



PPIE members needed

for a study aiming to better identify and support individuals with life-limiting illness and caregivers experiencing loneliness or social isolation

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

Are you living in the UK?

Are you living with a life-limiting illness, bereaved or currently providing unpaid care for someone else living with a life-limiting illness?



PPIE members will:

- Work with researchers Dr Lisa Graham-Wisener, Dr Phoebe McKenna-Plumley and others 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 £27.50 per hour for meetings and preparatory/review work, and £5 per meeting in expense payments

What is the study?



Many people living with serious, life-limiting illness and their caregivers experience loneliness and/or social isolation. Loneliness is a personal, subjective feeling of being disconnected or unseen, which may or may not match the amount of contact someone has. Social isolation refers to having limited social contacts or opportunities for interaction. Although loneliness is increasingly recognised as important in palliative and end-of-life care, we still know surprisingly little about how it is experienced, how best to identify it, or what support works.

This project will lay the groundwork for a future UK-wide programme of research on loneliness and social isolation in palliative and end of life care. Working closely with patients, caregivers, clinicians, commissioners and researchers, we will: develop a clear, shared understanding of what loneliness means for people with life-limiting illness and caregivers; co-design and pre-test a new loneliness questionnaire tailored to palliative care; and agree, across England, Northern Ireland, Scotland and Wales, how screening and support could work in hospitals, hospices and community services.

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.



Who are we inviting to be involved?

As we are applying to UK funders, 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 does the role involve?

The role involves joining a PPIE advisory group. The initial task will be to help develop several funding applications which will be submitted by January 2027. If the applications are 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 commitment?

It is anticipated that three online meetings will take place before mid December 2026. 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 or individual meetings. Further long-term opportunities to be involved will become available should the research team be successful with the funding applications.

Who are the researchers doing the project?

The project is being led by Dr Lisa Graham-Wisener, Dr Phoebe McKenna-Plumley and colleagues 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). 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 Lisa who will give you an
application form and answer any questions
you may have.**



Email: l.graham-wisener@qub.ac.uk