

PPIE members needed

for a study aiming to understand access to specialist psychology services in palliative and end-of-life care

We are seeking 3-4 people to join a Patient and Public Involvement and Engagement (PPIE) group to help develop a funding application

Are you living in the UK?

Do you have personal experience with palliative or end-of-life care services? You may be living with a life-limiting illness, bereaved or currently providing unpaid care for someone else living with a life-limiting illness



PPIF members will.

- Work with researchers Dr Lisa Graham-Wisener, Dr Tracey McConnell & Stephanie Crawford from Queen's University Belfast
- Collaborate with others who share similar experiences to ensure that the research is relevant
- Join 3 online meetings until mid December (dates and times will be arranged to suit you). If our application is successful, you will have the opportunity to support the project further
- Receive £25 per hour for meetings and preparatory/review work

What is the study?

Patients living with a life-limiting illness and their families are at a greater risk of psychological distress. Individuals need to be given timely access to psychological support to maintain a good quality of life. All patients should receive general emotional support from their healthcare team. However, people with the most complex needs may need additional support from trained mental health professionals. Access varies to specialist psychological services. Some patients and families receive timely specialist input, while others with similar needs do not. Currently, there is a lack of clarity on how specialist psychological services should be organised to improve access and generate meaningful outcomes. This research project aims to understand which approaches work best, for whom, and in what circumstances

What are specialist psychological services?



All patients living with a life limiting illness should receive general emotional support from their healthcare team. Although, those with the most complex needs should have access to specialist care from trained mental health professionals, usually practitioner psychologists (NICE Level 4 care)

What is research?

Research can mean lots of different things, but generally it means a process of finding things out by collecting information (data) to answer questions and provide new knowledge. For this project we are trying to understand how specialist psychological services in palliative and end-of-life care should be organised to improve access to psychological support

Who are we inviting to be involved?

As we are applying to a UK funder, we are inviting individuals living in either Northern Ireland, England, Scotland or Wales to join the group. Individuals must have personal experience with palliative and end-of-life care. This includes individuals living with a life-limiting illness, those who are bereaved and those who are currently providing unpaid care for someone else living with a life-limiting illness. As a research team, we want to ensure that our findings apply to everyone. Therefore, we invite individuals of all backgrounds and communities to be part of this PPIE group

What is a PPIE group?

A PPIE group is a group of individuals who have lived (i.e. personal) experience of the topic being researched. This group can make the research more relevant and ensure it addresses the things that matter to people. Lots of research is funded by public money, so people have a right to a say in how it is spent



What does the role involve?

The role involves joining a PPIE advisory group. The initial task will be to help develop a funding application which will be submitted in January 2026. If the application is successful there will be further opportunities to be involved with the study. In this role, your tasks will include commenting on research ideas, reviewing information for participants and draft documents and, ensuring that the research design reflects personal experience. You don't need any prior experience of being a PPIE representative as the research team will provide all necessary support. We appreciate that personal circumstances often change over time and understand that you may not be able to be involved for the entire duration of the project. If you need any adjustments or additional support, the research team will make every effort to provide them. You are also welcome to bring a supporter/advocate to assist you

What is the time committment?

It is anticipated that three online meetings will take place before mid December 2025. We'll meet with each member individually first to make sure you're comfortable with the online meeting setup and have any support you need. This will be followed by two small group meetings. Further long-term opportunities to be involved will become available should the research team be successful in the funding application

Who are the researchers doing the project?

The project is being led by Dr Lisa Graham-Wisener, Dr Tracey McConnell and Stephanie Crawford from Queen's University Belfast

If I get involved, what will you do with the information I give you?

Only people working with you on the project team will have access to your personal information (name etc). When we record or write about our discussions, these will be anonymous. This means that when we write things about people's involvement in the project we will not use people's names. Recordings and personal information such as your application form will be kept in a secure online folder at Queen's University Belfast

Interested in taking part?
Please contact Stephanie who will give you an application form and answer any questions you may have.



Email: s.crawford@qub.ac.uk