



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

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

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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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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.

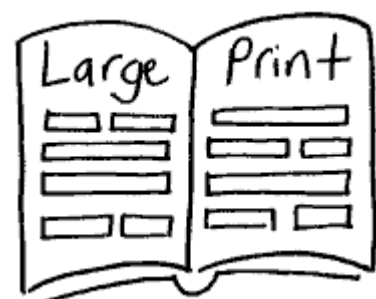
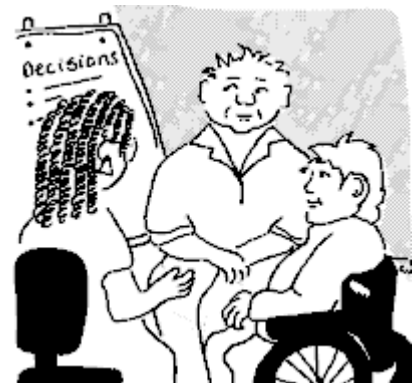


- Some researchers and research organisations have a lot more power than service users and their organisations. This makes it difficult for service users to stand up for themselves and be listened to. Some people do not take what they say very seriously.
- Institutional oppression means that service 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

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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