

**Participant Information Leaflet**

**Health Assets and Needs Assessment of the Tallaght Community**

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| **Study Title** | **Health Assets and Needs Assessment of the Tallaght Community (HANA)** |
| **Research Site** | Tallaght Community |
| **Principal Investigator (PI) and Co-Investigators (Study Team)** | Prof Catherine Darker (Project PI),  Prof Noel McCarthy,  Dr David Loughrey,  Kaye Stapleton (Research Assistant).  Study team are all from the Institute of Population Health, School of Medicine, Trinity College Dublin, |
| **Study Funders** | HSE and Adelaide Health Foundation |
| **Data Controller** | Trinity College Dublin |
| **Data Protection Officer (Research Data)** | Data Protection Officer  Secretary’s Office  Trinity College Dublin  Dublin 2 |

We would like to invite you to take part in a research study that is being carried out by the Institute of Population Health, School of Medicine, Trinity College Dublin. The study involves completing an interview in your home.  Before you decide whether or not you wish to take part, please take time to read this information leaflet carefully and discuss it with your family, friends or GP if you wish. If there is anything which is not clear, or if you would like more information, please ask the researchers. Don’t feel rushed or under pressure to participate or to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you.

**Do I have to take part?**

No, you don’t have to take part in this study. It is entirely voluntary and up to you. If you decide not to take part, it won’t affect your current or future medical care. You can change your mind and opt out at any time even if the study has started.

This leaflet has 5 parts:

*Part 1 - The Study*

*Part 2 - Data Protection*

*Part 3 - Approval, and Funding*

*Part 4 - Further Information*

*Part 5 – Next steps*

**Part 1 – The Study**

**Why have I been invited to take part in this study?**

You are being invited to take part in this study because you are living in the Tallaght area. We want to understand your health needs and your satisfaction with the health services provided in the Tallaght area. We are hoping that 420 households will take part in the study.

**Why is this study being done?**

We are doing this study to assess health needs in Tallaght. This will be compared with previous assessments which were carried out in 2001 and 2013.

**What does taking part in the study involve?**

Taking part in the study involves an interview with a researcher. We will be using a market research company, IPSOS, to complete these interviews. Each researcher will carry an identity card. The researcher will come to your home.  They will discuss the study with you and answer any questions that you have. They will ask you to sign a consent form which you will be given a copy of.

They will go through a series of interview questions with you. The interview will take between 45 minutes to one hour. We plan to conduct the interviews during the daytime and also between 6 pm and 9 pm each evening. If this time does not suit you, the researcher will arrange an alternative time to call.

We will ask you about the health of your household members and your satisfaction with the health services provided in the area. We also want to find out what other services you think are needed.

Please note that you do not have to answer any questions that you do not want to. If you become distressed or upset during the interview, you have the right to stop the interview without giving an explanation.

If you require support after the interview, we have also arranged for a Drop-in Counselling Services within Russell Building, Tallaght which can be contacted at 01-7957601. We would also recommend that you contact your GP. You can also contact the PI of the Project, Professor Catherine Darker, to discuss this.Email: catherine.darker@tcd.ie

**What are the potential benefits of taking part in this study?**

We hope that by taking part, you will have a say in creating better health care services for people in your local community. The main benefit is to help improve community health services for the Tallaght community. For example, since the last HANA survey in 2014, Tallaght University Hospital have new services looking after your memory, heart care, older persons' care, and they have more staff.

**Are there any possible disadvantages or risks from taking part?**

There are no known risks involved in this study. At all times, the well-being of participants takes priority over research activities.

Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.

**What will happen to the results of the study?**

The study results will be used to help plan health service in the Tallaght area. The results of the study will be reported in medical/scientific/educational journals and presented at medical/scientific conferences.

**Part 2 – Data Protection**

**What information about me (personal data) will be used for this study?**

We will need the following information about you: your household address to arrange an interview, demographics (age, gender, racial/ethnic background), other background questions (employment status, educational level, debt), health related factors and information relating to your family and your lifestyle and social circumstances.

IPSOS will collect your name and mobile number so that they can complete a quality check with you. However, please note that your name and contact number will not be shared to the TCD research team.

**Who will access my personal data?**

We will be using a market research company to conduct the interview. The market research company is called IPSOS. They will replace your household address with a code before uploading to a separate secure research database accessible to Trinity College Dublin.

**How is the information kept confidential and secure?**

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality. We have a contract in place with IPSOS to ensure the confidentiality of your personal information. IPSOS use servers to keep your data secure. These servers are located in Bulgaria (within the EU) and a back-up server is located in the UK.

**Limitations on Confidentiality:** Confidentiality may be breached in circumstances in which: The research team has a strong belief or evidence exists that there is a serious risk of harm or danger to either the participant or another individual.

**How long will my personal information used for this study be retained for?**

Your personal information will be retained for until the study is completed on 30th September 2024. After that period of time, we will break the link between your household and your interview. Two years after the completion of the study, we will delete any data that could be used to link the information back to you, thereby making the data anonymous.

We will archive the information after a period of seven years, in anonymous format.  It is considered ‘good scientific practice’ that research data is archived and made available for other researchers to use it at a later stage. We intend on archiving the data collected as a part of this research in a data archive so as that other researchers (both in Ireland and outside of Ireland) may use it in the future.

There is no way at this point that your data can be traced back to you in any way.

Your consent form will be retained for a period of 7 years and then deleted to protect privacy.

**What is the lawful (legal) basis to use my personal data?**

We will only use your personal information for this research project, which we hope will improve health services and assets and inform health policy in line with (Article 6(1)(e) and 9(2)(j) of the GDPR. We will also ask for your consent as a requirement of the Irish Health Research Regulations.

**What are my rights under Data Protection law?**

You are entitled to:

* object to our use of your personal data or any further use;
* request access to your personal data and to receive a copy of it;
* request inaccurate personal data be corrected or deleted;
* request restriction of our use of your personal data (if it is inaccurate);
* request deletion of your data.

By law you can exercise the above rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. For example, if the study results / information is about to be published then we may not be able to delete it. You can exercise these rights by contacting your study researcher Prof. Catherine Darker or the Trinity College Data Protection Officer, Secretary’s Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: [www.dataprotection.ie](http://www.dataprotection.ie/)

**Part 3 Approval, Organising and Funding**

**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 (REC). Approval was granted on April 4, 2024. An annual report will be provided to the REC and on completion of the study.

**Who is organising and funding this study?**

This study is being conducted by the research team in the Institute of Population Health, School of Medicine, Trinity College Dublin. IPSOS have been contracted to collect the data on behalf of the research team. This study is being funded by Adelaide Health Foundation, and the Health Service Executive (HSE). The Steering Committee for this research includes representatives from multiple external organisations - Adelaide Health Foundation, Health Service Executive, Community Health Organization 7 (HSE, CHO7), HSE Health Intelligence, South Dublin County Council, Tallaght University Hospital, General Practitioners and the Childhood Development Initiative. They will be provided with an anonymous report. They will not have access to your personal data.

**Is there any payment for taking part?**

No, we are not paying participants to take part in the study.

**Part 4 – Further Information**

**What happens if I change my mind?**

Your participation in this study is voluntary and you can change your mind even if the study has started up to the point when your information is anonymised as after this point, we will no longer be able to identify you. You do not have to give a reason for changing your mind. If you would like to withdraw from the study, please contact the Project Coordinator, Kaye Stapleton (kstaplet@tcd.ie) who can take you through the process outlined below and organise this for you.

Please note that we will not be able to remove personal data which has been shared or pooled for use in publication before your request for deletion.

**Who should I contact for information or concerns?**

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

Principal Investigator: Prof Catherine Darker. Email: catherine.darker@tcd.ie

If you have any questions in relation to your rights under data protection law, you can contact the Data Protection Officer, Secretary’s Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: [www.dataprotection.ie](http://www.dataprotection.ie/)

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to raise a concern with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: [www.dataprotection.ie](http://www.dataprotection.ie/)

**Part 5 - Next Steps**

If you would like to take part in this study, please contact [Ipsos contact details] who will arrange a mutually suitable date and time for the interview with you.

**Will I be contacted again?**

IPSOS will contact you in seven (7) days’ time, to give you time to consider your participation in the study, by calling to your door. If you are not in they will leave note to arrange a suitable date and time for the interview with you. If they do not hear back from you, they will contact you on one further occasion and if they do not hear from you after that, they will not contact you again.

*Thank you for taking the time to read this Participant Information Leaflet. You will be given a copy of this Leaflet and the signed Consent Form to keep. Please retain these in case they are needed for future reference.*