Working with members of the public
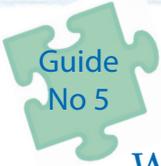
A guide for JIGSAW-E partners

What is PPIE?

PPIE stands for Patient and Public Involvement and Engagement. It is a way to keep the patient perspective at the heart of both research and implementation by learning from the patient's expertise of their condition

Patient Expertise

Remember, patients have the knowledge of living with their condition 24/7, which is something that none of the team have. It is important to listen to their opinions and take on board what they are saying as much as possible. This will help you to keep the project patient centred.

Working with patients and the public - good practice

1. Communication

- Please try to make sure all written materials are clear and in plain lay language. For example manypeople know that they go either to their doctor or to the hospital, they do not describe these as primary care or secondary care in the way researchers would. Perhaps use the word 'family doctor,' 'General Practitioner' or 'Practice Nurse.'
- Many terms commonly used within the health environment are not easily understood by the general public. e.g. acronyms.
- Working with patients and public is a different way of working, but a very rewarding one.
- When arranging meetings with RUG members please remember to allow in extra time for comfort breaks and be prepared to allow time at the end for any questions they may need answering.
- It is also good practice to give members at least two weeks notice before a meeting providing them with at least a week to read through any paperwork for the meeting, along with a contact name or number for anything they may need to ask about.

2. Regular Contact

- It is good practice to feedback at regular intervals to the members of the Patient Panel taking part in your project. This allows you to update them on what stage the project is now at even if there is nothing new to report. This keeps them involved and shows that you value their input within the project team.

Conducting meetings effectively

- Talk to members of your team to find out a little about the background of your Patient Panel members and their experiences of PPIE.
- Discuss whether it might be useful for them to have a pre meeting with yourself or another member of the team to discuss any parts of the agenda that they may like some help with.
- Identify areas within your agenda where a patient perspective could be brought to the discussion
- Ensure that someone will be there to welcome the Patient Panel members as they arrive and introduce them to the rest of the team if they have not met before
- Make sure that all relevant info has been sent out two weeks before the meeting to the PPIE members by post as well as by email.

Points to remember

- Members of the public are not used to professional debate and criticism and may need reassuring on where their input has been particularly valuable.
- Make sure that important contributions made by Patient Panel members are noted and correctly attributed in the minutes
- Patients may want to provide additional thoughts after a meeting, so make sure someone is available to enable them to do this either by telephone or email.

Managing the discussions

- At certain points within the meeting, summarise the discussions into plain language to ensure they are clear on what has been discussed.
- Recognise that patients bring a range of skills and experience to the meetings, so may be able to comment on issues other than PPIE.
- Treat Patient Panel members the same as you would any other member of the project team – be sensitive to those who are quiet, by trying to draw out their expertise but feel free to tactfully insist that the discussion moves on if it has drifted from this topic.

If you need any further advice or guidance on good PPIE practices please do contact the PPIE team at Keele

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