

Public involvement on commissioning boards

Guidelines for commissioners

Introduction

This is one of a series of seven guidelines produced by INVOLVE providing information about public involvement in research commissioning. For a list of the guidelines available, see the back cover.

This guideline is written for commissioners interested in involving the public on commissioning boards. Other guidelines in this series are for members of the public and researchers.

If you would like to comment on anything included in this guideline or require further information, please get in touch with INVOLVE.

INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR). We aim to promote public involvement in NHS, public health and social care research.

We produce a range of publications, including all the guidelines in this series, which are free and can be ordered or downloaded from our website www.invo.org.uk. Please contact INVOLVE if you would like any of our publications sent to you - see the back cover for contact details. We also have a research database on our website, with examples of public involvement in research.

If you need a copy of this guideline in another format please contact us.

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1. What does public involvement in research mean?

When talking about 'the public' in this context INVOLVE means:

- patients and potential patients
- people who use health and social services
- informal (unpaid) carers
- parents/guardians
- disabled people
- members of the public who are potential recipients of health promotion programmes, public health programmes, and social service interventions
- groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos)
- organisations that represent people who use services.

Other organisations have different definitions of this term.

Involvement in research refers to **active** involvement between people who use services, carers and researchers, rather than the use of people as participants in research (or as research 'subjects'). Many people describe involvement as doing research **with** or **by** people who use services rather than **to**, **about** or **for** them [1, 2].

2. Why involve the public on commissioning boards?

INVOLVE believes that involving members of the public can lead to research that is:

- more relevant to people's needs and concerns
- more reliable
- more likely to be used.

Also if research reflects the needs and views of the public, it is more likely to produce results that can be used to improve health and social care services.

Members of the public can offer a valuable contribution on a commissioning board. This may include:

- knowledge and experience of a particular condition or service relevant to the research topic
- a public perspective
- experience of being a research participant
- identifying priority topics and important research questions
- helping to develop specifications for public involvement in research projects
- advice on the appropriateness of the public involvement proposed in research grant applications.

The National Forensic Mental Health Research and Development Programme is committed to the involvement of service users in all aspects of the research commissioning process. One of the reasons they give is that they believe users provide a fresh, interested look at the research and may bring new thoughts and ideas to the research process. www.nfmhp.org.uk/user.htm

Members of the public cannot be representative of everyone who uses a particular service, but they can offer their own perspective, and often that of other people.

3. How to identify members of the public to be on commissioning boards

This is not straightforward and requires time and adequate resources.

You may need to consider contacting and developing relationships with one or more of the following:

- voluntary organisations relevant to the research topic(s) under consideration
- organisations that represent or are controlled and run by people who use services
- individuals with a specific experience or from a particular group.

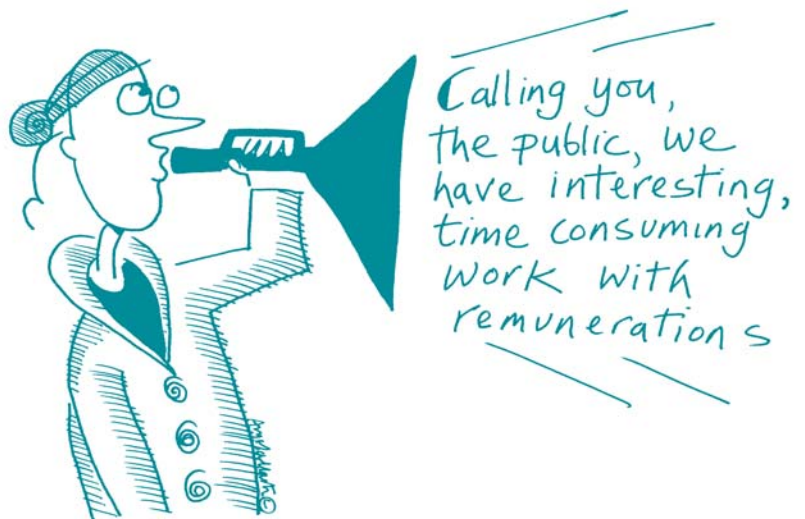
Some potential ways of finding people to get involved include:

- Asking colleagues with experience of public involvement.
- Via the internet which has a wide range of sites set up to provide support and information links for service users and carers [3].
- Making direct approaches to other organisations (relevant to the research topic), for example community groups, carer support groups, GP surgeries and pharmacies.
- Advertising - for example using local media, local businesses, consumer or community groups. See also INVOLVE's website notice board. www.invo.org.uk/Noticeboard.asp

“ We found our service users by a variety of means - word of mouth, by contacting relevant charities and organisations - sometimes people just contact you and it is hard to know how they found out about possible involvement. ”
(Research commissioner)

You will also have to think about the different sections of the public who could usefully contribute to a commissioning board. For example:

- older people
- young people
- black and minority ethnic groups
- people with learning difficulties
- people from different types of communities (for example rural or urban) or from different parts of the country [4].



4. Practical issues to consider

To support public involvement on commissioning boards the following are some practical issues to consider.

Time

It is important to recognise that achieving public involvement on commissioning boards may take additional time.

- Allow time to get to know people and organisations in order to understand the issues that are important to them and to talk through the process so members of the public understand what is needed.
- Think about the time, particularly if contacting organisations, as they may need to identify someone to be a member of a commissioning board.
- Explain the length of time that the member of the public will be asked to serve on the commissioning board.
- Explain the time commitment needed in being a member of a commissioning board. For example:
 - how often the group meets a year
 - how far in advance dates are set
 - how long the meetings last
 - the preparation time required before the meetings - this will depend on the number of proposals to be considered
 - the length of time allowed for discussion at meetings
 - the deadlines involved and how they will be explained.
- Allow more time at meetings, a slower pace can enable members of the public to participate more fully.
- You may need to think about changing the time of day that meetings are held to accommodate members of the public.

Clarity

It is important to explain your role as a commissioner, the role of the commissioning board and where it fits into the commissioning process. INVOLVE's definitions of these terms are:

Commissioner: the person (or organisation) who asks for a piece of research to be carried out.

Commissioning Board: a group of people who oversee the commissioning process. It is made up of research funders, researchers, health and/or social care professionals and often includes people who use services and carers.

Commissioning usually involves:

- identifying funding for a piece of research
 - preparing a research brief
 - advertising the research topic
 - selecting a shortlist of researchers who apply to undertake the research
 - arranging for proposals to be peer reviewed
 - making a decision about which researchers are going to be awarded the funding
 - agreeing a contract.
- Explain why you are asking members of the public or the organisation to be involved and the value of their input.

“ It is hard to say what difference my involvement has made. I think that just by being there and being labelled as ‘the consumer’ or ‘the lay member’ you can remind people what they are primarily there for - to benefit people who use the NHS - not to benefit anyone’s research career. I think I have been able to influence discussion (although I’m not sure I’ve influenced decision making). I have also tried to influence the way the programme as a whole tries to involve the public. ”
(Member of the public)

- Provide a description of the role and a person specification that includes the sort of skills, experience and expertise you are looking for so the member of the public knows what is expected of them.

The National Institute for Health Research Health Technology Assessment Programme has a job description for service user panel members which outlines the main duties and sets out the attributes and experience needed by a service user panel member:

- previous committee experience
- a willingness to familiarise yourself with medical/research language
- an understanding of what having a public perspective means
- good communication skills; ability to listen to others and express own views in discussion.

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“ Most often my participation is about being an outside eye who is able to ask the basic questions. They are not ‘simple’ questions. They are the core and point of research: But why are we doing this? What will it mean to patients? Will services change? ”
(Member of the public)

- Explain that members of the public may be asked to read more than one research proposal and that they are often lengthy and scientific.

- Be clear about the number of members of the public you will ask to join the commissioning board. Involving at least two members of the public means they can offer each other support and encouragement [5].
- Provide specific information on what you are asking members of the public to do and how the board is conducted. For example:
 - who chairs the meetings
 - how the chairperson is selected
 - role of the chair
 - whether members' views are noted and recorded
 - how the process of decision making works and whether members of the board will have an equal say in the decision
 - length and structure of meetings.
- Explain that the final decisions about which research to fund are not always clear cut and require a certain amount of discussion and even compromise.
- Provide details about the membership of the commissioning board, for example the relevant experience of other people on the board.
- Consider the language used at meetings. Chairs and other members of the board may need to be reminded to use plain language and not to use jargon. Members of the public should be encouraged to ask for explanations if they do not understand the jargon.

Support

The following are some ways that you might consider providing support.

- Providing an induction process or training for members of the public - see INVOLVE's training database. www.invo.org.uk/Database.asp

The National Forensic Mental Health Research and Development Programme has produced a 'User Involvement Induction Pack.' This gives information about its advisory committee and also answers to questions members of the public may ask if they are asked to become a member. www.nfmhp.org.uk/user.htm

- Providing training for the chairperson and other members of the commissioning board on public involvement.
- Developing good practice guidelines for conduct of meetings.
- Offering support e.g. a mentor or someone who is available to talk about any difficulties that may arise and how these can be tackled/rectified.

The National Institute for Health Research Health Technology Assessment Programme provides a help sheet for members of the public who sit on their advisory panels. The help sheet has tips on preparing for a panel meeting and attending a panel meeting.

The most common advice that experienced service user panel members would give to new service user panel members are:

- ask as many questions as possible
- have a few key questions
- be confident, prepare thoroughly and do not be scared to ask for clarification
- remember most of the other panel members only know about their field too so there is no need to feel intimidated
- it does get easier - familiarity with the panel meetings will make it easier for you to contribute.

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Accessibility

The following are some suggestions for ensuring that the information provided for members of the public is clear and accessible.

- Ask grant applicants to provide 'plain English' summaries of the research.



- Provide explanations of specialist or technical language that might be used at the meeting or in the meeting papers e.g. a glossary of terms and explanation of acronyms.
- Check with the member of public their accessibility needs e.g. whether they need the information in a special format in order that they can participate, for example a loop system, sign language, a translator.

- Consider the accessibility of the venue e.g. whether there is disabled access, whether there is a car park and whether it is on a public transport route.

Payment

It is important that the public know whether or not they will be paid for their involvement prior to becoming involved.

Guidance that has been agreed with the Department of Health for the National Institute for Health Research Programmes on payment to the public is as follows [6]:

For attendance at and preparation for a committee meeting (e.g. a commissioning board, advisory group or panel meeting) a daily rate of **£150.00** is offered **provided the person is not in receipt of a full time salary from public funds.**

If the member of the public works for a voluntary organisation you may be asked to reimburse their organisation for the time they spend at commissioning board meetings.

You should also offer to reimburse childcare and carer costs as well as travel and subsistence.



It is good practice to make payments easy and quick to claim. Payment to members of the public for public involvement in research is a complex issue. The potential impact payments may have on a person's Social Security benefits or tax position can be confusing. It is important that whether the claims are handled directly by the commissioning organisation or delegated to researchers or other bodies, members of the public involved are fully informed and know where to get further advice on this [7, 8, 9].

Feedback

It is good practice to provide feedback on the outcomes following the commissioning board meeting.

- Consider providing feedback to the members of the public on their input to the meeting.
- You may also find it helpful to have feedback from members of the public on their experience of being a member of a commissioning board. This may help identify areas where positive changes could be made to the process.

5. Key reference and text notes

All INVOLVE publications are available on our website www.invo.org.uk.

Key references

INVOLVE. (2003) Report of commissioning workshop. INVOLVE.

Hanley B et al. (2004) Involving the public in NHS, public health, and social care research: Briefing notes for researchers. (second edition) INVOLVE.

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The information for this guideline has also been drawn from the following:

- Hanley B for the Toronto Seminar Group. (2005) Research as empowerment? Report of a series of seminars organised by the Toronto Group. Seminar 2: Involving service users in peer review. Joseph Rowntree Foundation. www.jrf.org.uk - see Bookshop.
- Smith E, Ross F, Donovan S, Manthorpe G, Brearley S, Sitzia J, Beresford P. (2005) User involvement in the design and undertaking of nursing, midwifery and health visiting research. Nursing Research Unit, King's College London. www.kcl.ac.uk/schools/nursing/nru - see Research Reports.

Text notes

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2. SURGE (Service Users Research Group England) (2005) Guidance for good practice: service user involvement in the UK mental health research network, UK Mental Health Research Network www.mhrn.info - see Service User Involvement.
3. Internet sites try: www.patient.co.uk www.findsupport.co.uk www.self-help.org.uk
www.mywavelength.com www.ukselfhelp.info www.volresource.org.uk
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7. For more detailed information about payment and the impact it may have on benefits and taxation see Steel R. (2006) A guide to paying members of the public actively involved in research. INVOLVE.
8. Department of Health. (2006) Reward and Recognition: The principles and practice of service user payment and reimbursement in health and social care. A guide for service providers, service users and carers. Department of Health. www.dh.gov.uk - see Publications and Statistics.
9. Turner M and Beresford P. (2005) Contributing on equal terms: service user involvement and the benefits system. Social Care Institute for Excellence www.scie.org.uk - see SCIE's Resources and Publications.

6. Acknowledgements

This guideline is an INVOLVE publication written by Jane Royle and Maryrose Tarpey at the INVOLVE Support Unit. Special thanks to Sarah Buckland and to the members of the public, researchers and commissioners who helped in writing this guideline.

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The guidelines in this series are:

P1 Getting involved in research grant applications: Guidelines for members of the public

P2 Peer reviewing research proposals: Guidelines for members of the public

P3 Being a member of a commissioning board: Guidelines for members of the public

C1 Public involvement in research grant applications: Guidelines for commissioners

C2 Public involvement in peer reviewing research proposals: Guidelines for commissioners

C3 Public involvement on commissioning boards: Guidelines for commissioners

R1 Public involvement in research grant applications: Guidelines for researchers

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