

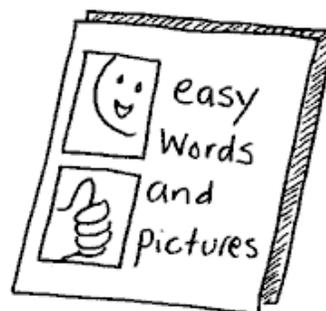
What User Controlled Research means, and what it can do.

An easy read summary of a report about user controlled research by Michael Turner and Peter Beresford, 2005.

Full Report:

Turner, M. Beresford, P. (2005) 'User Controlled Research: its meaning and potential' INVOLVE

- This summary tells you about some work that was done to find out about user controlled research.
- User controlled research is where service users are in charge of finding out about things that affect them.
- The summary tells you what service users thought about user controlled research.
- The summary is in different parts. You don't have to read them all at once. The next page tells you what is in the summary.
- There is a list of some difficult words at the back which tells you what they mean.



This is a list of the different parts of the summary. It also shows the page numbers where each part starts:

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What was this research?

- The **project** was to find out about research called '**user controlled** research'.
- **User controlled** research is where service users are in charge. They decide how they will do the research, so that it will be useful.
- This is very **different** from someone who is not a service user **deciding** what they think is **important** in research about service users.
- The money for the project came from an organisation called INVOLVE. INVOLVE is a national group that works to make sure there is more service user **involvement** in all kinds of health and social care research.



Who did the work?

The work of finding out was done by a group called Shaping Our Lives. This is a national **organisation** run by service users for service users.

The Centre for **Citizen Participation** at Brunel University was also involved.



'Service users' means people who use health and social care services, like:

- disabled people
- people with learning difficulties
- older people
- people who use mental health services.

Michael Turner and Peter Beresford did the work. They are both service users.

How was it done?

We knew that people sometimes have **different** ideas about what **user controlled** research is. We wanted to find out which ideas people had were the same, and which ideas were not.



We also wanted to find out:

- what service users thought was good about user controlled research
- and what **problems** there are about it.



The people who did the research wanted to do it carefully. They wanted to include many service users with **different** support needs who lived in **different** parts of the country. They wanted to get the big picture, so it was **reliable**.



The researchers decided to find out what people's ideas about **user controlled** research were in 3 ways:

1. They looked for what had already been written by service users, and others about **user controlled** research.



2. They talked with service users in groups in **different** parts of the country.



3. They talked to many **different** service users on their own.



What did they find out?

The researchers found that what the service users said, and what was already written, were nearly the same.

They found that:

- Service users thought that work by other researchers was sometimes not helpful to them.



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- Sometimes it made service users feel bad, because of the way the research work was done.
- When service users just take part in research their views are not always fairly listened to or talked about.
- This is why service users wanted to be in charge and do **user controlled** research.
- **User controlled** research is **different** from service users just being involved in research.
- Most service users say this difference is very **important**.



Making things better for service users:

Service users nearly all agree that **user controlled** research tries to:

- make the lives of service users better
- help service users have more say about what affects them
- make sure the people doing the research and the people taking part are treated equally.



Service users thought that user controlled research is helpful because:

- It helps them bring together ideas, **knowledge**, and understanding about service users, their lives, and the services they use



- it can and should be helpful to other people too (like people who make decisions in the government and local services)
- it is about making changes that service users think are important
- it makes **involvement** in research a good **experience** for people who take part
- it starts from service users' shared **experience** and **knowledge**
- it helps find out new, **important** things for service users to talk or think about
- it includes people who are often left out of research.



Should the researcher be a service user?

- Some service users say that it is not necessary for service users to do all the research so long as they are in charge. Others think that service users should do all the research. These are issues that service users themselves sometimes **disagree** over.



Worries and problems



People who run services often think that **medical** research is more valuable than other kinds of research. Some service users think that **user controlled** research is not valued by many people who run services because it is different.



Many service users are worried that **user controlled** research would be less valued in the future. It would then be more difficult to get money to do research **projects**.



Some researchers who are not service users say that **user controlled** research does not show the 'true picture', but only how service users see things. Service users agree that **user controlled** research is about how service users see things, but say this is valuable.



User controlled research often costs more money because it includes and supports people properly. Service users say that this means that getting money for **user controlled** research is more difficult.



Sometimes service users do not treat each other equally. This can sometimes



make **user controlled** research very difficult.



Sometimes doing **user controlled** research can be painful and stressful for service users. This might be because they have had similar **experiences** in life to the people they have to talk to. Support is needed.



What did people think should happen?

There were some things that service users thought were important for good user controlled research:

- There should be better information about user controlled research that reaches more people. Many people still do not understand what it is.
- Some of this information should go to people who pay for research so they know how to support **user controlled** research in their funding plans.
- There needs to be more service users who can do research. So training is very important.
- More work needs to be done on **user controlled** research by people from black and ethnic minorities.



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- Differences in the way research is done have already happened because of user controlled research. The learning should be brought together.
- More money is needed for bigger user controlled research projects.



That's the end of the main report. On the next page there is a list of some of the more difficult words we have used and what they mean.

This easy read summary was written by INVOLVE with the help of Maggie Brennan, and Jennifer Taylor from Lambeth People First, and Vic Forest.



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List of long words used in this easy read summary

Academic

- Work that is done at a place of learning such as a University, or
- someone who works in teaching or learning at a University

Carefully

With care. Trying not to make mistakes

Challenge

Something that is hard to deal with.

Citizen

Someone who belongs to a community or a country. In England we are all citizens.

Communities

Groups of people who live in the same place or in the same way.

Compared

Looked to see if one thing is the same or **different** to another.

Control

Being in charge and making things happen.

Deciding

Thinking about making a choice.

Disagree

Do not agree.

Discriminate/Discrimination

Treating people **differently** without a good reason, such as when they cannot speak well, or they look **different**.

Empowerment

Having a choice about being more in charge.

Equality

Everybody having the same rights and choices.

Experience

What you understand because of what has happened to you.

Explain

To talk about something so you can understand it.

Important

Of much worth.

Information

Tells you about things

Involvement

Being involved. Doing something with others

Knowledge

- What we know
- Or what is known

Medical

To do with the health of our bodies.

Minorities

Small group of people who are **different** from most people because of who they are.

Organisation

A big group that has a name and makes things happen, like running services, or giving **information**.

Participation

Being part of something, or doing something with others.

Possible

Could happen

Problem

What makes something difficult

Professionals

People who are specially trained and paid to do a job.

Project

Something to be done which has a beginning and end.

Reliable/Rely on

Something or someone you know is not going to let you down

Research

Finding things out in a careful, planned way, step by step

Researcher

Someone who does research

Summary

Main ideas from a piece of writing, discussion, or event

A full copy of the report by Michael Turner and Peter Beresford is available on the INVOLVE website, www.invo.org.uk

Please let us know what you thought of this summary, and if you think it could be made better.

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