



The Role of PPI Contributor

What will participation entail?

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the research study is about and what your participation would involve, to enable you to make an informed choice as to whether you participate.

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Background

What is this project about?

The purpose of this study is to investigate individuals' preferences for community-based care for those living with neuro-physical disabilities through a dedicated survey. This project is part of a PhD in Health Economics, looking to examine the economic and social value of community-based healthcare organisations, like the Crann Centre.

The role and its purpose

We are looking for people to help us design the survey. We want to learn about your perspective on what is important about community-based care services, allowing us to determine the following:

- What should be included in the survey?
- How should the survey be delivered/presented?
- Who should fill out the survey?

We also hope to evaluate the PPI activities once the survey is complete.

Responsibilities:

- Attendance at and contributing to one meeting with other PPI contributors to discuss key elements of the survey design.
- Meeting will be approx. 2 hours long and will take place in March (location, date and time to be discussed).
- Once the initial survey is designed, contributors will be asked to take part in a one-to-one "Think-Aloud" online interview to refine the survey design.
- The lead researcher may contact you in between meetings to confirm meeting times or share additional materials.

What is PPI?



PPI stands for **Public and Patient Involvement**. PPI describes research done **'with' or 'by' members of the public**, rather than **'to', 'about', or 'for' them**.

It is a different approach to research where researchers and members of the public **work together** to plan and conduct research.

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- Anything discussed in the workshops/interviews will be kept confidential and all data protection guidelines will be adhered to.
- Once survey design is complete, contributors will be asked to take part in an online evaluation workshop to evaluate the PPI activities as part of the project (date and time to be discussed).

Person Specification:

We are looking to engage with:

- Any adult (18 years or older) living with a neuro-physical disability
- Any family member (adult, 18 years or older) of an individual living with a neuro-physical disability
- Experts in the provision of community-based care.

Experience engaging with a community-based healthcare organisation is preferable, but not necessary. No prior experience of participating in research is required.

Supports

The researchers conducting the workshop will fully describe the activities to take place at the beginning of each meeting. Any questions about the activities are very welcome. Additionally, at the end of this document, you will find links to UCC's PPI Ignite Network and other related PPI documents underpinning these research activities. Finally, any queries or concerns you may have about contributing to this project can be addressed to either Áine Gorman (PhD student and lead researcher) or Dr Aileen Murphy (Principal investigator and lead supervisor) (contact details listed below).

Duration of the Role

The role is expected to last approximately 6 months, starting in March 2025 and concluding in August 2025.

Acting as a PPI contributor on this project is completely voluntary! We do not anticipate any risks associated with involvement in this research project. However, if you wish to withdraw from contributing to the project, please discuss your intention to withdraw, through a phone call or an email, with either Áine Gorman or Dr Aileen Murphy (contact details listed below).

Recognition for Contributions

Unfortunately, financial reimbursement for contributing to this project will not be possible. However, all efforts will be made to acknowledge PPI contributions in a meaningful and appropriate way, for example, through acknowledgement in any academic and non-academic publications and reports, conference attendance and presentations.

Contact Details

If you have any additional queries, please contact:

1. Áine Gorman (PhD Student): Phone (086) 403 6505 or E-mail 115432892@umail.ucc.ie
2. Dr Aileen Murphy (Principal Investigator): Phone (021) 490 3489 or E-mail aileen.murphy@ucc.ie

Additionally, you can contact the project email address at DCEsurvey@ucc.ie

Additional Links

- UCC's PPI Ignite Network - <https://www.ucc.ie/en/ppi-ignite/>
- PPI Ignite Network Values and Principles - <https://ppinetwork.ie/wp-content/uploads/2023/01/PPIIgniteValuesPrinciplesFramework2022.pdf>
- HSE Patient and Public Involvement in Research Guidelines - <https://hseresearch.ie/patient-and-public-involvement-in-research/>
- Health Research Charities Ireland PPI Guidance - <https://hrci.ie/publications/patient-public-involvement/>