



1. Introduction

This document is based on a series of good practice examples identified from the evaluation of BIG's Research Grants programme. It offers examples about what has worked for other research projects and is designed to help third sector organisations and their research partners with engaging users in the planning and delivery of research. Other good practice guides in this series address good practice in relation to partnership working and dissemination.

2. Definition of user involvement

BIG wants the people who will benefit from the research to have the fullest possible involvement in it*. In practice this can mean involving the users or beneficiaries of the research in the design, delivery and dissemination of the project and can include areas such as:

- ▶ Identifying the focus of research and research questions
- ▶ Commissioning research
- ▶ Undertaking the research
- ▶ Collating and analysing data
- ▶ Producing findings
- ▶ Developing and carrying out dissemination plans
- ▶ Deciding on and undertaking follow up action.

The evaluation of the Research Grants programme found that the term 'user involvement' has occasionally been misunderstood by some projects. User involvement should include opportunities for the meaningful involvement of service users and beneficiaries.

3. The benefits of user involvement

Some advantages and disadvantages to user involvement are detailed in the table below:

* 'Third Sector First (2007) Research' programme guidance notes. 'Designing and Managing Research', London, Big Lottery Fund

Advantages	Disadvantages
<ul style="list-style-type: none"> ▶ Involving beneficiaries empowers them ▶ People are given the opportunity to learn new skills and build confidence ▶ People are exposed to new experiences and opportunities ▶ Shapes research according to needs and views of beneficiaries ▶ Users can monitor progress of the research, address problems and provide useful feedback ▶ Helps projects to get better insights into their experiences – useful when the project team is considering the potential impacts of approaches and techniques on beneficiaries 	<ul style="list-style-type: none"> ▶ People may not wish to be involved ▶ Researchers have to adopt a different role – that of supporting rather than doing ▶ Expectations of beneficiaries may be raised only to lead to disappointment – for instance, if their views are not heard and actioned ▶ There may be conflict between what is expected by the 'research community' and that which is delivered by users – for instance, what is deemed 'scientifically respectable' ▶ A lot of time and commitment can be required to involve users

4. Approaches to involving users in research

Most research projects recognise the importance of involving users in research. However, some find it difficult to translate this from aspiration to practice. Users can lead and influence research in a variety of ways such as helping to identify relevant research topics, advising on suitable research strategies, commenting on the acceptability and relevance of particular methods and helping to shape the

dissemination approach. The evaluation found that many projects were keen to avoid tokenism and identified aspects of the research process where users could genuinely add value. Drawing on the findings from the evaluation of the Research Grants programme, the table below illustrates the main approaches to user involvement:

Intended outcome	User involvement approaches which tended to be most effective in achieving this outcome
Ensuring relevance to the client group (e.g. providing lay advice; helping select research projects to fund; identifying research priorities)	Including users in project advisory groups, reference groups, or steering groups.
Facilitating access to and engagement with the beneficiary group	Having designated ‘user experts’ that members of the research team can engage with to: <ul style="list-style-type: none"> ▶ Gain insights into the needs of the beneficiary population (to inform the design of the research in the first place) ▶ Provide access to that population for engagement purposes ▶ Gain understanding of how other beneficiary participants in the research might be feeling ▶ Drive the dissemination of findings
Enhancing legitimacy/credibility of the project	▶ Having users involved to a greater extent than simply as research participants brings a greater degree of relevance, and a more considered approach – whether this is through participation in groups/panels or just providing lay advice. This is felt to have a significant impact from an academic perspective because the project is more likely to stimulate interest than if it were purely academic-led.
Building capacity and skills	<ul style="list-style-type: none"> ▶ Involving users in research teams – e.g. as field staff, or in governance groups – has the potential to enable them to acquire new knowledge and skills, which may – and in many reported cases does – open up opportunities to further their interests via learning or work or leads to increases in confidence and self-esteem ▶ In particular, involving participants with disabilities or learning difficulties has been reported to bring these groups huge amounts of confidence.

Case study

An organisation working with visually impaired people from Black and Minority Ethnic groups invited four users to join its project steering group. The users provided a unique insight into the experiences of visually impaired people and helped to ensure that cultural issues were reflected in designing questionnaires and topic guide for the research.

5. Points to consider

- Be clear about the roles and responsibilities for user involvement in the project

It is important at the outset of any engagement with users to establish their roles and responsibilities. In particular clarify users' expectations about what they will be doing for the project and what can be achieved. Having this clarity should help to give users more confidence and will also help other contributors to the research understand where the users and beneficiaries fit in to the overall programme of research.

- Understand the resources and support that may be necessary to ensure that users can participate fully and effectively

Users participating in research sometimes need training and support to fulfil their role. Depending on the role, they may need training in interviewing, research, administration or communication. This training needs to be budgeted for appropriately in to your research proposal.

You should consider the other forms of support that may be necessary to help users get the most out of their experience, such as mentoring, coaching or supervision. Depending on the users that you are involving, you will need to consider any appropriate provision to help them engage and participate properly. For example, some people may need specific provisions for accessibility or technology which should be factored in to your budget.

It is important to think about financial support for users. Users, unlike academic researchers, are not salaried participants in the project and may find themselves out of pocket if they have to travel to attend meetings, or if they incur other costs. Consider the likely costs of user participation in the research and include it in your budget.

Projects should also consider any ethical implications from involving users and beneficiaries in the research. Further guidance is available on the Research Programme website at www.bigresearchprogramme.org.uk

Case study

A national drugs charity employed a former heroin addict to act as the point of liaison between drug users involved in the project and the academic research team. The individual was able to empathise and relate to the experiences of the research participants and gain their trust. The lead researcher for the project suggested that the involvement of this individual was a significant factor in the project's success. The user who was involved in the project has gone on to work as an academic.

6. Where can I find out more?

For further guidance about user involvement please visit the Research Programme website at: www.bigresearchprogramme.org.uk

The list below provides some additional sources of information about user involvement.

- ▶ Third Sector First (2007) Research programme guidance notes. Designing and Managing Research, London, Big Lottery Fund
- ▶ INVOLVE (www.invo.org.uk/) promotes public involvement in NHS, public health and social care research.
- ▶ The Toronto Group is an informal network of researchers with a particular interest in user involvement. The report on a series of seminars held in 2004 has been published by the Joseph Rowntree Foundation and can be read or downloaded from www.jrf.org.uk/knowledge/findings/socialcare/0175.asp
- ▶ The Alzheimer's Society run an award winning Quality Research in Dementia (www.qrd.alzheimers.org.uk/QRD_advisory_network.htm) programme, which is an active partnership between carers, people with dementia and the research community.
- ▶ The James Lind Alliance (www.lindalliance.org) promotes cooperative approaches to clinical research that combines the interests and views of patients with the expertise of clinical specialists.
- ▶ Peter Beresford, Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University, has written a paper entitled 'User Involvement in Research: Connecting lives, experience and theory' (www2.warwick.ac.uk/fac/soc/shss/mrc/userinvolvement/beresford/), which explores the methodological and practical issues raised by the idea of involving service users in research.
- ▶ The Leonard Cheshire Disabled People's Forum has produced a useful paper that outlines some of the main issues to consider when involving disabled service users in research (www.extra.rdg.ac.uk/equal/Methodology/Clare_Evans.pdf)
- ▶ Kemshall, H., and Littlechild, R., (2000), User Involvement and Participation in Social Care Research: Informing Practice. London: Jessica Kingsley.
- ▶ Social Research Association (2003) Ethical Guidelines, available at: www.the-sra.org.uk/documents/pdfs/ethics03.pdf