

Public involvement in research grant applications

Guidelines for researchers

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 researchers interested in public involvement in research grant applications. Other guidelines in this series are for members of the public and commissioners.

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

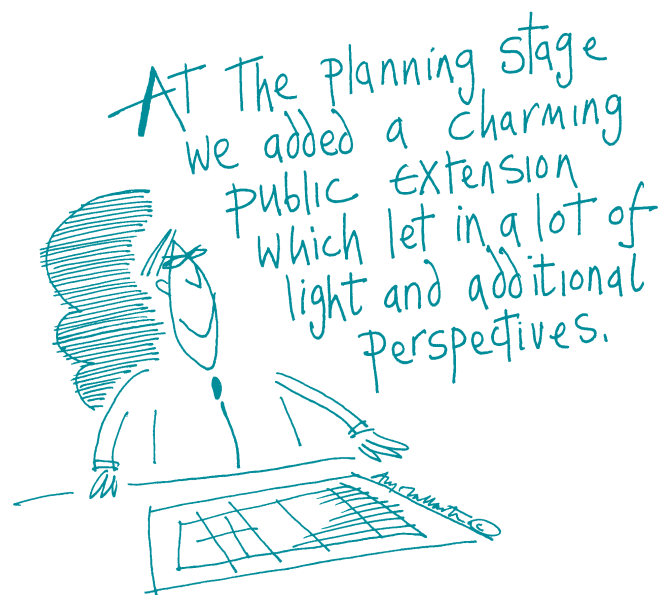
INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR). We aim to promote public involvement in NHS, public health and social care research.

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 in applying for research grants?

Increasingly, public involvement is a requirement of applying for research funding and used by commissioners as an indicator of the quality of a research application [3, 4]. It is based on the view that members of the public can bring:

- knowledge and experience of a particular condition or service relevant to the research topic
- a public perspective
- views about the best ways to involve other users and carers in research [5, 6, 7].

Members of the public can help to:

- improve the design and focus of the research
- advise on 'best practice' for public involvement throughout the research
- advise on ethical issues.

“ User involvement in the development of a research bid provides a key opportunity for shaping a project around the perspective of users, at a point where aims and methods may not be decided and so involvement can have most impact. ”
(Researcher)

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 get involved

This is not straightforward and requires time and adequate resources to do well. 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 [8].
- Making direct approaches to other organisations (relevant to the research topic), for example community groups, carer support groups, GP surgeries and pharmacies.

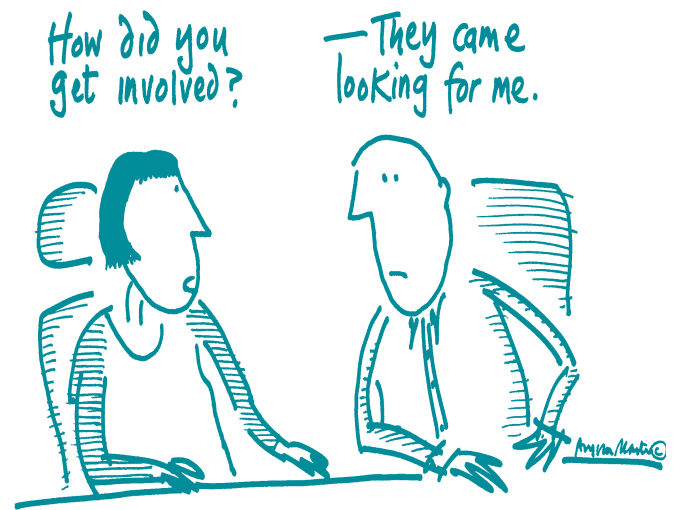
“ We found our service users by a variety of means - word of mouth, by contacting relevant charities and organisations - sometimes people just contact you and it is hard to know how they found out about possible involvement. ”
(Research commissioner)

- Advertising - for example using local media, local businesses, consumer or community groups in addition to the websites mentioned above. See also INVOLVE's website notice board. www.invo.org.uk/Noticeboard.asp

The Cancer Care Research Centre at Stirling University successfully advertised in local press and radio to recruit members of the public to get involved in their research projects. www.cancercare.stir.ac.uk

You will also have to think about the different sections of the public who might have an interest in being involved in a research grant application. 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 [9].



Lay people who choose, or are invited, to become actively involved in research may not directly represent others, any more than professionals can be said or required to represent other professionals. Indeed it could be argued that the influence of a variety of people with diverse views should lead to greater robustness in research planning and design [10].

4. Ways members of the public can get involved in a research grant application

Researchers involve the public in a variety of ways [11]. For example through:

Public consultation

Researchers may consult members of the public about ideas for their proposed research, for example through individual contacts, focus groups or public meetings. If the application is successful researchers may continue to consult members of the public. For example, by recruiting members to the research advisory group or by consulting them on other stages of the work such as research methods and/or analysis and dissemination of the research findings.

Research collaboration

Researchers may work in partnership with members of the public on the grant application. The researcher will usually remain the lead grant applicant. This can involve a significant amount of time and cost both for researchers and members of the public. It takes time to identify people willing to be involved and researchers should plan in plenty of time at the beginning of the application.

User-led or user-controlled research

Members of the public choose or are asked to be the lead grant applicant rather than the researcher [12]. This is often, though not always, through a community or voluntary organisation with public membership.

As with research collaboration, this approach may require more time than usually allowed for preparing a research grant application. It does not mean that researchers are excluded from the process, but in contrast to the other two approaches researchers tend to play a more advisory or supporting role.

User-led or user-controlled applications may also require additional resources from the potential commissioner of the research in terms of providing advice, support and training.

The Big Lottery Fund, for example, make research grants to organisations that are not run to make a profit and are community led. They will not make grants to individuals, statutory bodies (for example, local authorities or universities) or profit-making businesses. Research projects without user involvement will not be funded. www.biglotteryfund.org.uk

For further guidance on how to involve the public see Section 6 - key reference and text notes.

5. Practical issues to consider

Practical issues of time, clarity, accessibility, payment and feedback - all discussed below - are important to consider at all stages of research. However if not tackled at this early stage in the process it can make it more difficult to promote active public involvement later on in the research [13]. Ideally, there should always be at least two members of the public involved.

Time - short and long term

A serious barrier to public involvement in research grant applications is the fact that usually there is a very limited time to put an application in. With planning, this can be overcome, particularly over the longer term. Allow members of the public as much time as possible.

In the short term:

- Check that timescales for involvement in the application process are realistic. Allow time for making contact with organisations and then time for them to contact individuals. It usually takes longer than you think!
- Meaningful involvement in research applications requires planning and adequate resources, otherwise it is no more than a tick box activity. It is not appropriate to leave it to the last few days before a submission.

The Learning Difficulties Research Team found that: 'a lot of people had not really thought about involving people with learning difficulties as researchers. This needs to be thought through when a grant proposal is being developed, as it requires the right budget to make it happen. One researcher said she would now involve members of the public when putting a proposal together but also recognised that this demanded more time' [14].

For the long term:

- Invest time developing networks with user groups interested in the research topic/subject area prior to making an application. The effort required to build effective relationships with members of the public in support of a particular grant application, can be carried over into subsequent applications.
- Establish a procedure for public involvement. This may be lengthy at the beginning but will provide a framework for future public involvement in applications.
- Assess the support, mentoring and training needs of both your research team and members of the public potentially willing to get involved in this process. Consider approaching commissioners for funding to help meet these needs.

Clarity

In the detailed guidance on completing the application form commissioners are likely to request clarification on issues related to public involvement in the proposed research, such as who will be involved, how they will be involved and the underlying reasons for the public involvement.

- Consider the nature of the research - for example primary or secondary, small or large scale - and the implications this may have on the way members of the public can be involved in the application.
- Consider what level of public involvement you are proposing (for example, consultation, collaboration, user-led or user-controlled research).
- Consider the different perspectives of everyone involved in the process and the mutual respect this requires.
- Consider how this involvement will link in to the following stages of the research process if the application is successful, for example, by being part of the research advisory group or member of the research team [2]. This should also be documented in the grant application.

Information for members of the public:

- Provide a clear and unambiguous statement of the reasons for the research and an explanation of the grant application process.

- Explain why you are asking members of the public to be involved in the application and what skills and experience you are asking for.

“ I would have liked a proper job specification, really setting out what skills I would need. I could then have skilled up before I started. This is an important issue as so often users are employed just because they are users, with no thought given to the required abilities. ”

(Member of the public)

- Describe the opportunities for involvement. Explain whether members of the public can choose to be involved in all parts of the application or are being invited to concentrate on a particular aspect of the application.
- Provide a clear timetable of what needs to be done, when and by whom.

A study exploring the personal experiences of people involved in the TRUE (Training in Research for service Users: Evaluation) found that an initial course of action might be to ask all potential ‘involvers’ and ‘involvees’ why they want to embark on a project. Finding out the motives behind each stakeholder is vital to a frank exploration of why and how to start the project. Ideally, for a project to succeed, there should be some overlap in the motives across stakeholders; but, failing that, achieving some honesty about where each is coming from and an understanding about their different perspectives is vital [15].

- Provide practical information covering:
 - **personal opportunities** - for example, flexible working arrangements, role development, etc.
 - **decision making** - plans for drafting/rewriting the application
 - **management issues** - when differences of opinion occur how they will be handled
 - **information on payment** for involvement and support arrangements (see accessibility and payment below)
 - **ongoing involvement** - opportunities for continuing involvement in the research
 - **contact details** of the research team.

This information is sometimes provided in a format similar to a job description, but should not be too prescriptive.

Accessibility

It is important that the information provided to members of the public is clear and accessible. This includes both verbal explanations and written information.

- Explain in clear terms what the research grant application involves.
- If the funders have not provided a ‘plain English’ summary of the commissioning brief, consider

producing one. This should explain the use of abbreviations and specialist or technical terms used in the brief.

- Check with the people getting involved to establish what information they require to sufficiently understand the proposed research subject and how they would like to be briefed. Some may already have a detailed knowledge of the topic, others may not.
- Ask how best to meet people's specific accessibility needs. For example, people with visual impairments, learning difficulties, chronic illness, non-English speakers.
- Do not assume that everyone has easy access to a computer or the capability to print out long documents.
- When drafting and rewriting the application avoid acronyms and jargon and if necessary provide an explanation of specialist or technical language.

Payment

Given that this stage of the research is not usually funded there is a serious difficulty with payment for involvement in writing an application. That said:

- It is important to consider how you can pay members of the public willing to be involved in research grant applications. At a minimum, you should offer to reimburse travel and other expenses. It may be possible to approach research commissioners or other sources of funding such as Primary Care Research Networks for financial support to help promote public involvement in this stage of the research process. For example the Social Care Institute for Excellence (SCIE) provides funding to assist public involvement in writing applications.



- 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 you and those involved are informed and know how to get further information on this [16, 17, 18].

Feedback

- Whether or not the application is successful, share any feedback you receive with members of the public who became involved in the proposal. When sharing feedback from, for example, peer reviewers, be prepared to offer explanation and support.

- Whether or not the application is successful, explore ways to remain in contact for further applications. Develop other links with individuals and organisations representing service users who may be interested in applying for future research grants. It may be useful to let commissioners know that you have established these partnerships.
- If successful, ensure that the public involvement outlined in the research grant application is fully implemented and documented.

6. Key reference and text notes

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

Key reference

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

Text notes

1. 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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8. Internet site examples include: 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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18. 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.

7. Acknowledgements

This guideline is an INVOLVE publication written by Maryrose Tarpey and Jane Royle 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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