with intellectual disabilities.
	TILDA is a study about the lives of people over the age of 50 in Ireland.
	The EuCan study wants to find out what can help people to access services and detect cancer in time.
	We want you to take part in the EuCan Study.

2. Who is responsible for the EuCan Study?

	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. Trinity is working in partnership with the Irish Cancer Society, who is paying for the study.
	Dr Martin McMahon is the Principal Investigator and is responsible for the study.

3. What will you be asked to do?

	You will be asked to take part in an interview.

	You will give your permission to take part in the interview.
	We will ask you some questions about your experience with cancer.
	You will ~~be encouraged to~~ help us help other people with cancer by taking part.

4. How will the interview be carried out?

	You will be asked to speak to us on the phone or in person.

	You will tell us about your experience with cancer.
	The interview will last for 60 minutes and be fully confidential.

5. Do I have to take part?

	No. It is **your choice** to take part or not in the interview. **You can change your mind and stop taking part at any time.** Your decision will not affect the supports you receive.
	You will be asked to sign a form to confirm: 1. You agree to take part in the interview. 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?

	We do research in Trinity.
	We do it to understand things better.
	We do it to make things better.
	You can choose to take part.

	You can choose to say 'No' to the study.
	It is ok to say 'No' to this study.
	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.
	You have **a right to stop us** from using your information until the data and reports are released and printed by the researchers.
	You have a right to use any of the information we have about you.
	You can contact Dr Martin McMahon in Trinity College about any of these rights on martin.mcmahon@tcd.ie.

7. What do I do next?

	If you wish to talk to other people, you can share this information you're your family and others who support you. ~~**Share this information** with your family and others who support you, if you wish to talk to other people.~~
	If you wish to take part, you should **complete the expression of interest form.**
	Return the expression of interest form in the envelope.
	After we receive your form, **we will contact you to arrange a meeting and to get your consent.**

	If you have any more **questions** about the study, you can contact Ms Shauna Walsh, Research Assistant for this study. **Email: WALSHS89@TCD.IE** **Phone: 086 1966824**

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