Involving public and patients in decision making

Top Tips for research leaders from public and patients who've done it.



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Well ahead of the meeting

Planning

These guidance sheets are designed for meeting leaders to get the best out of lay group member contributions for research. They have been produced by public and patients in light of their own experience inputting into r esearch.

Draw up information on the role of the lay person in the project/group/meeting, in the context of a wider role and provide this to lay people, researchers and others.



Enable some kind of early discussion in the following stages:



Provide lay people with a briefing, suggested reading or a paragraph explaining the background of what they will be involved in.



Follow this up with a chat, to give lay people an idea of the issues at stake and the focus of discussions to come. Ask them what they think about what they have learned so far of the issues and what priorities, interests and concerns they might have.



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Before the meeting

have a pre-meet to:



Discuss agenda items. Explain agenda items, ask lay people their opinions, so chair can have an idea of when and where to invite comment from them.



Provide a glossary of acronyms. List who is attending and what they do, with pictures if possible.



Ideally this should occur before each meeting, perhaps allow for a short pre-meet just before the meeting.



Chair to identify/consider a couple of issues/ questions to raise for patient perspective before the meeting and forewarn lay people. This does not preclude people from having a role in the meeting but may give them confidence to speak up.



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During the meeting

the Chair could:



Encourage lay people to speak and allow time for it in the agenda.

Make questions and comments from lay people a specific item on the agenda.



Take a "no question is too stupid" approach.



If people are finding it difficult to input as "how does that look from a lay person/ patient perspective?"



Encourage researchers and other attendees to recognise the value of lay people.

