Public involvement in research grant applications

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 encouraging researchers to involve the public in research grant applications. 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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**VALUE**

In the picture, there is a handwritten note that says, "I have things to say of 7!"
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.

Public 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 the application process?

Increasingly public involvement is a requirement of applying for research funding and is used as an indicator of the quality of a research application [3, 4]. Commissioners are basing this 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 the ‘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)

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 promote public involvement in grant applications

Commissioners can play a key role in promoting public involvement in this stage of the research [8].

Some commissioners directly approach members of the public to get involved in applications, but more commonly, they delegate the responsibility of ensuring public involvement in grant applications to the researchers applying for funding [9].

“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)

Either approach - direct or delegated - aims to actively involve communities who might have an interest in the topic of the grant application, for example older people, young people, black and minority ethnic groups and people with learning difficulties. This is not a straightforward process and takes time and resources to do well. It involves contacting organisations that represent, or are controlled and run by, people who use services, as well as individual members of the public, who may or may not, be part of an organisation. Potential contact routes include internet websites, direct approaches to relevant service user organisations and other forms of advertising, and use of notice boards [10, 11].

4. Ways members of the public get involved in research grant applications

The public may get involved in a variety of ways [12]. For example through:

Public consultation

Members of the public are consulted for their views on proposed research, for example through
individual contacts, focus groups or public meetings. Commissioners usually delegate this form of consultation to researchers.

**Research collaboration**

Researchers 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 both for researchers and members of the public and may require deadlines for completed applications to be longer than the usual six to eight weeks. It takes time for researchers to identify people willing to be involved.

An evaluation of consumer involvement in the London Primary Care Studies Programme found that there are no easy answers as to how to carry out collaborative research smoothly and successfully. There are however a number of key issues that can help ... the two that stand out are adequate support and supervision, and appropriate training for everyone involved [13].

**User-led or user-controlled research**

Commissioners invite members of the public or are approached by members of the public who wish to be the lead grant applicant [14]. This is often, though not always, through a community or voluntary organisation with public membership.

A group of people with learning difficulties were commissioned by the Department of Health to research user involvement in 12 research projects. In their report they talk about being researchers, running the project, managing the money, making all the decisions and helping to bring about changes [15].

As with research collaboration, this approach may require a longer timescale than is customary for preparing a research grant application. Researchers are not necessarily excluded from the process altogether but if they are involved, they tend to play a more advisory or supporting role.

User-led or user-controlled applications may also require additional involvement from the potential commissioner of the research in terms of providing advice, support and training.
5. Practical issues to consider

Commissioners need to consider the ways in which they can encourage public involvement in research grant applications [2] and the following are some practical issues to consider.

**Time - short and long term**

It is important to recognise that achieving public involvement in research grant applications may take additional time.

- In the short-term - acknowledge the need for additional time by ensuring the deadlines for submission of research grant applications are realistic.

- For the longer-term - establish a procedure within the commissioning framework for public involvement throughout the research cycle including the early stages of agenda setting and applying for funding.

- Develop links between researchers and members of the public with a shared interest who may wish to apply for future research grants [8].

**Clarity**

It is important to be clear in the commissioning brief what public involvement is required in applying for the research grant.

- Provide information on whether public involvement is an essential or desirable criterion.

- Specify how the public involvement should be documented in the application. For example, ask for clarification on who will be involved (the organisation(s) or individual members of the public), how the public will be involved and the underlying reasons for their approach to public involvement.

SURGE (Service Users Research Group England) suggest the use of a simple check box inserted into the grant application form to record the type and level of public involvement used to develop the application. This box could also be used for other stages of the research if funded [2].
• Provide guidance to the commissioning board members and peer reviewers on how to assess and rate the public involvement elements of applications to ensure that involvement is not tokenistic. For example, you will need comments from them on the appropriateness of the public involvement proposed (both in terms of the people involved and the nature of the involvement), and the resources allocated to support those involved in the research.

Support

Acknowledge the need for support for everyone involved in the process and the value of building relationships.

• Nominate one person (plus a deputy) as a single point of contact for all queries regarding public involvement in research grant applications. List full contact details (name, phone and email) in the application pack.

• Consider meeting with short-listed applicants proposing public involvement to ensure that the proposed collaboration is appropriate and established.

Accessibility

It is important that the information provided about the grant application is clear and accessible. This includes both verbal briefings and written information.

• Members of the public should be consulted on the process, information and format of grant applications.

• Applicants should be required to produce a ‘plain English’ summary of the proposed research.

• Throughout the commissioning brief avoid acronyms and jargon and, if necessary, provide an explanation of specialist or technical language.

Payment

It is important that the public know whether or not they will be paid for their involvement prior to becoming involved.
Some research commissioners provide financial support to help promote public involvement in grant applications [16]. Commissioners need to recognise the time and resource implications for both researchers and members of the public interested in public involvement at this stage.

- Consider possible ways of making funding available to pay members of the public willing to be involved in a grant application. At a minimum, you should offer to reimburse travel and other expenses.

- Consider making extra funding available to pay for public involvement in research projects, including the grant application stage.

- Encourage grant applicants to build in adequate costs for public involvement.

- It is good practice to make payments easy and quick to claim, however 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 income tax 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 [17,18, 19].

Feedback

Whether or not the application is successful, it is good practice to give feedback to applicants including comment on the public involvement aspects of the proposal.

- Consider providing opportunities to applicants to revise and resubmit their original application and explore ways to encourage further applications.

Although the Big Lottery does not provide funding for this stage of the research, it has a policy of encouraging user-led grant applications. If not initially successful, the Big Lottery gives detailed feedback and may encourage applicants to rework and resubmit their application for further consideration. www.biglotteryfund.org.uk

- If successful, ensure that the public involvement outlined in the research grant application is fully implemented and documented. Consider mechanisms for monitoring the process.
6. Key references and text notes

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

Key references


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

Royle J, Steel R, Hanley B, Bradburn J. (2001) Getting involved in research: a guide for consumers. INVOLVE. (Note: this is being rewritten and will be replaced by an information pack in January 2007.)

Text notes


9. Commissioning examples of direct and delegated approaches to public involvement in research: www.qrd.alzheimers.org.uk www.nfmhp.org.uk
10. Internet site examples include: www.patient.co.uk  www.findsupport.co.uk

11. Local media, advertising, for an example of this use see: www.cancercare.stir.ac.uk
Information networks, for example see www.invo.org.uk/Noticeboard.asp

consumers. Consumers in NHS Research Support Unit, INVOLVE. (Note: this is being rewritten
and will be replaced by an information pack in January 2007.)

An evaluation of consumer involvement in the London Primary Care Studies Programme,
Peninsula Medical School, Universities of Exeter and Plymouth. Summary report available on
INVOLVE’s website.

Shaping Our Lives and the Centre for Citizen Participation, Brunel University. Full report and
summary report available on INVOLVE’s website.

15. The Learning Difficulties Research Team. (2006) Let me in - I’m a researcher! Getting involved

16. For example, the Social Care Institute for Excellence (SCIE) provides funding to assist public
involvement in writing applications. www.scie.org.uk

17. 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.

user payment and reimbursement in health and social care. A guide for service providers, service

19. 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

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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