
Diversity and inclusion:

What's it about and why is it important for public involvement in research?

This paper is about diversity and inclusion for active public involvement in research. In the paper we highlight why it is important to think about including the perspectives of a wide range of people and groups in research and the main barriers to involving them.

For ideas on how to involve a diverse range of people in research, please refer to the **Briefing notes for researchers** www.invo.org.uk/resource-centre/resource-for-researchers/ and the supplement **Strategies for diversity and inclusion in public involvement** www.invo.org.uk/posttypepublication/strategies-for-diversity-and-inclusion-in-public-involvement/

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1. What do we mean by the terms ‘diversity’ and ‘inclusion’?

When we talk about **diversity** we mean respecting and valuing all forms of difference in individuals. People differ in all sorts of ways which may not always be obvious or visible. These differences might include race and ethnicity, culture and belief, gender and sexuality, age and social status, ability and use of health and social care services. Below are some of the differences in the 61 million people who made up the UK population in 2007:

- 16% were aged over 61 years
- 90% were White British; in London this was 65%
- 19% had a long term illness or disability
- 77% identified with a religion (72% Christian, 3% Muslim, 1% Hindu and 1% other religions)
- an estimated 5-7% were lesbian, gay or bisexual

(Source: British Council www.britishcouncil.org)

It is recognised that some people and groups, because of a range of differences, find it more difficult to have their voice heard in mainstream society - their views, needs and perspectives may not be routinely taken into account, for example in planning services or undertaking research. **Inclusion** is about positively striving to meet the needs of different people and taking deliberate action to create environments where everyone feels respected and able to achieve their full potential.

A phrase often used in this context is **equality of opportunity**, meaning how we can ensure the full range of relevant people and groups have similar access to opportunities. This might be access to employment opportunities, access to services and civil society or, where our interest lies, in ensuring equal access to the opportunities to get involved in research. The **Equality Act 2010** includes certain duties to actively promote equality of opportunity for

some groups (see Appendix 1 for a summary of the Act). This legal framework applies mainly to public authorities, for example an NHS Trust or a university. So while it may not be necessary for research groups and those working on individual research projects to meet specific legal requirements about diversity and inclusion, it is still good practice to think about the issues raised, as highlighted by the Research Governance Framework (see below).

The **Research Governance Framework** (2nd edition, 2005) states:

‘Research, and those pursuing it, should respect the diversity of human society and conditions and the multicultural nature of society. Whenever relevant, it should take account of age, disability, gender, sexual orientation, race, culture and religion in its design, undertaking, and reporting. The body of research evidence available to policy makers should reflect the diversity of the population.’ (paragraph 2.2.7, page 8)

‘Research [should be] pursued with the active involvement of service users and carers including where appropriate, those from hard to reach groups such as the homeless.’ (Box B: Standards in quality organisations undertaking research: Ethics, page 16).

Available to download from the Department of Health website www.dh.gov.uk

2. Why is it important to think about diversity and inclusion for active public involvement in research?

The extent of public involvement in research has grown hugely over the past 15 years, with much greater levels of activity than ever before. However, while there is greater public involvement taking place, there is concern that the people getting involved with research do not always reflect the diversity of the population as described above.

As researchers and research organisations begin to actively involve people in research, we often find that those getting involved are the people who are the 'easiest' to involve. By this we mean people who are used to being involved, with an existing connection with the organisation, who are able to volunteer their time and energy, and who understand how organisations, such as research institutes, work.

While this is often a really good starting point – both for the researchers and the involved members of the public – we should recognise the limitations of this approach. It can mean that the same types of people, sometimes referred to as 'the usual suspects', have access to the opportunities to get involved, rather than a wider pool of people. We do not have detailed information on who is getting involved in research (yet!), but data from other arenas of public participation shows that those getting involved in public life are more likely to be older, from white ethnic groups and higher socio-economic backgrounds (Pathways through participation, 2009). While these people often develop useful skills and become experienced in active involvement, they come from a relatively narrow section of the population, and may have a limited range of experiences and perspectives to draw upon.

People who use NHS and social care services, or who are the target of public health initiatives, encompass a wide range of differences across

the population. It is well established that some parts of the population experience greater ill health, disability and reduced life expectancy than others (Black, 1980). Inequalities by ethnic group and gender, for example, can be demonstrated across a wide range of measures of health (Acheson, 1998). In 2010, the Marmot Review concluded that health inequalities are a result of social and economic inequalities across the population - 'put simply, the higher one's social position, the better one's health is likely to be' (Marmot 2010, page 10).

Example: Diabetes and South Asian and African Caribbean people

People from South Asian and African Caribbean communities are two to six times more likely to develop Type 2 Diabetes than the white European population – yet some of these communities rarely participate in research.

The National Institute for Health Research (NIHR) Diabetes Research Network attended the Baishakhi Mela (celebrating the Bangladeshi New Year) in the Brick Lane area of East London. Over 100,000 people attended from across London and the South East. Network staff offered blood glucose checks and ran a survey. The survey asked about people's awareness of diabetes, their attitudes to clinical research and any cultural or religious barriers to taking part in research.

Stewart D (editor) (2011) Making the Difference. Actively involving patients, carers and the public. Patient and Public Involvement The Way Forward: Examples and evidence from the Clinical Research Network. NIHR Clinical Research Network

Apparent exclusion or lack of diversity in those becoming actively involved is unlikely to be intended. It is more likely that it comes about through inexperience and unfamiliarity with the issues. But this creates a mismatch between those most affected by health and social care services and those opting to get involved to influence services and research. The risk is research will not benefit from the insights and experience of those most affected and who potentially have a lot to offer.

The challenge for many researchers and organisations is that meaningfully involving a diverse range of people in research means doing things differently. Positive action is required to attract people to get involved in research and then creativity and innovation is needed to ensure the involvement is accessible and appropriate to their needs. It is also likely that different people will bring views which challenge or even oppose the dominant orthodoxy. So not only do we have to be prepared for different ways of working, we also have to be prepared for alternative ways of thinking about the world.

3. Who are we talking about?

We have identified above that there are risks when people from diverse backgrounds do not have equal opportunities to get involved with research. But who are we talking about – who is it that we want to open up the involvement opportunities to? One starting point is to look at the nine equality strands of ‘protected characteristics’ identified in law: race, sex, sexual orientation, disability, religion or belief, being a transsexual person, having just had a baby or being pregnant, being married or in a civil partnership, and age (for summary of the Equality Act 2010 see Appendix 1).

However, these nine characteristics are limited in scope as they do not reflect the full range of diverse experiences and perspectives relevant to NHS, public health and social care research, for example prisoner health or experience of seeking asylum. In this paper we have decided not to attempt to list all the groups and people who may find it more difficult to have their voice heard. Primarily, this is because we think it is impossible to produce a comprehensive, exhaustive list that would be fully inclusive; any such list will always be partial and incomplete. Moreover, it is not necessarily up to us to identify who finds it more difficult to have their voice heard – it will depend upon people’s own perception of this which may vary across different areas and contexts.

Producing a list of types of people or groups can also perpetuate ideas which may be unhelpful when trying to promote positive thinking about diversity and inclusion.

Groupings and labels can:

- suggest sameness within groups, for example groups such as lesbian, gay, bisexual and transgender (LGBT) people include a wide range of differences with varying experiences and perspectives

- promote a simplistic view of individual people, for example service users have talked about how they have been ‘pigeon holed as being from one group or another’ rather than being seen as having more complex identities which inform their perspective (Branfield and Beresford, 2010; Begum, 2006)
- risk reinforcing stereotypical characteristics, for example the stereotype that older people are not very good working on computers, therefore older people will not be interested in getting involved in research if this involves using computers
- suggest that people in the different groups experience different barriers to involvement, whereas many have reported common and shared barriers (see section 4)
- risk the continuation of historic segregation faced by some groups, for example separate services for people with different disabilities or impairments
- suggest that different groups of people are competing for recognition, whereas the ideal position is to work across all groups to improve diverse involvement and inclusion
- risk a tokenistic approach to inclusion, for example an organisation invites a person from a black and ethnic minority community to get involved because they think they will be demonstrating diversity if their committee has a range of people on it.

Given this complex picture of experiences and identities, it is perhaps unsurprising that people have reported that their feelings of exclusion or marginalisation can often be amplified. For a discussion setting out how people can experience simultaneous discrimination which creates multiple barriers to involvement see Joseph Rowntree Foundation (2006).

So rather than thinking about the different groups and types of people to involve in research, it is more important to think about the particular perspectives to include in the research – as with any involvement, identifying the experience, perspective, skills and knowledge required is the best starting point.

But thinking carefully about the diversity of perspectives that will give added value and how to ensure all the relevant people have the opportunity to consider getting involved in the research is just as important.

Having done this, it may be necessary to tailor the plans for involvement to make sure they suit the people interested in getting involved (and don’t just suit the researchers and ‘the usual suspects’!).

Are people ‘hard to reach’?

As the section from the Research Governance Framework above indicated, a term sometimes used in the context of public involvement is ‘hard to reach’. However, use of this term has been challenged by some (Begum, 2006). The principle argument is that ‘hard to reach’ suggests the individuals who are not getting involved are at fault in some way, or the problem lies with them - they are distant, have removed themselves from places where they can be reached and are unwilling to get engaged with services or research. Rather, it is important to recognise that the difficulties more often lie with the organisations and agencies who want to involve people. Their approaches to involvement may not be reaching out effectively in a way that enables a broad range of people to find out about or feel positively welcomed to involvement.

It is worth thinking about the phrase ‘hard to reach’ from a member of the public’s point of view. They may feel that researchers and research organisations are ‘hard to reach’, in that they seem remote from the community and people’s everyday lives. For example, at INVOLVE we receive calls from members of the public who want to get involved with research and to make contact with researchers but don’t know where to start. People within the communities you are trying to involve are unlikely to identify themselves as ‘hard to reach’. For the people they have regular contact with, for example friends, neighbours and others within their own networks they are ‘easy to reach’.

Example: Service user researcher's contact with diverse groups

One service user researcher described how he made a list of 30 organisations of disabled people, survivors of mental health systems and groups of lesbian, gay, bisexual and transgender people in order to recruit 30 people to a study. He sent a letter to just one of these organisations and was overwhelmed with 72 responses!

Branfield and Beresford, 2010

At INVOLVE, we use the phrase **people and groups often overlooked or ignored by mainstream society** when talking about diversity and inclusion. The power to open up involvement opportunities most often lies with those already working in organisations, institutions and services, rather than with those outside them. Using language which signals (i) there is no blame for people not yet involved and (ii) research organisations have a responsibility to ensure all sections of the community have opportunities to become actively involved, is intended to positively influence how we think and act in relation to diversity and inclusion.

Who should be getting involved with research?

It is usual for the people and groups getting actively involved in research to have personal experiences which are directly relevant to the research being undertaken. (An exception to this is where a public perspective is required for issues around governance or accountability). In most cases, that means if you are concerned with research on an issue that is specific to a particular group, people from that group should be involved in that research.

Example: Deaf people's mental health pathways

This project came about following the Department of Health's Towards Equity and Access report on mental health and deafness. The project explored Deaf people's experiences of mental health services with a view to improving their pathways through services for the future. The organisation commissioned to undertake the research, Vision Sense employed two Deaf researchers to work on the project. Their role was to contribute to the design of the project and undertake the fieldwork and data analysis. The project team reported that this led to the study design taking account of Deaf people's culture and enabled direct access to the relevant community.

Faulkner A (2010) *Changing Our Worlds: examples of user-controlled research in action*, INVOLVE Eastleigh. This report and a short film about the project are available to download from www.invo.org.uk/find-out-more/user-controlled-research/

Thinking about diversity is important when undertaking research on any topic. It is always important to think about how the relevant range of people is able to influence the direction and nature of the research. For example, in a hypothetical study on access to and uptake of 'talking treatments' for depression, such as counselling or psychotherapies, it may be important to involve people with experience of depression who are not well represented in talking treatment services, such as men, older people and people from black and minority ethnic groups. Including their perspectives will help to design research which will better address questions around access and uptake.

In the examples below, researchers have taken positive action to actively involve people from groups often overlooked by mainstream society, not because the issue being examined is exclusive to these groups, but because of the diverse population affected by the issues being examined.

Example: Understanding and improving transitions of older people: a user and carer centred approach

This project focused on older people and their transition between different services and agencies in health and social care. It sought to investigate the information, advice and support needs at times of transition. The project team purposefully selected case studies to reflect the range of experiences including where transition is likely to be complex or not well understood. This included older people from a minority ethnic community and people with dementia.

www.invo.org.uk/posttyperesource/how-to-find-people-to-involve/case-study-one/

Example: Born in Bradford

Born in Bradford is a study of over 13,000 babies born at the Bradford Royal Infirmary since March 2007. The study is trying to find out why babies born in Bradford are more likely to die than babies born in other areas and to find ways to address this. Parents can get actively involved in the study through the Advocacy and Scrutiny Committee. As half the babies in the study have parents from Pakistan, the research team and members of Committee reflect this diversity. A Project Development Worker speaks Urdu and Punjabi as well as English so people who use these languages are able to get actively involved.

www.invo.org.uk/posttypenewsletter/autumn-2008/ and the project website www.borninbradford.nhs.uk

4. What are the common barriers to diversity and inclusion?

In this paper, we are thinking about the diversity of people and groups that make up our society and about ways to promote equal access to opportunities to get involved with research. As we identified earlier, although people have diverse backgrounds and experience diverse circumstances there are many common, overarching reasons why some groups and people find it more difficult to have their voices heard. These common reasons can create barriers, shared across groups and people, which reduce or prevent access to opportunities. Before we look at some of the barriers, it is useful to think about what we mean by **access**.

When we think about the term **accessibility** it usually brings to mind issues about access to a building for people with mobility or physical impairments. Other common ideas about accessibility relate to communication and ensuring we communicate in ways that are appropriate for people with different needs, for example translators, Braille and hearing loops. While accessibility includes these issues, a much wider range of considerations can inhibit access, including cultural and institutional practices, psychological and emotional barriers and financial constraints. Therefore, taken in this wider sense, accessibility is about providing people with equal opportunities to participate fully in whatever is being offered.

Cultural and institutional barriers

Members of the public may not be familiar with NHS and other services undertaking research and may not be aware that these organisations and the practitioners involved in their care are undertaking research. When we invite people to get actively involved in research, we are usually asking them to join in with this existing community - broadly the 'research community' - which has its own cultures and established practices. People new to involvement in

research are not likely to be familiar with the established practices and cultures, including the use of technical, specialist language and acronyms. These practices and cultures can be confusing and alienating to people unfamiliar with them and can directly inhibit their contributions. If we do not consciously de-mystify these cultures and processes for people and develop open and welcoming working practices, they may be reluctant to get involved (Branfield and Beresford, 2010).

Attitudes and beliefs

Whether conscious or unconscious, attitudes which underpin and influence our behaviour can have a strong effect on people. Attitudes can therefore be fundamentally empowering (enabling people's involvement) or disempowering (inhibiting people's involvement). Such attitudes can work in obvious or, frequently, in subtle ways.

The health and social care system in this country is underpinned predominantly by a biomedical approach, based on a biological understanding of the body and medical approaches to ill health, and as such, this influences not only the types of treatment available, but also ways of viewing health, ill health and disability. However, a range of other beliefs and models for understanding health and disability co-exist and may be held by people getting involved in research. Alternative models may align more closely with their world view and, from their perspective, may better explain their experiences. It is also worth remembering that people may hold to ideas and principles from a range of different models at the same time – using whatever approach is most helpful for them in given circumstances. When involving people it is important to acknowledge and work with these different models of understanding. As examples, we set out two alternative ways of thinking about health and disability:

■ **Social model of disability**

From a biomedical standpoint, disability is often viewed as an impairment or medical condition affecting the individual. The solution is to 'fix' or minimise the impairment so disabled people are more like 'normal' people

and able to play their part in society. Within the disability movement an alternative view, the social model of disability, has become prevalent. With this approach, people are considered to be disabled by the barriers society creates by failing to take into account the wants, needs and aspirations of a portion of the population. Rather than the person being 'fixed', the solution is changing attitudes and organisational and physical structures to enable people equal access to participation.

■ **Cultural health beliefs and alternative therapies**

As described above, the biomedical approach focuses attention on the body and responses to ill health or disease are focused on symptom management and fixes to bodily functions. In other cultures, health may be viewed as related more closely with the environment and social factors. One example of this is traditional Chinese health beliefs, whereby good health rests on equilibrium and balance between the body and soul and between the individual, social, natural and supernatural domains (Gervais and Jovchelovitch, 1998). The solutions to health problems are therefore different to medicine practised in Western countries. We should respect that people from China and other countries bring these different health beliefs with them when they settle in this country.

Emotional and psychological barriers

Feedback from people who have become actively involved in research, is that researchers should not underestimate the confidence it takes to get involved. Without emotional and psychological strength involvement is much more unlikely.

- The establishment of a legal equalities framework (see Appendix 1 for information on the latest legislation), was because of the historical marginalisation and discrimination experienced by people with certain characteristics. These experiences lead to stigma and reluctance to publicly identify with these characteristics. If people are unable to disclose their experiences, they

are effectively removed from the pool of people available to get actively involved.

- People are often asked to get involved in the structures and practices of the research community – usually in a university or service setting. People who feel that their voice is often overlooked or ignored, may experience fear and apprehension about what is expected of them. This influences their decision about whether to take up an involvement opportunity.
- As well as having the confidence to accept an involvement opportunity, people also need to believe they have something useful to contribute once they are there and that their views and experiences will be taken seriously. Someone from outside academia may not see how their experiences will be helpful and may be worried how their contributions will be treated. Research and healthcare cultures place high value on specialist and expert knowledge, usually generated through research and scholarship. People may fear that their everyday knowledge grounded in their personal experiences may not be valued to the same extent as other types of knowledge and information.
- Experience of some health conditions mean that people's emotional and psychological abilities, and therefore their capacity to contribute, may vary, sometimes on a daily basis. But (as with issues of mental capacity below), this should not be used as a reason to exclude them. Rather, the involvement can be designed to accommodate these variations.

Issues of mental capacity

Some groups and people may not be approached to get involved with research because of concerns about whether they have the mental capacity to decide whether to get involved and then contribute effectively once they are involved. A person's right to make their own decisions is now protected by the principles of the Mental Capacity Act (2005) – see Appendix 2.

Using the official language of the Act, the issue of mental capacity relates to people who have an impairment of, or a disturbance in the functioning of, their mind or brain which affects their ability to make a decision for themselves. A lack of mental capacity may be due to, for example:

- a stroke or brain injury
- a mental health problem
- dementia
- a learning difficulty
- confusion, drowsiness or unconsciousness because of an illness or the treatment for it
- substance misuse

(Social Care Institute for Excellence, 2010).

The experience of a condition that may lead to impairment does not mean a person automatically lacks the capacity to make decisions. The approach promoted by the legislation, is that:

- you should assume a person has capacity, unless there is proof which demonstrates they do not
- all appropriate steps should be taken to enable people to make their own decisions
- a person's capacity is specific to each decision, so if they are unable to make a decision about one area of their life, does not mean they cannot decide for themselves at all times.

There are many examples of people who have an impairment or disturbance in the functioning of their mind or brain, getting actively involved, and indeed, controlling their own research. Therefore, the existence of a condition or belonging to one the groups listed above should not be barrier to involvement.

The legal framework of the Mental Capacity Act applies specifically to participation in research studies and there are a number of helpful guides which set out things to think about when doing research with people who may lack capacity (see Appendix 2). While these have been developed mainly for participation in research, similar principles can be applied to involvement. Underpinning any involvement with people who may have impairments and reduced functioning to make decisions is the general principle of making the involvement appropriate for them. Measures to think about include:

- how to make sure people understand the reasons for getting involved and the types of activity they will be involved in
- how to support people to make an informed choice to get involved
- using different methods of involvement to achieve the most effective outcomes
- making sure the involvement is proportionate to people's abilities.

Example: Connect Works by Connect in the North

A group of people with learning difficulties at the Connect in the North project carried out some research into what people with learning difficulties want from a personal assistant. A worker from the project supported the researchers in making decisions about how to do the research. The researchers sought the views of 89 people with learning difficulties through group sessions and questionnaires. In the group sessions, the researchers started with an ice breaker and then asked people the questions. The researchers put the answers up on the wall and asked people to put stickers or ticks against the things that were important to them.

Faulkner A (2010) *Changing Our Worlds: examples of user-controlled research in action*, INVOLVE Eastleigh. This report, an accompanying easy read summary and a short film are downloadable from www.invo.org.uk/find-out-more/user-controlled-research/

Example: Alzheimer's Society Research Network

The Alzheimer's Society has a Research Network of over 200 carers, former carers and people with dementia. Research Network volunteers play an integral role in the research programme. Their duties include:

- setting the research priorities
- prioritising and commenting on grant applications
- sitting on grant selection panels
- monitoring on-going projects funded by the Alzheimer's Society
- telling others about the results of research.

People with dementia and their carers make a unique and valuable contribution to the research of the Alzheimer's Society. Their knowledge and passion ensures research funding is allocated to projects that address the real needs and concerns of people with dementia and their carers.

www.alzheimers.org.uk/researchnetwork

Financial barriers

As people from low income backgrounds are less likely to get involved with local services (see section 2), financial considerations are important to open up access to involvement opportunities. Many of these issues are discussed in the INVOLVE Payment for Involvement guide (INVOLVE, 2010). Other financial barriers which may exclude different people include:

- Many institutional practices require involved people to pay for their expenses and claim these back after the event – this can be a barrier for those with limited access to funds.
- People may have higher than average costs to get involved, for example people with impairments may have higher transport costs or they may require a personal assistant or carer to accompany them.
- Some groups, simply by the nature of their circumstances, for example refugees and asylum seekers, receive reduced levels of welfare benefits (Patel and Kelley, 2006) and therefore have additional restrictions on their budgets.

5. How can we overcome these barriers?

It is unlikely that achieving greater diversity and inclusion will come through 'quick fix' solutions. Organisations working to promote diversity and increase inclusion argue that involving people from diverse backgrounds requires real commitment to equal opportunities and implementation of effective practical measures (Joseph Rowntree Foundation, 1996). Like involvement more generally, effective diversity and inclusion is often about changing the culture of an organisation and its ways of doing things. A range of ideas and practical information for promoting diversity and increasing inclusion are set out in the Strategies for diversity and inclusion in public involvement supplement as part of the INVOLVE Briefing notes for researchers (see section 6).

Some starting points are to think about organisational-wide approaches, flexible ways of working and innovative ways of involving people.

Organisational policies and procedures

Addressing equal opportunities often needs to be taken into account at an organisational level as well as within individual research projects. Demonstrating commitment to diversity and inclusion in relevant organisational policies and procedures might be a starting point to address organisational, attitudinal and cultural barriers.

Example: National Voices: Equal Opportunities policy

National Voices, a coalition of national health and social care organisations, has a specific policy to promote equal opportunities as an employer and partnership organisation.

The policy can be viewed at www.nationalvoices.org.uk/files/110705_equal_opportunities_policy.pdf

Example: National Institute for Health and Clinical Excellence (NICE): Patient and public involvement policy

In the policy setting out the principles and practice of patient and public involvement in the NICE programme of work, it states that NICE is committed to 'engaging with groups protected by equality legislation to ensure their views are heard, and that issues of equality are considered in developing its guidance.'

available to download from www.nice.org.uk/getinvolved/patientandpublicinvolvement/patient_and_public_involvement.jsp (page 5)

Example: Social Care Institute for Excellence (SCIE): Race equality discussion paper

As part of a commitment to race equality, SCIE commissioned a discussion paper looking at the characteristics of social care organisations that successfully promote diversity. This paper identifies barriers to diversity and steps that organisations could consider to help them promote diversity. These tools could be helpful in thinking about the cultures and practices within research organisations. See Social Care Institute for Excellence (2006) Are we there yet? Identifying the characteristics of social care organisations that successfully promote diversity. Stakeholder participation discussion paper 3 summary. See www.scie.org.uk/publications/raceequalitydiscussionpapers/redp03.asp

Flexible ways of working

A key principle which underlies increasing diversity and promoting inclusion is that every situation is different and individual people are different in the scope of their needs and abilities. It is also important to note that strategies put in place to promote access for some people may reduce access for others. It is good practice to develop a range of options that will enable access for a range of people.

Example: Changing Our Worlds: films about user-controlled research in action

When INVOLVE was producing films about user-controlled research we wanted to ensure they were accessible to the full range of groups and people who had been involved in producing them. Therefore, we decided it was essential to include subtitles and British Sign Language as people from the Deaf community were part of the team. However, people with learning difficulties, who were also involved in the project, can find the busyness of a screen with subtitles and a sign language interpreter distracting, making the film difficult to follow. Therefore we have two versions of the films available – one with subtitles and a sign language interpreter and one without. These films can be viewed on YouTube:

With subtitles and sign language interpreter: www.youtube.com/watch?v=uXP5kioqR5g

Without subtitles and sign language interpreter: www.youtube.com/watch?v=sNWIOryWd5I

Innovative ways of working

When we talk about promoting equality of opportunity, we do not mean that the same way of working needs to be used in every circumstance - in fact, having rigid or fixed practices can be exclusionary. To ensure everyone has the same access and opportunities to get involved in research may require adopting different practices which best suit relevant people and groups. A common way of involving people in research is to invite them to a meeting about the research project, often on the university or hospital premises. However, feedback from people who have been involved suggests that this can be very daunting, especially if they have limited experiences of meetings (Branfield and Beresford, 2010).

Think about how to engage people in the topic, enable them to contribute their experiences and perspectives in non-threatening and interesting ways. As a researcher, think about making yourself 'easy to reach' by being 'out and about' in the communities you want to engage with and using methods that will appeal to people in those communities. Below are a few examples of innovative and creative ways of involving people.

Example: Born in Bradford

The Born in Bradford (BiB) study, described in section 3, uses different ways to involve parents and families in the project, most of which take place in the places and locations where the families are:

- information meetings at local Children's Centres
- family network days, including an annual teddy bear's picnic in a Bradford park
- BiB film and photo gallery which records the children and families throughout their participation in the study.

www.invo.org.uk/posttypenewsletter/autumn-2008/ and the project website www.borninbradford.nhs.uk

Example: Let's talk about genes and I don't mean trousers

The cancer charity Tenovus, funded researchers at the Genomics Policy Unit, University of Glamorgan to carry out some work with children, exploring the interaction between the genetic and environmental influences on cancer. The approaches they used included using stories, games and creative activities. The pupils, aged 12 and 13, worked with Story Works - animators and musicians - to produce a rap that they hope conveys to other children what they should know about cancer, inheritance and the role that families play in health and disease.

www.tenovus.org.uk/research/in-the-community/innovation-grants/lets-talk-about-genes-.aspx

View the rap here - www.youtube.com/watch?v=oMNHUFmLOsc&sns=em

Example: Design for Ageing Well study

This project focused on the inclusive design of technical outdoor walking clothing for older people. A multi-disciplinary team incorporated researchers from technical textiles, wearable electronics, information and communication technologies and social care with the active involvement of older people. As well as project meetings, the older people were actively involved in co-designing the outdoor clothing.

Activities they undertook included:

- equipment and prototype testing walks
- visiting a manufacturer
- mystery shopping in outdoor clothing shops
- workshops looking at the products (base layer, bras, technology), critiquing samples and placing structures (zips, seams and so on) and a show and tell with their own preferred outdoor clothing.

The project was funded by the New Dynamics of Ageing research programme and undertaken by the Universities of Wales (Newport), Westminster, Ulster and Salford, which led on the user involvement.

www.newdynamics.group.shef.ac.uk/design-for-ageing.html

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6. Find out more about diversity and inclusion

INVOLVE publications

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

Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers (INVOLVE 2012) www.invo.org.uk/resource-centre/publications-by-involve

Payment for involvement: A guide to making payments to members of the public actively involved in NHS, public health and social care research (INVOLVE, 2010) www.invo.org.uk/resource-centre/publications-by-involve

What you need to know about payment: An introductory guide for members of the public who are considering active involvement in NHS, public health or social care research (INVOLVE 2011) www.invo.org.uk/resource-centre/publications-by-involve

Changing Our Worlds: examples of user-controlled research in action (Faulkner, 2010) www.invo.org.uk/resource-centre/publications-by-involve

Count us in!: Involving everyone in health and social care research, a report of a service user workshop run by Shaping Our Lives for INVOLVE (Shaping Our Lives/INVOLVE 2010) www.invo.org.uk/resource-centre/publications-by-involve

Other useful links

Equality and Diversity Forum www.edf.org.uk/blog/

Equalities and Human Rights Commission www.equalityhumanrights.com/

Government Equalities Office www.equalities.gov.uk/Default.aspx

Joseph Rowntree Foundation www.jrf.org.uk

Local Government Improvement and Development www.local.gov.uk

Shaping Our Lives www.shapingourlives.org.uk

Social Care Institute for Excellence www.scie.org.uk

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Appendix 1: The Equality Act 2010

The **Equality Act** became law on 1 October 2010. The main aim of the Act is to bring a number of existing laws together in one place so that they are easier to understand and use. These laws are intended to protect the rights of individuals and advance equality of opportunity for all regardless of their background and characteristics. The Act sets out the personal characteristics (called 'protected characteristics') that are protected by the law and behaviour, for example discrimination, that is unlawful.

The nine 'protected characteristics' covered by the Equality Act are:

- race
- sex
- sexual orientation (lesbian, gay, bisexual or heterosexual)
- disability
- religion or belief
- being a transsexual person (transsexuality is where someone has changed, is changing or has proposed changing their sex – called 'gender reassignment' in law)
- having just had a baby or being pregnant
- being married or in a civil partnership
- age.

The provisions within the Equality Act are:

- definition of the different types of unlawful discrimination and harassment
- setting out duties for public authorities to have due regard to the need to:
 - eliminate discrimination, harassment and victimisation
 - advance equality of opportunity
 - foster good relations
- setting out positive action provisions which permit proportionate action to overcome disadvantage, meet need and tackle under representation

- specifying which bodies are required to publish information about the engagement they have undertaken with people with an interest in their equality performance.

The Equality Act applies to public authorities which include:

- local authorities
- education bodies (including universities)
- health bodies (including NHS Trusts)
- police, fire and transport authorities
- government departments
- other organisations who exercise public functions, for example voluntary sector organisations commissioned to deliver public services.

Responsibility to comply with the Act usually sits at an organisational level, for example with a university, rather than with units or departments within a university. Therefore individual researchers and research teams will not be assessed for their compliance with the legislation. However, it is good practice to ensure all parts of an organisation contribute to meeting the overall performance for equalities compliance and duties. If you want to find out more about how your organisation complies with the Act and whether you can take any action within your area, contact your equalities office or officer - there should be one within all public sector organisations.

Find out more about the Equality Act 2010

Government Equalities Office
www.equalities.gov.uk/equality_bill.aspx

Equality and Human Rights Commission
www.equalityhumanrights.com/advice-and-guidance/new-equality-act-guidance/

Appendix 2: The Mental Capacity Act 2005 and its application to research

The Mental Capacity Act 2005 provides a legal framework for people who lack capacity and those caring for them by setting out key principles, procedures and safeguards. The legislation applies to wide range of settings where decisions have to be made, including all research. It is of particular relevance to health and social care research.

The principles underpinning the Act are as follows:

Principle 1: A presumption of capacity – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

Principle 2: Individuals being supported to make their own decisions – a person must be given all practicable help before anyone treats them as not being able to make their own decisions.

Principle 3: Unwise decisions – people have the right to make decisions that others might regard as unwise or eccentric.

Principle 4: Best interests – anything done for or on behalf of a person who lacks mental capacity must be done in their best interests.

Principle 5: Less restrictive option – someone making a decision or acting on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the person's rights and freedoms of action, or whether there is a need to decide or act at all. Any intervention should be weighed up in the particular circumstances of the case.

How to decide whether a person lacks the capacity to take part in research

A person is deemed unable to decide whether to take part in research if they cannot:

- Understand information – does the person understand what the research is about?
- Retain information – can the person hold the information in their mind long enough to use it to make a decision?
- Use or weigh up the information – can the person consider the benefits and risks of taking part?
- Communicate their decision – whether by talking, writing, sign language or other means of communication.

The British Psychological Society (2008)

Regulations applied to research

To undertake research with people who lack capacity to consent now requires approval from a specially nominated Research Ethics Committee (check with the National Research Ethics Service for details www.nres.nhs.uk) and needs to fulfil the following requirements:

- The interests of the individual must always outweigh those of science and society.
- The research must relate to a condition or impairment that affects the individual or the treatment of the condition.
- It must not be possible to conduct equally effective research with adults who have the capacity to consent.
- The potential benefits of the project should outweigh the risks: the level of acceptable risk depends partly on the possible benefit to the individual.
- Views of those close to the participant should always be sought, unless this is not possible due to particular circumstances.
- A participant who lacks capacity should only be included in a study when there are no indications that he or she objects to this.

Medical Research Council (2007)

Find out more about the Mental Capacity Act

For more information about the Mental Capacity Act (2005) see Justice Department www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/

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