



Count us in! Involving everyone in health and social care research

Report of a service user
workshop run by
Shaping Our Lives for **INVOLVE**

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About this report

This report was written and compiled by Fran Branfield and Peter Beresford following a workshop run by Shaping Our Lives for INVOLVE

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Foreword

The growing understanding of the value of public involvement in research amongst policy makers, researchers, research funders and commissioners has ensured that the opportunities to, and scope for, members of the public to influence what research gets done and how it is carried out are now greater than ever before. Moreover, there is more information available about what difference involvement makes to health and social care research.

Although we have travelled a considerable distance in recent years, our role at INVOLVE is to continue to help improve how involvement is put into practice and pay particular attention to those areas where extra effort may be required. One key concern of ours is to ensure people from the full range of backgrounds and sections of the community have the chance to influence health and social care research. We often get asked by researchers what they should do to better involve people who do not always step forward - how can they reach beyond the 'usual suspects'? Therefore, addressing issues such as wider inclusion and diversity is important to the work of INVOLVE.

Working with Shaping Our Lives, gave us the opportunity to work with a diverse range of service users to begin to understand, from their perspective, what researchers and members of the research community can do to open the doors wider. The participants at this workshop told us that a whole host of practical measures could be put in place to enhance inclusion. But overall, the systems and cultures within the research community can, at times, feel difficult to negotiate or find a way through. However, what we need to do to address these issues is less clear. While research evidence (around community engagement) has also identified organisational, cultural and professional barriers to involvement, there is less evidence about which factors can help to overcome them (1).

Our task now is to consider the issues raised by the service users who very helpfully shared their ideas and experiences with us at the workshop. We can use this information to start helping researchers find answers to their questions and continue to build on the impact greater public involvement is having on research.

Sir Nick Partridge

Chair, INVOLVE

Chief Executive, Terrence Higgins Trust

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Summary

Shaping Our Lives was asked by INVOLVE to have a meeting with service users who were interested in research in health and social care. The aim was to find out how more people can be actively involved in research. We especially wanted to know how people and groups who often get left out or ignored in wider society can be involved in research.



INVOLVE wanted us to find out what service users think about taking part in research and to tell them about any barriers or things that might stop service users from taking part in research. INVOLVE wanted to ask service users what they thought would be the best way to get more people and different types of people to become involved in research.

Eleven service users who were all interested in research came together to talk about taking part and doing research. People said that there are many things that stop people taking part and doing research.

These are the main things people said:

- There remain real difficulties for service users to get actively involved in research in a truly meaningful way. Many service users find it difficult to take part in research. It is even more difficult for some people who don't usually get involved in research.
- Service users said that a lot of the people who want to do the research do not understand disability and impairment from an equalities point of view. They see disability as a medical problem and not a problem caused by other people's attitudes or how society is run.
- Some researchers and research organisations have a lot more power than service users and their

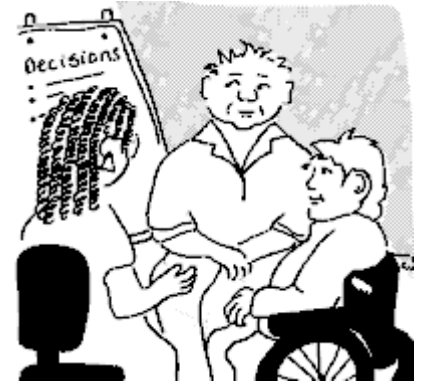


organisations. This makes it difficult for service users to stand up for themselves and be listened to. Some people do not take what they say very seriously.

- Institutional oppression means that service users are made to feel as if they are worthless everyday in little things, such as the way someone might look at you or say something bad about you. Service users think it would be good if more research could be done about such oppression in everyday life.
- Service users said that they were not just one thing, like a service user but they were also perhaps gay or lesbian, transgendered or bisexual. They might also come from a black or minority ethnic community and they might be young or old. This can result in what is called simultaneous oppression. All these things made them who they were and that researchers should pay attention to all these things.

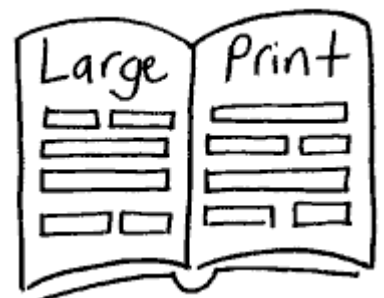
- Some service users said they would like to take part in research but they had never been asked.

- People said it was important to remember that most service users do not belong to groups and that researchers needed to ensure service users who are not associated with a group have opportunities to get involved as well as those in groups.



- Some service users are also researchers. For some people who did their own research this was a good experience. For other service user researchers this was difficult as other researchers saw them as primarily service users and did not properly value their research skills and experiences. On the other hand, they may be seen as researchers and their needs as service users not appropriately considered. This meant it could be very lonely.

- Service users talked about the way that their access needs were not often full met.



They meant all types of access including information in the right format, access for people to be able to get around, plain English and a good friendly atmosphere.

Recommendations made by the service user participants

The service user participants felt there are still major barriers in the way of involving all service users in research. These pose particular problems for developing diverse involvement and need to be addressed. They identified key areas for future work suggesting collaboration between service users, their organisations and INVOLVE. These are presented below¹.

- Challenging the **hierarchical relationships** and **discriminatory structures** that are still commonplace in research organisations
- Enabling more user involvement and more diverse user involvement in **developing research agendas** so they are relevant to as wide a range of service users as possible
- Extending **education and training** needed for researchers and research organisations to support and encourage user involvement and develop **diverse user involvement** as part of that
- Encouraging and supporting '**champions**' of diverse user involvement in both service user and research organisations
- Recognising the unhelpful dominance of the medical model and to support learning about social approaches and the **social model of disability** among researchers and research educators

¹ As we did not attempt to prioritise the recommendations during the workshop they are considered of equivalent priority and have been grouped according to theme.

- Supporting forums and **safe spaces for service user researchers** to overcome isolation, gain skills, peer and mutual support
- Acknowledging that some **traditional research approaches**, particularly those based on a medical model **discourage diverse involvement**. It is important to encourage research methods and methodology that is strongly supportive of diverse involvement including user controlled and emancipatory disability research.
- Encouraging a greater proportion of **research funding** to be directed towards new **user-led research approaches** which are strongly supportive of diverse involvement
- Supporting more research which focuses on **routine discrimination in people's everyday life** which will offer insights into the **discrimination and exclusion** that narrows the range of service users who currently can get involved in research.
- Increasing recognition of the **effects and implications of simultaneous oppression** and the complexity of people's identities as service users, rather than pigeonholing them in one or other category.
- Recognising **increasing tensions between diversity and equality** which are associated with moves from single equality organisations to more generalised and consensual diversity policies and programmes
- Acknowledge and recognise **the experience of simultaneous oppression**. This is not a hierarchical layering of oppression but rather the recognition of the unique experience of being oppressed, for example, as a lesbian, as coming from a Black and minority ethnic community and of being disabled. It is the interplay between all three aspects of a person's identity that shapes that person's experience of oppression.
- Action to ensure **inequalities for lesbian, gay, bisexual and transgendered (LGBT) people** are addressed through

holding a one day seminar specifically for LGBT service users and members of the public to talk about their issues for research.

- Developing greater understanding of the **wide range of access issues** that need to be met to ensure truly diverse involvement and improving policy and practice in this area
- Working to improve communication in research to ensure that it is based routinely on **plain English** and **avoids jargon** and **obscure terminology**
- Working to **build links, alliances and understanding** between researchers and research organisations and user controlled organisations.
- **Reaching out routinely** to engage and involve non-affiliated service users who are not part of service user groups or organisations

Background to the workshop

INVOLVE has been working since 1996 to encourage and support active involvement in NHS, public health and social care research. When we talk about getting involved in research, we mean the active partnership between service users, patients and / or carers and the researchers in the research process. Involvement means people having an active part in deciding what research is done or how it is carried out. This would include, for example, deciding on the focus of research, advising on a research project, assisting in the design of a project, or in carrying out the research and leading research projects and shaping dissemination and follow-up action.

The opportunities for service users to get involved in research – both individual research projects and with research organisations – has increased markedly over that time. There are now many good examples of collaborative relationships between researchers and service users, where the direct influence of service users in shaping what research is done and how it is carried out can be seen (2).

However, one area that requires greater attention and is a frequent concern of both service users and their organisations and researchers is how to ensure that diversity and inclusion are addressed in public involvement in research.

Shaping Our Lives was approached by INVOLVE and asked to run an event to find out, from a service user perspective, how more people could get actively involved in research – in particular people and groups who are often overlooked or ignored by mainstream society, and who seldom get their voices heard in research and by the research community. Although the idea for the workshop came from INVOLVE, Shaping Our Lives took the lead in deciding how the workshop should be carried out, inviting service users to be involved and facilitating the discussions on the day.

The event aimed to find out more about what might make it hard for people from a diverse range of groups, backgrounds and experience to get actively involved in research. We wanted to do this by learning from people with first hand experience of such issues and ideas about them.

INVOLVE's previous work in this area includes writing a consultation paper to stimulate thought and discussion on this issue (3) and the development of a checklist for researchers to help them think about the range of issues to consider when involving people with a wide range of support and access requirements (4).

It was intended that this workshop would build upon this earlier work and be part of a continuing programme to promote greater diversity in the groups and people getting actively involved in research.

Who took part in the workshop?

Eleven service users took part in the workshop. We wanted to involve a wide range of people and groups in the workshop to ensure that a number of different voices and perspectives were heard. However, we recognise that it was not be possible at such an event to involve all those people and groups who may feel they are often overlooked or ignored by mainstream society.

Service user participants were either recruited through SOLNET, Shaping Our Lives' networking website which hosts an active notice board or by invitation from Shaping Our Lives to a few members who we knew had experience and interest in this topic.

Six people connected with INVOLVE took part in the workshop. This included four members of the INVOLVE Advisory Group, including researchers and service user/public members and two members of the INVOLVE Coordinating Centre team.

Across all workshop participants there were eight men and nine women, five people identified as belonging to a Black or minority ethnic community, three people identified as being from the Lesbian, Gay, Bisexual or Transgendered community. There was a broad range of ages. Some people had physical and/or sensory impairments, others were mental health service users and/or people with learning difficulties. Some participants had long term health conditions, which were not obviously visible and therefore felt their needs were often overlooked. People did not fit easily into one group. The service user participants all had experience of

disabling barriers and all participants had an interest in participatory research and user involvement in research.

What happened at the workshop?

The workshop was intended to be interactive and participatory. Therefore, there were not any formal presentations or talks. The purpose was to learn about people's experiences and this was best carried out through discussion.

Shaping Our Lives ran the whole day proposing our usual ground rules for workshops and meetings. The day was in two parts.

Morning: service user session

The first part of the workshop was for service users only. We hoped this would encourage an open discussion of the wide range of reasons why some groups and people find it hard to get involved in research.

Afternoon: joint session

After this, a mixed session with service users and people from INVOLVE enabled the participants to learn from each other about the key barriers to achieving greater diversity in active involvement in research.

See appendix 1 for the workshop timetable.

Summary of the discussions from the service user session: what the service users said

The participants were all pleased to have the opportunity to discuss with other service users the barriers that prevent service users from being equally and meaningfully involved in all aspects of health and social care research. They particularly welcomed the opportunity to meet alone with other service users, in order for them to clarify and develop what they wanted to report back to INVOLVE.

1. Barriers

All the participants were quick to identify many barriers that stood in the way of service users being meaningfully involved in research. These are barriers which can have a negative effect on the involvement of all service users, as well as limiting the range of service users who are able to or want to get involved.

Research paradigm

Underpinning the discussions that took place in this workshop was a shared understanding that the dominant cultural view of disability and service user issues is framed in a medical and individualistic model. Disability is seen as a medical problem. Equally participants shared a different understanding of disability and service user issues based on equality, parity and human rights. People said:

The reality is that the dominant type of research that takes place in health and social care is based on an unexamined medical model. That is the dominant kind of research.

If we are thinking about barriers the whole basis on which you're doing the research might be itself a barrier to meaningful involvement. Quite a fundamental thing.

It is about the kind of knowledge base the researchers come from; their understandings of what disability is all about. I'm sure similar points could be made in relation to other equality groups but there is an absolute need for researchers, particularly within health and social care research, to

examine the starting point. If they come from what we know as a medical model, an individual tragedy model, if they make that the basis of their approach to working with disabled people, then it doesn't matter how well organised, how well planned or even how physically accessible, if basically an unquestioned medical model is the basis for the research then it is impossible for researchers to identify impairment as anything but personal tragedy. This creates as has been said, power inequalities, unequal power relationships. This involves a failure to take the perspectives of service users seriously. There is a need for people to critically examine their perspective in terms of whether they are coming from a social model perspective or from various developments in terms of the disabled people's view.

Researchers need to think critically about their knowledge base and their understanding of what things are about. They need to examine their starting point.

Power inequalities

Workshop participants identified power as a major barrier for achieving meaningful involvement. The unequal distribution of power and, importantly, the lack of acknowledgement of this by those who hold power, was a theme repeatedly returned to throughout the workshop. People said:

There are still power inequalities and a failure to take service users seriously.

They don't think of us as proper people, they don't think of our contribution as being worthwhile or as good as what they do. They don't appreciate when they treat us unfairly. They don't even see it.

That is right. Somehow we and our organisations, we are just not quite proper. And I don't know what we can do about that.

Where power structures are hierarchical and unequal people don't really want to get involved. Not just because it won't be a good personal experience but also because it won't make

a difference and you can end up inadvertently validating rubbish.

Participants were keen to point out that imbalances in power alongside an acceptance of the prevailing attitude towards service users, as passive recipients, were the key elements to barring meaningful involvement.

Devaluing Service User knowledge

Participants at the service user workshop said that one expression of unequal power and the acceptance of a medical understanding of disabled people and service users, was the common and equally unconsidered assumption that service user knowledge was not as valid or legitimate as academic or 'researcher' knowledge. People said:

Universities and other powerful institutions are built on knowledge and knowledge that is seen to be valid. The problem for us, as disabled people, as service users, is that what we know, our knowledge, is a different type of knowledge gained through our lived experience. All too often research institutes, quite unintentionally I'm sure, don't respect us for what we know at all and really you are given the impression that they know best because they have studied something for many years. Not like us who have merely lived it!

I think one of the points made was relating to the lack of respect for what we call grey literature, [and] our research - service user research. I teach students and everywhere I go, it is so hard to find any reference [by] academics about our work.

I absolutely agree. I was at an interview at a university on Monday. It was a potentially fantastic research project involving the university and a number of organisations *for* rather than *of* disabled people. They produced an extensive research list that they had based their project plan on and they made a statement: "There's very little research been carried out on disabled people's attitudes to risk". The reference came from medical, occupational and physiotherapy literature. Apart from one reference. They

had not looked at any of the literature emerging from disabled academics within disabilities studies. It is a failure to take grey literature, disability studies literature, the perspectives of service users into account in planning research.

Qualitative research does not have the kudos of quantitative research.

This person illustrates how important the research question is, and how the researcher's own cultural and historical position and potential bias dictates the research findings:

There was some research about black people. But it was research to show why it was that black people did not do well in jobs, they didn't do well at school. It was all explained by white researchers in terms of their individual lack of ability. That was in beginning of the second half of the twentieth-century when larger numbers of black people came to this country. The researcher who made this point said that still in research there are not many black people who have key roles. The point he was making was that they are not there, in powerful positions even though research has had to change and no longer can be framed in terms of 'what is wrong with these people that they don't do well'. I know it is still that problem, I know there are not many black professors, fewer black women professors and research leaders in Britain still, not an equal number. How do we then if the overall context is not equal, how do we get equality for people as service users and diverse involvement as service users in research? How does this relate to other things like LGBT issues and so on. Is it, for example, that people from LGBT communities will think to themselves, as disabled people and service users do, that the way to make any difference isn't by being involved in research, it is by doing things through our own organisations, through our own 'grey' research.

The position of Service User Researchers

One way in which the disability and service user movement has challenged orthodox research is by coming together and developing their own ideas, sharing their own experiences and designing and carrying out their own research. Within the morning workshop at least half the service users had experience of being 'user researchers'. Some of them found this experience very positive:

For me, I have done ... I put some things about myself and learning disabilities people doing the research. I think INVOLVE should get people like us to do a research. I am doing my life story, what I have done in my life and everything and I think it is really good for me to write about it because I have been through that. And not other people and so we should do our research.

Some service users thought that as a service user researcher the power imbalance between service users and non service users was still in evidence:

There is still a hierarchy – user researchers are below purely academic researchers in the pecking order.

Yes I think that somehow doing anything around disability or social care is not viewed as 'Important Work' or at least not worthy of real academics.

Some service user researchers said that 'wearing two hats' could be problematic:

I work as a service user researcher and I found when you do this and you are working collaboratively with people, you don't identify as a service user. You can be seen by those people as if the research part of your identity is completely overlooked and they just see you as a service user. Similarly I find service users who don't work as researchers often see you as a professional holding power in the same way that other non service user researchers do. We have to work on that over time.

I agree. The point for me is that you can end up feeling quite isolated, falling between two groups that don't quite see you as belonging to either of them. The important thing for me is to have support from other people who are in the same position as me. That is who are both service users and researchers and particularly those researchers who are not producing 'grey' research but who work in more traditional research organisations.

Can I give an example of that point? I worked collaboratively with a quantitative researcher, someone experienced in working with numbers and statistics and I was experienced in qualitative research - interviews and things like that. All the recommendations I made from the qualitative side she checked out with another qualitative researcher. She wouldn't trust me to do anything. Because I was a service user.

Institutional discrimination

As Shaping Our Lives has previously evidenced (5, 6), in many areas of life service users, including disabled people have experienced attitudinal discrimination. In this workshop service users spoke of the institutional oppression they experienced from some universities and organisations as well as of the disablist attitudes of some researchers that effectively barred their involvement in research.

A lot of universities still have discrimination 'in the system' in terms of class, gender, sexuality, disability and impairment, race and ethnicity, belief and age.

The thing about institutionalised oppression is that it is experienced at the everyday level. This can be in terms of the smallest interactions people experience, whether employment, or relating to professionals, or relating to people at the bus stop or the news agent or supermarket. Oppression takes place in the details of everyday life which is why it is so difficult to understand it as oppression. There's a need, I would suggest for health and social care research to engage in more qualitative research, getting the views of people in terms of their experience of every day life because that's where oppression happens.

There are operational issues within institutions. For example, relating to payments. If, lets say, you want to include a diverse range of people, and you recognise the need to pay them in relation to their time and expertise but you can't pay them because the only means you have to pay is via bank accounts. Many service users have not got a bank account.

Because you are treated as 'the problem' you are put in a position of being a boring moaner and going on and on about access and you are made to feel a nuisance and it is like it is something you are specially asking for, for you, when it should be something for everybody.

Simultaneous Oppression

Participants in this workshop said that they were frustrated by the fact that they were usually only seen to be two dimensional. People were clear that they experienced their own sense of self in a much more complex and intricate way. This is what people expressed during the workshop:

It is important to recognise the issue of simultaneous oppression

We get pigeon holed by researchers as being from one particular group or another. Within us there are different layers of people. They often don't see us as having a more complex identity.

It is important that you don't just experience oppression as a lesbian, as a member of BME community, but for example, as a black lesbian with mental health issues or whatever. It is not making a hierarchy of oppression as multiple oppressions. It's about how that specific identity experiences oppression.

I try and understand the problems that people face when they are from different minority groups... because I have a similar situation regarding my blindness with my own community because once people become blind, they are protected and they don't get opportunities to do or encouragement to come out and do things.

People should be given the chance to be involved whoever they are.

It is important for our involvement that it is recognised that we have all these facets to our identities and that what we experience is as a direct result of all these aspects of ourselves. So when I speak as a black woman who is a mental health survivor I am not just speaking as a woman, or as a mental health survivor or as a black person, I am speaking as a black, woman, mental health service user/survivor.

I think perhaps one of the outcomes of today should be that we ask INVOLVE to recognise the experience of simultaneous oppression.

Lack of access

It quickly became apparent in the workshop that other barriers in the way of people's participation were still firmly in place, despite positive policy and legislative change. It was sad to hear that people's access requirements were still, routinely not being met. Participants all agreed that:

People don't take access seriously.

They have a very simple view of access.

People generally haven't a clue about ensuring access.

Access is a complicated issue, not everyone can know everything.

I would like to echo what everyone is saying about access. For me it is about access to information. This affects a lot of people. And mobility.

I am blind. I agree with the previous speaker about access and mobility. I have been working with a college but in order to do so they had to spend thousands of pounds which if I were not blind they would not have had that cost. And not every organisation can afford to pay what you need. Also

mobility. It is difficult as there are so many objects on the pavements.

People can give up because they've tried [to explain their access needs] but nothing seems to change. It is very disheartening.

Even in places where they are positive about involvement, access can still be a problem especially for people who communicate differently.

There needs to be something or somebody who ensures that access is taken absolutely seriously.

Specific access issues were identified which had a particular resonance for service users wanting to become involved in different aspects of research. As these people explain:

I think access again has been raised quite a number of times but access in the widest definition, not just physical. I think access in terms of attitudes that researchers have towards service user involvement. For me, I think a particular example when I was asked to help in the application stages of a research [project]; who would go on to do the research, etc etc and it was great. "Come on, we do need a diverse group of people", etc etc. So we went to the first meeting and over time, what came out for me, the issues, was there wasn't appropriate support to help me do the function they demanded of me. So, for example, paper work would come in and we would have to respond within five days. Some people need to read things several times over before it goes in and it is a slow process. I suggested solutions which I felt I should be able to do. I asked if it were possible to have ten days. But it was ignored. That's what I feel about the power relationship. I had to drop out at the end because I couldn't manage to do things the way they wanted it to be done. That was the thing. I didn't see it as a partnership working relationship so for me, I think there needs to be recognition of the impact of what they do, how it makes someone feel.

There is a tendency amongst non-disabled people to think that you will automatically get the help or assistance you need. This is not the case at all. When I, as a visually

impaired student, was at college I had to spend money on appropriate software. You can apply for grants but it takes a lot of time and you often need to buy the software before the grant has come through. And equally you might not get the software until half-way through the research project. And then you might have to wait even longer for someone to tell you how to use it or install it.

2. Challenging the barriers

User controlled organisations

Everyone agreed that:

Researchers should get involved with user controlled organisations, ask them what their research priorities are, rather than telling us what they want to research which we might have no interest in.

People felt that building such links and cooperation was crucial:

Research organisations should be funding user controlled organisations to carry out their own research

There also was a feeling that whilst not everyone wanted to be in a user controlled organisation and there might not be one local to them, people should still have the opportunity to be involved in research:

My thing is to do with people relying on users who are in groups all the time. I am kind of concerned about that because most people are not a member of a group from what I have seen. Some people don't want to be in a group and why should they. Some people have not got a group to join. There is no group for my condition so does that mean I never get a chance to be involved in research because I am not a member of a group? I don't know. I think it is a bit like what was discussed before, it is kind of like pigeon holing people, if you have a condition, therefore you are in that group and perpetuating that, making it worse I feel. I think individuals should be able to get involved in their own right.

Another participant said that they had carried out some research but no researchers or policy people came to their group to ask if they wanted to do any more:

We did some research. We talked to people with learning difficulties. We wrote 'We Are Not Stupid' and everyone should be given a chance – I have done my life story. I know how I feel in my life. If someone asked me to take part in more research I would like to but no one has asked me.

It became clear through the morning discussion that service users feel that there was still a real difficulty in involving *any* service users in research in a truly meaningful way. Service users felt that if the aim is to involve a diverse range of service users, including those whose voices are seldom heard, there first needed to be recognition of the barriers that all service user experience to be in the way of their involvement. The next stage would be to work with service users in such a way as to dismantle and overcome these barriers. A fairer, more equal bedrock needed to be established, where service users and researchers could work together in trust, partnership and co production as a basis for extending engagement with 'seldom heard' service users.

As this participant made clear:

It seems from what everyone is saying that there is a problem involving service users. There still is a problem of involving people at all, because some of the research approaches, if we are honest about it, are opposed to that. So, in a way, that makes the task of trying to involve everybody, all the 'seldom heard from' service users even bigger and more difficult, which I had not thought before. I realise I am not getting us anywhere by saying that but it is a reality we need to take account of. If we then get down to things like involving service users from other minority groups, like older people, BME, on LGBT, it looks like another big mountain to climb.

This service user raised important questions about why researchers want to involve service users, particularly those who tend to be ignored. They made it clear that it was important for them to examine their motivation.

First service user

What research organisations need to understand is that if service users organise separately from them, it is not a challenge to them. There will still be networking, people working together, but we need the space to explore our own issues ourselves and draw strength from one another. So that is my first point. My second point is that when researchers are wanting to reach what they think of as 'hard to reach' service users, what are their motives? Why are they doing it? Why do they want to reach them? Are they examining [their own] reasons as to why they are doing it? Are they simply ticking boxes? If they are, we will know they are. People are stretched. There are lots of opportunities to get involved in things and people will select the things that tally most with their own ethics and what it is they want research to achieve. When research organisations are involving people, are they involving people in research agendas they have set, or allowing the community to generate their own research problems, the things that they want to explore? One of the things I thought coming here was about research into medication. Who wants to get involved in research on medication compliance? If you are setting the research agenda to the extent you think medication compliance is a really important topic, you won't reach any service user.

Second service user

Research organisations have a clear agenda about things like that?

First service user

I think they do, yes. You are expected to tie into that. 'Come and get involved with what we have already decided.' It is not an offer, not something service users want to take up.

Ways Forward

During the last part of the morning workshop participants reminded themselves that:

INVOLVE want to find out from us about the barriers we see to involvement, particularly diverse involvement, about ways we see of overcoming them and what we think should happen next.

These are the main points that the workshop participants decided that they wanted to feed back to INVOLVE. These are the things that service users felt would enable researchers and their organisations to find inclusive, helpful and positive ways of working with service users.

- A key barrier is the hierarchical relationships that continue to exist between researchers and research participants. There is often the assumption that the researcher develops research agendas. There is a need to involve users of services in developing such agendas. This is likely to come from more participatory, user controlled and emancipatory research.
- This will mean that user controlled and emancipatory research will need to be better understood by the research community – ‘If its not understood, it doesn’t get a look in’.
- It will be helpful to look for and cultivate ‘champions’ of diverse involvement in research departments and organisations. There were examples of these given in the discussion. For instance, a professor who identified as a lesbian woman and who has had her own direct experience of ‘battling with the system’, being supportive of service user involvement in research in her department.
- It is important to keep ‘drumming home’ equality and diversity and access issues and the right to be respected in terms of difference.
- Service users and user researchers need to be there to challenge traditional assumptions. For example, extending

understanding of the social model of disability. It is easy for people to say they understand the social model and are working in the context of the social model even if they don't really. There needs to be no excuse for such lack of understanding.

- Service users and user researchers will need to work to challenge power structures that exclude and marginalise service users in research, particularly 'seldom heard' service users .
- There needs to be a shift from large scale quantitative research projects in health and social care, to researchers talking to people and grounding research in their lives to make better sense of people's everyday lives.
- Peer support is the bedrock of diverse user involvement in research. It increases people's confidence
- Service users and user researchers need more spaces and opportunities to get together on the basis of their own identity and to develop their own supportive forums. It is not a negative challenge if service users organise separately – but instead provides a basis for positive networking with researchers.
- There needs to be a joint campaign between mainstream researchers and service users for more funding for 'non traditional research' which encourages diverse involvement. It is important to promote understanding of participatory research which is committed to change.
- Unequal power structures must be open to change if there is to be effective and diverse involvement. Moves away from addressing single equality issues, such as discrimination experienced by Lesbian, Gay, Bisexual and Transgendered, towards broader diversity bodies have had some negative effects in weakening the voices of some diverse groups. However, it was recognised that trying to compile lists of the groups and people often overlooked or ignored is never going to be exhaustive. This issue has implications for

encouraging diverse involvement in research which needs to be acknowledged and addressed.

- Trust-building is essential if the diverse range of service users is to have equal opportunities to be involved in research. Key to making this possible is providing good feedback so people know what changes their involvement has led to. Feedback, trust-building and supportive individuals are all key.

Summary of the discussions in the joint Shaping Our Lives and INVOLVE session

In the afternoon, the INVOLVE participants were welcomed to the meeting and a reminder of the ground rules was given. The service user participants began to feedback the main points and a joint discussion with all participants took place.

The INVOLVE participants were affected by the powerful messages that the service users conveyed and were broadly in agreement with the main points that were considered the barriers to meaningful and diverse involvement in research. Some explained that the session had changed their thinking about the issues.

I have sat here listening to the comments and it has been mind blowing. It was a journey travelling here today but an even greater journey listening to you! In the Empowerment sub-group [of INVOLVE], certainly my thinking was let's find out how researchers could have wider diversity of people involved in research. People often come to me and say how can we make sure we have greater representations of people in research projects than we do? I scratch my head and think 'gosh! What sort of things do we need to make sure it is accessible?' But now the answer is 'I wouldn't start from this point if I were you!' This has just been fantastic, because clearly, it is a much bigger, a much wider issue.

There was an acknowledgement that there were no 'quick fix' answers to the issues of diversity and that to systematically address this in involvement in research would require fundamental changes to the structures and institutional systems which are currently in most frequent use across the academic and research communities.

The report from the morning discussion provides a detailed description of the main barriers to greater involvement and diversity which were raised and discussed by the service user participants. In this report of the afternoon discussion, we have focused on the main points raised and also report any new areas of discussion from the joint session. We do not repeat detailed discussion if it was covered in the report of the morning session.

Research Paradigm

The discussion between the Shaping Our Lives and INVOLVE participants similarly highlighted the dominance of the medical model in health and social care research. One person said that

There is a hierarchy in universities that favours the medical model and those that don't follow the medical model have challenges in terms of their work being heard or seen as having value.

One proposal for countering what was viewed as an unhelpful dominance of one approach was by introducing more reflective research methods.

In terms of developing research practice, in universities, all round sources for people in research there could be placed a requirement on research practitioners to be reflective and reflect upon their own position where they are coming from. If that was made not just optional, but something to be added on, if that was put at the core of research evaluation, for example, what evidence is there that the researcher has developed or reflected practice? That could be an effective tool for changing the practice of research.

Other people agreed that using approaches such as participatory models were likely to be important to address these issues. This type of research was important because it happens when 'people actually what to see change' and such methods would increase the likelihood that research is looking at the 'problems people recognise and think are important', rather than those set by the researchers. This is particularly important because people would be more interested in getting involved in research if they could see that it was connected to their own ideas.

People are stretched and pressed for time so they will select things closet to their own ethics and beliefs.

We also discussed whether it would be appropriate for INVOLVE, and others concerned about involvement, to prioritise getting involved in research that is participatory or emancipatory.

Participants thought this was a hard question to answer but people said

If you had a choice between concentrating on supporting people to be involved in mainstream research or supporting people to do research in entirely different way, absolutely you should concentrate on the latter, in my view.

To address the relations of research production and the involvement, that implies an answer, that yes, you need to go along the lines of at least participatory research or where possible emancipatory.

Those who worked in the university and academic settings thought changes were happening, for example, more service users being involved in the educational setting, but it was acknowledged that the 'pace of change is agonisingly slow'.

Issues of access

The wide notion of access that the service users had highlighted was also a striking feature of the afternoon discussion. It included issues like communication, tradition and culture, and control of the research. Also, participants said that researchers need to think about how welcoming their approach is to engaging with service users.

Easy to reach

The service user participants gave examples, to show that if you use the right approach and methods for reaching service user they can be very 'easy to reach'. Approaches, such as 'snowballing' and linking into appropriate networks were identified as good methods.

For example, one service user researcher had made a list of about 30 organisations of disabled people, survivors of the mental health systems and groups of lesbian, gay, bisexual and transgender people in order to make contact with 30 people. He sent one letter out to one of these organisations and got 72 responses.

Variation in experiences and practices

The service user participants were often involved in both research and the delivery of local health and social care services. We talked about how practices around diversity in involvement in research compared to practices in health and social care services. In their experiences particular sectors were not necessarily better at managing involvement and promoting diversity. It was often dependant upon and a result of local practices. This type of activity was often driven by particular individuals.

It depends upon who you are with. Some people are great, some are not so great. People who champion involvement are actually committed to it. There are good and bad workers in every profession.

One example was noted where a senior member of a NHS Trust team was considered to be brilliant and was changing attitudes. The service user had been involved in the appointment of this person. Scope for service user involvement in the appointment of senior researchers was noted as a way in which greater emphasis on involvement and diversity in research might be achieved.

Political and economic pressures

People felt that the democratic principles, such as involvement and greater diversity did not fit with the current political agenda and it may be that it was going backwards. Greater diversity would start to shape the existing power structures and it had been discussed that when politicians had started to speak about local involvement, they saw this might happen and had backed off. People said

If service users and diverse groups of people are going to be involved in research, it has to be acknowledged from the beginning it is going to challenge the power structures and that if people are not aware of that at the beginning it is not worth starting... So it is not just asking what you think and ticking the box, it is accepting it will affect the power structure.

It was also noted by the workshop participants that the current economic climate, with significant cuts in public spending expected, also has the potential to inhibit involvement and

promoting greater diversity. Those who had contact with academic settings recognised the pressure researchers would be under to bring in income for doing research and the ways in which university are rewarded for doing research relates to the Government's economic agenda, rather than promoting, in a serious way, involvement of diverse communities. This is also likely to apply with even greater intensity to service user organisations.

Close of the workshop

The workshop closed by thanks being extended to all the participants for their valuable contributions and to INVOLVE for following the Shaping Our Lives suggestion for the format of the workshop - there had been very honest and safe discussion in the morning, with helpful feedback in the afternoon.

Reflections on the workshop

Six of the service user participants completed the feedback form after the workshop.

Participants indicated that the workshop had been interesting and in particular they had valued the opportunity to discuss and share ideas with peers. Most indicated that their support and access requirements had been fully met.

Some people had found it difficult to take in all the information as the discussion moved very quickly and some would also like the option of talking individually rather than in a group.

Taking part in the workshop had highlighted some issues, for example,

- raised awareness of the need for structural change in how research is funded and commissioned
- raised awareness of the need for service users and researchers to come together to resolve diversity issues
- issues such as sexuality and racial group which cut across other diversity considerations.

What will happen next?

The people who took part in the workshop have read and commented on the draft version of this report. Their comments have been incorporated.

This workshop was commissioned the INVOLVE Empowerment working group. The report was discussed by this group at their meetings in June and September 2010. The group will think about how to respond to the service user perspectives described in this report, recommendations for further actions and the other ways in which we can develop work to promote greater involvement in research by people and groups often overlooked or ignored by mainstream society.

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- (4) Steel R (2003) **Brief summary and checklist for researchers, research commissioners and research groups for involving vulnerable and marginalised people**, INVOLVE, Eastleigh
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(Also available from:

<http://www.shapingourlives.org.uk/ourpubs.html> (20.4.10)

Appendix 1: Workshop information

INVOLVE



Count us in! Involving everyone in health and social care research workshop

Workshop outline

Purpose of the workshop

INVOLVE and Shaping Our Lives are holding an event to find out about how more people can get involved in research – in particular people and groups who are often overlooked or ignored by mainstream society.

When we talk about getting involved in research, we mean the active partnership between service users, patients and / or carers and the researchers in the research process. Involvement means people having an active part in deciding what research is done or how it is carried out. This would include, for example, advising on research project, assisting in the design of a project, or in carrying out the research and leading research projects.

The aim of the event is to find out more about the issues which might make it hard for people from a diverse range of groups to get actively involved in research. We want to do this by learning from people who have experience in this area or ideas about it.

There may be common issues of concern, but there is also likely to be diversity in the needs across a range of people and groups. We wish to find out more about these.

This is the first event in a series to help us think about including the views of the diverse population. We want to build on this work later in 2010 to find out more about researchers perspectives on this issue and give them information about service user perspectives.

These events will contribute to an information guide to help greater involvement in research by people and groups who are often overlooked or ignored by mainstream society.

Workshop participants

There are places for 10 service users to attend this event. We are mainly interested in hearing from people and groups who experience additional barriers to involvement.

We would like to hear from people who have been actively involved in research. This will help us find out what helped people to get involved and also what things could be done better.

We would also like to hear from people who are interested in getting actively involved in research but have found it difficult – this will help us understand the barriers that make it more difficult for people from a diverse range of groups to get involved.

We would like to involve a wide range of people and groups in the workshop to ensure that a number of voices and perspectives are heard. However, we recognise that it may not be possible to involve all those people and groups who may feel they are often overlooked or ignored by mainstream society.

Format of the workshop

The workshop will have an interactive or participatory style. This means people will be invited to share their experiences and views. Shaping Our Lives will be running the whole day.

The day will be in two parts -

- The first part of the workshop will be for service users only. This will encourage an open discussion of the reasons why a range of groups and people do not get involved in research.
- After this a mixed session with service users and people from INVOLVE will enable the participants to learn from each other about the key barriers to involvement.

This will be done through a combination of presentations and small group discussions. Through these methods it will be useful to explore what are the things that helped meaningful involvement and the things that made meaningful involvement harder to achieve.

Appendix 2: Workshop timetable

Count us in!
Involving everyone in health and social care research

Workshop timetable

Wednesday 24th March 2010
10.30 am – 3.30pm

Ashton Room, Deaf Cultural Centre
Ladywood Road, Birmingham, B16 8SZ

INVOLVE and Shaping Our Lives are holding an event to think about how more people can get actively involved in research – in particular people and groups who are often overlooked or ignored by mainstream society.

Workshop facilitator: Peter Beresford, Chair of Shaping Our Lives

10.30am **Arrival, welcome and refreshments**

11am **Morning session*: Shaping Our Lives**

The first part of the workshop will focus on service user perspectives to think about how a diverse range of people can get actively involved in research. Key questions to think about might include:

- What works to ensure a diverse range of people and groups can get involved with research?
- What are the barriers that may prevent people and groups from diverse backgrounds getting involved?

1pm **Lunch**

2pm
INVOLVE

Afternoon session*: Shaping Our Lives and

This part of the workshop will include:

- Participants learning from each other about the barriers to involvement
- Feedback from the morning session
- Discussions about how the key issues could be taken forward

3.30pm

Close

* breaks will be built into these sessions as required

Appendix 3: Ground rules used at the workshop

Shaping Our Lives Suggested Ground Rules for Meetings

How we like to do things

- At the start of each meeting we will go round the table and people will say their name.
- Respect what each person needs to join in the meeting
- Respect and value that everyone is different and will think differently about things. We are happy that everyone is different and thinks differently
- Listen to each other
- Only one person speak at a time
- When you speak you need to say your name and to raise your hand or do whatever you can to let others know you are the speaker
- Do not interrupt speaker. If you need to, ask the chair-person.
- Use plain and simple English. Do not talk for too long, and talk slowly. We understand that for some people with some impairments it might be necessary for them to speak for a longer time and that is O.K.
- If you don't understand what someone is saying, please ask them to repeat it or explain it. You are probably not the only person who doesn't understand.
- Be aware that covering your mouth when speaking might make it difficult for people to read your lips or hear what you say.
- Use words in full, like Shaping Our Lives instead of SOL.
- Respect each others personal space

- During the meeting we will make every effort to keep to agreed timings
- In any reports or discussions after the event do not use people's names when personal things have been discussed, for example when people talk about something that has happened to them in confidence.
- Be polite, don't be rude to each other. If you disagree about something concentrate on the thing you are talking about not the person involved.
- If you disagree with something someone says say so either during that meeting or during the next meeting. Do not argue about it outside of the meeting.
- If you want to leave the room for any reason that is O.K.
- Switch off mobile phones
- Make every effort to turn up on time
- If you have any concerns about the Ground Rules not being respected please speak to the Chair of the meeting.

Appendix 4: Equal opportunities monitoring information

All workshop participants were asked to complete an equal opportunities monitoring form. Eleven of the 17 participants completed this. This information is summarised in the table below.

	Number (n=11)
Gender	
Male	4
Female	7
Transgender	0
Racial group	
Black Caribbean	1
Black African	1
White British	4
British Indian/Asian	2
White British/Greek	1
Religious or faith group	
Church of Scotland	1
Muslim	1
Catholic	1
None	3
Age	
Under 26	0
27-60	7
Over 60	3
Sexuality	
Heterosexual	8
Lesbian	1
Bisexual	2
Gay	0

Appendix 5: Shaping Our Lives

Who are we?

Shaping Our Lives National Network of Service Users and Disabled People is an independent user-controlled organisation, think tank and network. We started as a research and development project but became an independent organisation in 2002. We work with a wide and diverse range of service users and disabled people.

What do we want?

Shaping Our Lives National User Network's vision is of a society which is equal and fair where all people have the same opportunities, choices, rights and responsibilities – a society where people have choice and control over the way they live and the support services they use.

What are our aims?

- to support the development of local user involvement that aims to deliver better outcomes for service users
- to give a shared voice to user controlled organisations
- to facilitate service user involvement at a national level
- to work across all user groups in an equal and accessible manner
- to improve the quality of support people receive
- to enable groups to link to other user-controlled groups
- to develop links with world wide international user-controlled organisations.

Our working values

Shaping Our Lives will:

- reflect the priorities and needs of its member organisations
- encourage user-controlled organisations to learn both from each other and from wider best practice
- reflect the diversity of the network in its work
- apply equal opportunities practice in its governance, practice and as an employer.

Shaping Our Lives National User Network is an independent user-controlled organisation, think tank and network

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INVOLVE is a national advisory body that is funded by the National Institute for Health Research to promote and support public involvement in NHS, public health and social care research and development.

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