



Patient and public involvement (PPI) in research groups

Guidance for Chairs

Version 1
February 2010

Foreword

As a doctor and researcher, I chair a number of research groups which include patients and members of the public. These PPI members can have a powerful impact on research – chairs play a vital role in enabling them to do this – but we need to know how best to work together effectively. This guidance, which aims to help chairs like me, is most welcome, timely and very useful. I commend it to you.

Ade Adebajo

Consultant Physician in Rheumatology

Honorary Senior Lecturer

University of Sheffield Medical School

Member of INVOLVE

Who this guidance is for

This guidance has been written to assist Chairs of research groups that include PPI members. It focuses on the aspects of chairing that PPI members have identified as being important. It does not aim to provide general advice on good chairing. However many of these suggestions are likely to benefit all group members – whatever their background – and will help groups to work together more effectively.

You are welcome to reproduce this guidance and to make amendments and additions, so that it is tailored to your group or organisation – provided you do not do this for commercial purposes. Please acknowledge the source as: “TwoCan Associates for the UKCRC and NCRI: Patient and public involvement (PPI) in research groups – Guidance for Chairs”

Evaluating this guidance

NCRI and NCRN would like to evaluate how useful this guidance is for members working in their research groups. Comments are welcome at: ppi@ncrn.org.uk. Please contact k.inns@ncrn.org.uk if you require any further information in the interim.

General principles

- Make sure you get to know your PPI members
- Make PPI members feel welcomed, included and respected
- Make clear to all research group members that PPI perspectives are valued
- Treat PPI members as equals – equivalent to other members of your group
- Ensure PPI members are given practical support so they can meaningfully and effectively contribute to meetings
- Help other group members understand the benefits of PPI and encourage them to give the PPI perspective due consideration.

Practical advice on chairing

Welcoming new PPI members

- Ensure you are well briefed about your PPI members - find out about their wider background as well as their experience as a patient.
- Make time to meet new PPI members.
- Ask every group member to produce a short, written biography and circulate to all members.

Preparing for meetings

- Identify points on the agenda that may be of particular interest to PPI members and be prepared to bring them into the discussion.
- Consider whether there are any sensitive areas of discussion and be prepared to handle them tactfully e.g. discussions about morbidity.
- Think about the PPI angle on all agenda items and try to ensure PPI is part of the whole discussion, not a separate, discrete issue.

At the beginning of a meeting

- Ensure someone welcomes new PPI members as they arrive. It is important that new people aren't left alone while everyone else networks.
- Ask everyone to introduce themselves to the group – explaining their area of expertise and the experience that they bring.
- Explain and clarify what the meeting is about, without assuming anyone has any prior knowledge.
- Ask all members to use plain English wherever possible and to avoid using jargon, abbreviations and acronyms.
- Ensure name plates and/or badges are provided at meetings – this is especially helpful in large groups.

During the meetings

Managing the discussions

- Ensure decision-making is transparent and that PPI members are included in the process.
- Encourage people to ask questions if they are unclear.
- Summarise the discussions in plain English.
- Show that you recognise that PPI members bring a range of skills and experience – ask them to comment on issues other than PPI.
- Don't be afraid to constructively challenge PPI members and ask about their views in depth. An honest discussion is a respectful discussion.

Managing the people

- If there are cliques within your group, try to give equal thought and attention to the outsiders.
- Consider the power issues for different people in the group and don't allow the more powerful voices dominate.
- Establish 'ground rules' for your group e.g. how long one person may speak for - and apply them to everyone.
- Try to avoid giving PPI members preferential treatment – feel free to tactfully & respectfully 'shut down' a PPI (see Box A).
- Try to be sensitive to the varying levels of confidence amongst your group members - make efforts to include PPI members who are quiet (see Box B).

Box A:

To stop people who talk too much:

- ❑ Request that remarks be confined to the topic of discussion.
- ❑ Let people know when the discussion has drifted from the topic.
- ❑ Tactfully but firmly insist that the discussion moves on for example by interrupting and saying “Thank you for your contribution. You’ve raised some interesting points. I’m going to stop you there for the moment so other people can comment on this issue.”

Box B:

To draw out the quiet people:

- ❑ Ask questions that are likely to tap into those people’s expertise.
- ❑ Praise their good ideas.
- ❑ Openly note their contributions and summarise what less active members have said.
- ❑ Call on those that are shy or junior early on in the meeting.
- ❑ Try to engage people who haven’t spoken by saying something like “I know you’ve got your hand up, John, but I’m going to take Mary first as she hasn’t spoken yet.”
- ❑ Give opportunities to everyone to put forward their point of view by asking questions like “Does anyone else have any thoughts on this issue?” or “Is there anyone who hasn’t spoken yet who would like to say something?”
- ❑ Go round everyone in turn to get their views on a topic – when the meeting is small.
- ❑ Help people who find it difficult to speak in public by summarising what you think they are trying to say and then checking that you’ve got it right.

Managing the practical arrangements

- It is often helpful to plan the seating arrangements so that PPI members are in a position to be noticed by the Chair – make sure they aren't always sat at the far end of the table, nor always right next to the Chair.
- Ensure there is time on the agenda to discuss any PPI items – avoid creating the impression that these are being 'tacked on' as an afterthought at the end of the meeting.
- It is often helpful to have a 'break at any time' policy – this may be important for people who experience fatigue or have problems concentrating.

After a meeting

- Make sure important contributions made by PPI members are noted and correctly attributed in the minutes.
- Consider asking for feedback on your chairing - check it was effective and that the decisions were clear and acceptable to everyone.
- Try to be available to answer any queries, and provide open lines of communication for people to provide additional thoughts by email or telephone.
- Provide feedback to PPI members as to where their input has been particularly valuable.

Where this guidance has come from

The development of this guidance was recommended following an evaluation of PPI in the UK Clinical Research Collaboration (UKCRC – www.ukcrc.org) in 2009.

The UKCRC, in collaboration with the National Cancer Research Network, commissioned TwoCan Associates (www.twocanassociates.co.uk) to carry out this work. This involved carrying out some background research and asking chairs and PPI members to share their experiences of chairing. An email was sent to a range of organisations, including INVOLVE, The National Institute for Health and Clinical Excellence (NICE), the UK Clinical Research Network and the National Institute for Health Research Central Commissioning Facility. Around 90 people responded. TwoCan ran a workshop with some of the respondents to reflect on the findings. A final draft of the guidance was produced with help of a small group of advisors and sent for comment to everyone who took part in the project.

Terms used

We use the term ‘patient and public involvement’ (PPI) to refer to the active involvement of patients and members of the public in research and related activities.

We use the term ‘PPI member’ to refer to patients, carers and members of the public who become members of research groups or committees.

We use the term ‘research group’ to refer to groups or committees at a local, regional, national or international level that provide some form of advice or decision-making about health or social care research.

Further reading

Further reading about chairing meetings

Helping people to contribute effectively during meetings. Meetings.org
www.meetings.org/meeting3.htm (accessed 27 July 2009)

How to chair a meeting effectively. Imperial College Union Skills Guide 2005-2006.
www.union.ic.ac.uk/resource/skills/chair.html (accessed 27 July 2009)

Chairing a meeting. The Resource Centre, Brighton. (Nov 2007).
www.resourcecentre.org.uk/information/committee_members/info_pdf/Chair.pdf
(accessed 27 July 2009)

The Health Consumers' Council. (2009) Effective consumer participation in meetings
– A guide for Chairs.

Further reading about PPI in research

For information and guidance about PPI in health and social care research, please visit the INVOLVE website, www.invo.org.uk

For further information on 'Good practice in PPI', particularly for supporting and training PPI members: www.invo.org.uk/pdfs/GoodPracticeA5d3%20230209.pdf.

Acknowledgements

We would like to thank all the PPI members and chairs who contributed to this project.

We would also like to thank the following organisations for their support:

- Health and Social Care Research and Development Office in Northern Ireland
- INVOLVE
- Involving People/Cynnwys Pobl
- James Lind Alliance
- Medicines and Healthcare products Regulatory Agency
- National Cancer Research Institute
- National Institute for Health and Clinical Excellence
- National Institute for Health Research Central Commissioning Facility
- National Institute for Health Research Clinical Research Network Coordinating Centre
- National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre