

INVOLVE



*National Institute for
Health Research*

Strategies for diversity and inclusion in public involvement:

Supplement to the
briefing notes for
researchers

Supporting public involvement
in NHS, public health and
social care research

About this supplement

This supplement provides ideas and information to support the involvement of a wide range of people in research and to identify ways to reach out to members of the public who do not often get involved in research. It is a specialist supplement to support the general information on how to involve members of the public in research which can be found in the **INVOLVE Briefing notes for researchers: public involvement in NHS, public health and social care research** and should be read alongside them www.involve.nihr.ac.uk/resource-centre/resource-for-researchers/

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- the INVOLVE Inclusion project advisory group – Ade Adebajo, Hugh McLaughlin and Patsy Staddon
- the Inclusion project consultation and review group – Eleni Chambers, Tina Cook, Jo Ellins, Ranjan Jesrani, Graham Price, Angela Rogers, Angela Sweeney and Lois Thomas
- Fran Branfield who provided expert advice during the development of this supplement and accompanying background paper.

We would like to thank them for their insights, expertise and comments throughout the development of this publication.

Terms used

INVOLVE defines public involvement in research as research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

When using the term ‘public’ we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

The term ‘service user’ has been used when it reflects the way people describe themselves.

Other terms used in this supplement are **‘diversity’** – respecting and valuing all forms of difference in individuals, and **‘inclusion’** – positively striving to meet the needs of different people.

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INVOLVE, Eastleigh

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Introduction

It is important that the full range of people affected by health and social care research have opportunities to get actively involved in and influence research. Including people and groups who may feel they do not often have these opportunities – sometimes referred to as marginalised or seldom-heard – or people who feel overlooked or ignored by mainstream society. A more detailed discussion paper on these issues and the barriers to involvement can be found in Diversity and inclusion: what's it about and why is it important for public involvement in research? (INVOLVE 2012). www.involve.nihr.ac.uk/posttypepublication/diversity-and-inclusion-what's-it-about-and-why-is-it-important-for-public-involvement-in-research/

Diversity is not only important when the topic being researched is specific to a particular marginalised group. It needs to be considered in all research studies to allow a broad range of perspectives to be taken into account and to promote equal access to opportunities for public involvement.

This supplement is divided into the following sections:

- 1. How inclusive is your involvement?**
- 2. Laying the foundations for diverse involvement**
- 3. Ways of doing diverse involvement**
- 4. Budget and payment considerations**
- 5. Carrying out an access audit**
- 6. Accessible written materials and papers**
- 7. Hints and tips for involving different people and groups of people.**

1. How inclusive is your involvement?

Public involvement in research is a learning process and it might not be possible to carry out all of the following activities in every project, particularly if you are new to public involvement. Consider what will work best for your study and what you can adequately support and resource.

The following questions have been designed to help you think through some of the issues when involving a wide range of people in research. They link to relevant sections in the supplement.

- Have you considered how best to ensure that there is equal opportunity for a wide range of relevant people and groups to get involved in your research? (See section 2)
- What ground work do you need to do to develop relationships, build trust and develop shared learning about different cultures? (See section 2)
- Would providing training in equalities, diversity, disability or cultural issues be helpful for all research team members? (See section 2)
- Have you talked with the people you plan to involve to make sure that your plans are suitable for them? (See section 3)
- Have you budgeted for the resources needed to accommodate any specific requirements? (See section 4)
- Have the arrangements for payment of expenses and any fees for involvement been tailored to suit the people getting involved? (See section 4)
- Have you asked practical and appropriate questions about people's access requirements so you have accurate information? (See sections 5,6,7)

- Have you personally checked that any venues you may use are accessible to those you want to involve? (See section 5)
- Are the information and materials you intend to use in an accessible and culturally relevant form for those you want to involve? (See section 6)
- Have you allowed sufficient time for meaningful involvement of the relevant people? (See section 7)

2. Laying the foundations for diverse involvement

The Briefing notes for researchers (INVOLVE 2012) www.involve.nihr.ac.uk/resource-centre/resource-for-researchers/ provide an overview of who to involve in research and how to find people. In this section we highlight two issues that have been identified as particularly important for promoting diversity and inclusion.

Developing relationships and building trust

Feedback from members of the public and researchers, who have experience of involving seldom-heard people in research, has highlighted the importance of building a trusting relationship at the start of the process. Those who have spent time getting to know each other on an informal basis and learning about each other's cultures and practice have reported that this can start to challenge any misconceptions that both parties may hold and leads to a constructive working relationship.

Understanding and improving transitions of older people

The experience of a project team working with older people with dementia and older people from minority ethnic groups found the following steps enabled them to develop meaningful and trusting relationships. They also found that these measures supported recruitment to and participation in the research project:

- spending time with members of the community before getting underway with the research to try and understand them and their issues
- being honest about the research project, what's possible and what's not
- working with co-researchers from the community can help to foster links with the community, raise the visibility of the project, and support people's participation
- being clear about what you are going to do with the information gathered – communities who are often 'done to' by public services might be very wary (for good reason) about providing information about themselves.

For more information see case study one in the resource for researchers www.involve.nihr.ac.uk/resource-for-researchers-case-studies/ and article in the INVOLVE Summer 2011 newsletter www.involve.nihr.ac.uk/posttypenewsletter/summer-2011/

Learning about different cultures

If you are unfamiliar with the usual practices and cultures of the groups and people you want to involve in your research, it is vital to learn about them before you start.

This may involve:

- Finding out about people's existing social relationships, preferred activities, their specific needs and how you can meet them.

- Taking part in specific training to increase your awareness of relevant issues for the communities you want to involve, for example training in cultural competence or disability etiquette. Universities and NHS Trusts will have an equalities officer (or similar) who should be able to help you access training.

Likewise, for people not used to getting involved in research, the culture of the research community will be unfamiliar to them. You may be viewed as an elite, authority figure or remote from their own everyday lives. Going to meet people, telling them who you are and what you are doing and giving them an opportunity to ask questions and comment on your research and involvement plans will help them understand why you want to involve them and show that you are genuinely interested in their views.

Personal experience: A familiar location?

“As researchers we are all familiar with the university or college. I think it is really important to remember that other people, who could be local, might never have visited the site before. The actual setting might be very off putting and potentially intimidating for people. One way round this is to meet in the town in a venue that perhaps people are more familiar with.”

Fran Branfield

independent researcher,
consultant and service user

If the people or groups have not been actively involved in research before, developing a phased introduction to the idea of getting involved may be helpful. It will also help you to find out more about how people want to contribute. Some people may not be aware of the different ways they can actively contribute to a research project. Taking time to help people develop their awareness and understanding, being welcoming and making research a comfortable environment for people could help overcome any fears.

Patient panel at the Sheffield Bone Biomedical Research Unit

Researchers at the Bone Biomedical Research Unit in Sheffield feel that the first step to getting people from any background involved in research is to trigger their interest and to appeal to a wide cross section of the community. There is a need to go out and talk about research as much as possible. They gave a public lecture about their research activities which was well attended and the feedback from the audience was positive. Biomedical research can be complex but it is also interesting. Feedback from the patient panel now established at the Unit is that they find the work carried out there fascinating.

www.sheffieldclinicalresearch.org/for-patients-public/how-to-get-involved/the-lay-advisory-panel-for-bone-research/

Find out more

Briefing notes for researchers: public involvement in NHS, public health and social care research (INVOLVE 2012)

www.involve.nihr.ac.uk/resource-centre/resource-for-researchers/

Diversity and inclusion: what's it about and why is it important for public involvement in research? (INVOLVE 2012)

www.involve.nihr.ac.uk/resource-centre/publications-by-involve/

Case study one: Understanding and improving transitions of older people

www.involve.nihr.ac.uk/resource-for-researchers-case-studies/

INVOLVE Summer 2011 newsletter

www.involve.nihr.ac.uk/posttypenewsletter/summer-2011/

3. Ways of doing diverse involvement

To effectively involve a wider range of people, you may need to think carefully about the way you plan to involve them. Make sure that your plans suit their needs, abilities, interests and availability, rather than expect them to fit into the usual way of doing things or existing research structures.

Consider the following questions:

- What are the best ways to interest and get people engaged with your work?
- Can you ask them and involve them in thinking about this?
- Instead of the most obvious ways what other approaches would suit the people and groups you want to involve, for example remote / on-line methods or using creative exercises?
- Do people's preferred methods of communication suggest ways to involve them, for example developing approaches using pictures for people with learning disabilities or using talking mats for people with dementia? (See section 7)

Members of the public getting involved might value opportunities to come together as a peer group, away from formal project or organisational structures where professionals and the public are working together. Providing opportunities for this as well as formal involvement activities can help to overcome isolation and promote peer and mutual support enabling people to contribute more effectively.

Find out more

Case study seven: Connect Works

www.involve.nihr.ac.uk/resource-for-researchers-case-studies/

Count us in: Involving everyone in health and social care research, report of a service user workshop run by Shaping Our Lives for INVOLVE (INVOLVE 2010)

www.involve.nihr.ac.uk/resource-centre/publications-by-involve/

4. Budget and payment considerations

When planning to involve members of the public who may have particular requirements it is important that you have an adequate budget to support their involvement. Consider the following:

- Having a clear policy on what expenses you are able to cover and letting people know in advance.
- Additional resources to cover the costs of translators and other communication supports, for example palantypists (talk to text conversion), specific accommodation, carers or personal assistants, replacement carers, special transport or specialist equipment.
- Sensitive enquiries about access requirements and associated costs are important – it is vital to ensure public funds are used appropriately while recognising that some people may have higher than usual costs.
- Covering the cost of expenses in advance or directly this will be key to enabling some people to consider getting involved.

- Arranging access to specialist welfare benefits advice. This may be particularly important if you are involving people who are restricted in what they can earn, for example people receiving welfare benefits, asylum seekers and refugees.

Being flexible about methods of paying members of the public might also be necessary. However, it is important to note that any restrictions on the amount individuals receiving state benefits can earn will still apply whatever the method of payment. Any individuals receiving state benefits who are not sure of how the earning restrictions might affect them should be encouraged to seek advice before accepting payment. Consider:

- Paying people in cash or with cash alternatives, for example gift vouchers on the day. This will be helpful for people on low incomes but will be essential for people without bank accounts.
- Providing local and community organisations, that may have simple payment processes, with the budget to process the payments on your behalf.

Personal experience:

What expenses can be covered?

“Paying service users’ expenses can be a bit of a hot potato. Commonly used stipulations in expense policies such as ‘reasonable (standard class) expenses will be covered’ can be problematic for some service users. People who, for example, are frail or who have mobility impairments might not be able to travel in a busy train in standard class. Needing to stay in a hotel close to the venue, when other people might be able to travel the same distance that morning can equally be problematic for many service users for many different reasons. Having to justify one’s expenses can be very intrusive and negative.”

Fran Branfield
independent researcher,
consultant and service user

Find out more

Payment for involvement: A guide for making payments to members of the public actively involved in NHS, public health and social care research (INVOLVE 2010)

www.involve.nihr.ac.uk/resource-centre/publications-by-involve/

5. Carrying out an access audit

In this supplement, we provide practical advice on two key accessibility issues – carrying out an access audit for events (this section) and making written information accessible (see section 6).

If you hold a meeting or event it is a good idea to carry out an access audit. This not only makes sure that the venue you have chosen will meet your needs but, if you carry it out yourself, will also make sure you are familiar with getting to the venue and the available facilities. You will then be able to confidently answer any questions that people getting involved with your work may have and they will be reassured that you are involving them in an inclusive way. An access audit needs to consider venue location and venue layout / facilities.

Venue location

Things to think about include:

- how close is it to people’s home / local area?
- is it an environment they will be familiar with?
- how easy is it for them to travel there? Don’t assume people will have their own transport or feel confident on unfamiliar public transport routes. Consider for example:
 - what public transport routes are available?
 - is the train/bus/underground station accessible?

- are there low-floor buses?
- is there a taxi rank at the train station?
- what is the cost of the journey?
- is car parking available? and if so:
 - is there a cost for parking?
 - can parking be reserved in advance?
 - is there provision of large parking bays close to the venue?
- is the building easy to find?
- can you include a picture of the venue in the event information?

Venue layout and facilities

Things to look for at a venue include:

- building entrances – are they easy to find, what is access like, for example are there steps, ramps, doors, and is access open or restricted?
- routes around the building – are these well signed and obvious?
- greeting arrangements – will participants be welcomed and advised where to go?
- rooms to be used – are they large enough? Is there adequate lighting? Can the temperature be controlled? Is there a quiet room for those who may want to take some time out?
- location of accessible toilets – are they near your meeting rooms or in a different part of the building?
- availability of communication tools, such as induction loops for people with hearing impairments.

Personal experience: Finding out about people's access requirements

“People will know about their own access needs – so ask them. But it is important to ask questions of fact in neutral language, for example how will you travel to the venue? Do you have any dietary requirements? It is important to avoid asking for irrelevant information out of curiosity, for example how a person acquired a disability or what diagnostic label they may have been given. Try to avoid words and phrases which make some kind of judgement about how the disabled person or service user experiences their life regardless of the language they might themselves use. Words such as suffering and affliction are best avoided! Unless the information is required to support their requirements you do not need to know it.”

Fran Branfield

independent researcher,
consultant and service user

For a high profile event, you might want to arrange for an independent audit by a local company or consultant.

Access audit

The INVOLVE national conferences in 2008, 2010 and 2012 were held at the East Midlands Conference Centre, Nottingham. We commissioned an access audit of the venue from a local disability consultant. The audit was made available on the conference booking website so that delegates could find out more information about the venue before attending. The Conference Centre also found the audit helpful to understand how parts of the venue might pose problems for access for some people.

Find out more

Briefing notes for researchers: public involvement in NHS, public health and social care research (INVOLVE 2012)

Briefing note eight has information and things to consider when planning a meeting
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers/

Making events accessible (Social Care Institute for Excellence (SCIE))

A comprehensive online resource with information on accessibility for events, including planning, checking venues, invitations, catering, accommodation, travel and conduct at the event
www.scie.org.uk/publications/accessibleevents/index.asp

6. Accessible written materials and papers

Written materials and papers should be clear, using a friendly style and plain language.

Ask people with different needs which format they require materials in. The following information and resources will help you think through how to develop your materials.

- Specialist organisations can offer a wide range of formats to make information accessible. These include audio recordings, video, photostories, Braille, large print and different languages. See, for example, Inspired services – www.inspiredservices.org.uk
- Services to create alternative versions may also be available through your organisation or institution – check with the equalities office.
- Easy read versions may be required with pictures to aid understanding and short sentences. Further help and services to create these can be found at:
People First www.peoplefirstltd.com
CHANGE www.changepeople.org/

- Alternatives such as audio versions or DVD may be required for people who do not read English or for whom English is not their first language.
- Some people may prefer an informal meeting to go through written materials in advance of the formal meeting.
- People with visual impairments may use specialist software for accessing typed text for example, enlarging or converting to speech. You need to ensure documents are in the correct version for use with such software and have minimal formatting and graphic design.
- When working with people who do not understand English using translators to talk through the materials, rather than providing written translations, might be more effective.

Example questions to ask about format of printed materials

Do you require any of the following?

- Braille
- Standard print
- Audio
- Electronic
- Large print
(please circle required font size)
14 16 18 20
- Other – please say

Adapted from Shaping Our Lives
Suggested questions to ask participants before an event, available to download from www.shapingourlives.org.uk/accessibleevents.html

National Institute for Health Research (NIHR) Central Commissioning Facility

The NIHR Central Commissioning Facility manages a pool of members of the public who review research grant applications being considered for funding. The review process is conducted via an on-line information management system which requires physical input through a computer keyboard. Some reviewers are restricted through visual or physical impairments to meet this requirement and experience difficulty in typing their responses into the system. Therefore, the patient and public involvement team have met this need by developing solutions, such as providing printed copies of the information and, where appropriate, voice recorders for the reviewers to record their review. Increasingly, they are finding that reviewers are making use of technological solutions, such as voice operated software, for completing reviews.

Jean Cooper Moran, Senior Programme Manager, Patient and Public Involvement, NIHR Central Commissioning Facility
www.ccf.nihr.ac.uk/PPI/Pages/default.aspx

Find out more

The Social Care Institute for Excellence (SCIE) accessibility guidelines

– a comprehensive guide about producing information in an accessible way for people with a wide range of different requirements
www.scie.org.uk/publications/misc/accessguidelinespublications.asp

7. Hints and tips for involving different people and groups of people

In this section we provide a starting point for things to think about when involving different people and groups of people. However, there is variation and diversity within these groups too. A good guiding rule is **never assume, always ask**.

Personal experience: Same impairment; different strategies

“I think an important thing to remember when you are dealing with access issues for disabled people is that we are all different and manage our impairments differently, even if they are exactly the same. For example, I would never visit London without my guide dog. I have a colleague equally visually impaired who always leaves his guide dog behind. Some wheelchair users are happy to be lifted over a kerb, others are definitely not. Each person is individual and manages their impairment individually.”

Fran Branfield

independent researcher,
consultant and service user

Involving different age groups

Involving people from different age groups can require you to think through the needs of that particular group such as:

- obtaining parental / carer permission for young people, especially if the involvement takes them out of their usual activities, for example school/college, youth groups
- how best to involve working age adults who may have education, employment or family responsibilities
- careful timing of any activity for older people, for example when a bus pass can be used or during daylight hours. Many older people are also carers and may need a replacement carer for them to get involved.

For more information about involving young people see www.participationworks.org.uk/

Involving disabled people

Provide people with the opportunity to tell you about their individual support needs as these may vary even for people with the same impairment. Some disabled people will have a personal assistant so provision for them and meeting their costs will be required.

The following sections outline some of the support needs of people with impairments and contact details of organisations for further information.

Hearing impairment

Communication support for people with hearing impairments includes using microphones, hearing / induction loops, talk to text conversion (sometimes called palantype), sign language interpreters.

- Action on Hearing Loss (formerly The Royal National Institute for Deaf People) www.actiononhearingloss.org.uk has a helpful series of factsheets about working with different types of communication support.

Visual impairment

People with visual impairments may need written materials in a different format.

When using visual aids, for example PowerPoint presentations, make sure you read out or describe the visual materials to ensure access for anyone with a visual impairment.

- The Royal National Institute for Blind People www.rnib.org.uk has information about living with sight loss which explains the range of support people with visual impairments use to aid communication.

Mobility impairment

Ensure any involvement activities are suitable for people who may not be able to move around the room easily. Find out about individuals requirements, for example:

- some people with mobility impairments prefer steps with hand rails to ramps / slopes
- some wheel chairs require wider doorways and additional space in lifts and in meeting rooms.

Speech / communication impairment

There may be different causes for impairments of speech, language and literacy and this can result in a wide range of difficulties, for example:

- making the sounds needed to form words
- understanding spoken language
- selecting the right words to be understood
- having difficulty understanding written text.
- CONNECT www.ukconnect.org, a charity for people with communication difficulties, has developed ten top tips for communication www.ukconnect.org/toptips.aspx
- The Talking Mats Research and Development Centre at the University of Stirling www.talkingmats.com has developed a low tech communication framework involving sets of symbols designed to help people with communication difficulties to think about issues discussed with them, and provide them with a way to effectively express their opinions.

People with learning difficulties

Working with people and organisations who can facilitate and support people with learning difficulties to get involved in research has been a successful approach used by others. Think about and get advice on how best to involve people and provide the information in an accessible format such as audio, visual or easy read versions. For example, people with learning difficulties might benefit from having a meeting that is just for them rather than taking part in a mixed meeting, but it is always important to ask.

- CHANGE www.changepeople.org/ works for the human rights of all people with learning disabilities. They deliver training and produce accessible books, booklets, picture bank CD-ROM and individual pictures.

- People First www.peoplefirstltd.com is a good source of advice and information about working with people with learning difficulties.
- Let me in – I’m a researcher. Getting involved in research, Department of Health. A report on how to involve people with learning difficulties in research <http://tinyurl.com/phggsnd>
- Norah Fry Research Centre which aims to make a positive difference to the lives of disabled children, young people and adults – with a particular emphasis on issues for people with learning disabilities and their families www.bristol.ac.uk/sps/research/centres/norahfryresearch/

People with mental health problems

Public involvement in mental health research is well established and good sources of advice and support are available from a range of organisations, for example:

- Guidance for good practice: Service user involvement in the Mental Health Research Network www.crn.nihr.ac.uk/mentalhealth/resources/

Sexuality – Lesbian, Gay, Bisexual and Transgender (LGBT) people

People getting involved in your research might have different sexualities. If you are working with people from the LGBT communities, hold meetings in safe places at safe times – people from the LGBT communities (especially young people) don’t necessarily feel safe in the same places as straight people. There is a lot of diversity across the LGBT communities – preferences and cultural norms for gay men might be very different from those for lesbian women and transgender people.

- Stonewall www.stonewall.org.uk, a campaigning, lobbying, education and research charity working for equality and justice for lesbians, gay men and bisexual people.

Black and ethnic minority people

Find out in advance the cultural issues and social customs of the people you are working with, for example there might be cultural differences around body language, such as whether or not it is acceptable to shake hands or to look people in the eye. People from different ethnic groups may communicate orally in a particular language, but they may not read and write in it. Consider using interpreters, or putting translated versions of your written materials onto audio tape.

- The Race Equality Foundation www.raceequalityfoundation.org.uk promotes race equality in social support (what families and friends do for each other) and public services (what workers do with people who need support).
- Race for Health www.raceforhealth.org is a Department of Health-funded, NHS based programme to drive forward improvements in health for people from black and minority ethnic backgrounds.

People from different faith communities

A faith calendar can help you avoid weekly worship days and festivals for your events and meetings, for example www.interfaithcalendar.org/ Respect people’s convictions about food, dress, social etiquette and belief systems.

Further information:

INVOLVE (2012) Briefing notes for researchers: public involvement in NHS, public health and social care research www.involve.nihr.ac.uk/resource-centre/resource-for-researchers/

Other supplements to the INVOLVE Briefing notes for researchers available in this series are:

- Public involvement in clinical trials
- Public involvement in systematic reviews

www.involve.nihr.ac.uk/supplements-to-resource-for-researchers/

All INVOLVE publications are freely available to view or download from the INVOLVE website www.involve.nihr.ac.uk

For further information and resources on public involvement in research please visit the resource centre on the INVOLVE website (see www.involve.nihr.ac.uk/resource-centre)

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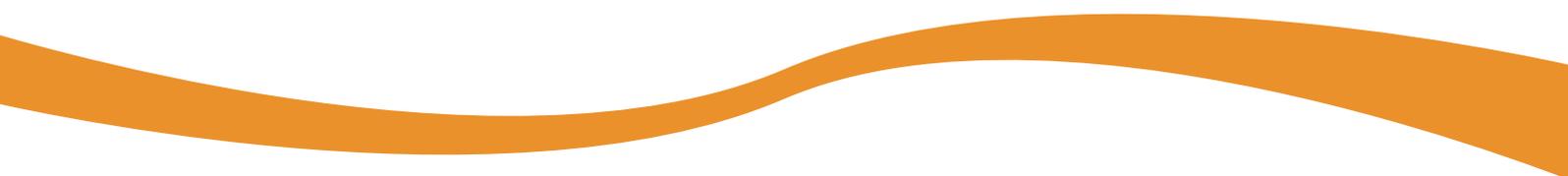
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Notes:



INVOLVE

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