Public Involvement in Research:
Guidelines for Good Practice

Information for health and social care professionals, academics, service users / patients, carers and other members of the public

1 **Educate researchers about public* involvement in research**

2 **Consult the community before setting the research agenda**

3 **Build enough time into the project for meaningful public involvement**

4 **Involve people* in the project as early as possible**

5 **Be clear about what is required from people involved in the project**

6 **Provide on-going support for people involved in the project**

7 **Make sure that there is clear communication between everyone involved in the project**

8 **Make sure that all materials, namely, research documents, communications and outputs, are accessible.**

9 **Involve everyone in dissemination of the project results or findings**

* Public/people: may be service users / patients, carers or other members of the public

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This poster presents a set of nine guidelines concerning good practice in public involvement in health and social care research. The guidelines are stated briefly above, and in more detail on the accompanying poster.

These guidelines were developed collaboratively by professionals, academics and the public (service users / patients, carers and other members of the public) through a series of workshops hosted by the University of the West of England, Bristol. They are also available on-line at http://hls.uwe.ac.uk/suci/research.aspx

For more information about public involvement in research in the UK, you can consult INVOLVE http://www.invo.org.uk/

If you require these guidelines in a different format (eg large print, tape, Braille) please email Katherine.Pollard@uwe.ac.uk

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1 Educate researchers about public* involvement in research

- Introduce researchers to the 'involvement continuum' (from consultation to user-led research).
- Highlight the different roles that people* can play in a project.
- Raise awareness of relevant issues (including appropriate payment).
- Highlight potential ethical issues.
- Provide examples of successful public involvement in research.
- Run a joint workshop so that researchers and people involved can increase their mutual understanding of relevant issues.

2 Consult the community before setting the research agenda

- Create real opportunities for people to influence what is being researched.
- Go into the community/use existing networks to find the 'right' people* to consult.
- Use community contact, networks, etc., to reach 'hard-to-reach' groups (need to be aware of cultural and other sensibilities).
- Create a database of people with details of interest and availability.

3 Build enough time into the project for meaningful public involvement

- Take time to understand people's motivation for involvement, as this will encourage commitment.
- Adjust the pace and way of conducting the project where necessary/ possible to suit the people involved.

6 Provide on-going support for people involved in the project

- Have a named person at the centre of the project who will be accessible to people and sensitive to potential issues.
- Negotiate appropriate payment and expenses for people involved.
- Run a joint workshop so that researchers and people involved can increase their mutual understanding of relevant issues.
- Set up an Advisory Panel to have a 'watching brief' on the conduct of the project.
- Be aware of the need to make accommodation for different kinds of diversity.
- Identify the training needs of people involved in the project.
- Provide appropriate funded training opportunities/ mentorship.
- Give feedback on a regular basis to let people know that their contribution is valued.
- Ensure that all those involved are aware of what has been achieved in the project, and of any possible next steps.

4 Involve people in the project as early as possible

- Involve people right at the beginning of the project, or as soon as you possibly can.
- Ensure appropriate resources, eg access to email, websites, etc.
- Offer real opportunities for so-called "hard to reach" groups to get involved at an early stage (you need to be aware of cultural and other sensibilities).

5 Be clear about what is required from people involved in the project

- Draw up clear person specifications for people involved in the project.
- Define/negotiate people's roles, allowing for flexibility when appropriate/possible.
- Ensure that people know relevant details about the start, process and completion of their involvement in the project.
- Make sure that researchers and people involved jointly decide the terms of reference and membership of any Advisory Panel.
- Ensure and share clear processes for planning and design.
- Avoid the use of jargon and acronyms when explaining plans and processes.
- Explain that people may have to make an effort to learn some of the language of research.

7 Make sure that there is clear communication between everyone involved in the project

- Make sure that researchers and people involved work together to decide appropriate lines of communication for the project.
- Adjust communication methods to suit people's available resources, eg e-mail, phone, etc.
- Schedule regular meetings of all involved so that all can be updated on progress.

8 Make sure that all materials, namely, research documents, communications and outputs, are accessible.

- Avoid the use of jargon and acronyms but also educate those concerned to avoid any "dumbing down" effect.
- Ensure that the design of research materials suits people's needs, eg pictures, language, font, colours.
- Work with people involved in the project to ensure that the design of any outputs suits the needs of the community concerned.

9 Involve everyone in dissemination of the project results or findings

- Invite and support people involved to contribute to disseminating the project results/findings: presentations, writing of academic and other publications as co-author, design of project outputs, etc.
- Acknowledge people's involvement in any presentations/publications from the project.

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