

# Summary

# Changing Our Worlds: examples of user-controlled research in action

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**INVOLVE**

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

# About this summary

**This summary was commissioned by INVOLVE and written by Alison Faulkner.**

The report has been written for a broad audience, but with the expectation that readers will have some understanding of research.

## Information about INVOLVE

INVOLVE is a national advisory group which supports greater public involvement in NHS, public health and social care research. We are funded by the National Institute for Health Research (NIHR).

For further information on INVOLVE please visit our website [www.invo.org.uk](http://www.invo.org.uk)

## Information about the author

Alison Faulkner has personal experience as a user of mental health services and a background in research and training. She has experience of leading and supporting research from a service user/survivor perspective and of enabling and supporting service users to become involved in research.

This summary should be referenced as:

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For further information please read the full report:

Faulkner, A. (2010) **Changing our Worlds: Examples of user-controlled research in action.** INVOLVE, Eastleigh.

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# Introduction

The aim of this project was to increase understanding and awareness of the role and value of user-controlled research, through exploring seven examples in depth.

## User-controlled research

There are different ways of referring to and defining research conducted or controlled by service users, and some people use the terms 'user-led' and 'user-controlled' research interchangeably. Turner and Beresford, in their report 'User-controlled research: its meaning and potential' published by INVOLVE in 2005, suggest that control by service users is the key defining characteristic of user-controlled research, but that making change happen is commonly identified as its central purpose.

Seven projects where service users or disabled people controlled the research process were selected and explored in detail (see table on page 4). Researchers and service users and other key people were interviewed about their project. Questions covered: the origins of the research, the methods used, the nature and extent of user control over the research, and the dissemination and impact of the research findings.

# The user-controlled research examples

Project title	Organisation	Theme
Deaf People's Mental Health Pathways	Vision Sense	Mental health
Comparison of urine and blood tests for thyroid function	Thyroid UK	General health
Connect Works (what people with learning difficulties want from personal assistants)	Connect in the North	Learning difficulties
Disability Hate Crime	DITO (Disability Information Training Opportunity)	Disability
The Rainbow Ripples report: (needs and hopes of Lesbian, Gay and Bisexual (LGB) disabled people in Leeds)	Rainbow Ripples	Lesbian, Gay and Bisexual
The Young Researcher Network projects: 1. Get the life you want (GLUW) – Making the Lives of Young People in Care Better 2. Have Your Say – How Looked After Children are involved in the Review Process	Supported by the National Youth Agency Young Researcher Network	Young people
Relationship Matters	Shaping Our Lives	General user involvement

More detailed information about each of these examples is available in the full report.

# Common themes and discussion

## 1. The reasons for doing user-controlled research identified by these seven projects were:

- To make change happen
- To highlight the needs of marginalised groups
- Because 'No-one else will do it'

## 2. The projects demonstrated a range of different ways of doing user-controlled research. These included different:

- Research approaches
- Organisational bases
- Levels of control
- Sources of funding

All of the projects originated out of a commitment to changing or improving the lives of their community of service users, whether directly or indirectly, locally or nationally. Findings from the projects suggest that user-controlled research often arises from within groups of people frustrated by traditional research that overlooks or excludes them and/or services that do much the same thing. Frustrated by the failure of mainstream research to capture their needs or research the things they thought important, they found ways of doing so themselves.



Somebody needed to tell the story of our lives as LGB [lesbian, gay and bisexual] disabled people.

**Rainbow Ripples**



Through raising awareness of the experiences and needs arising out of their lived experience, groups like lesbian, gay and bisexual disabled people, young people in care, disabled people and Deaf people with mental health needs placed themselves on the map of human experience and were able to exert some influence on local and/or national service or policy development.

Three projects employed or contracted service user researchers or disabled people to undertake the research; three adopted a 'capacity-building' approach in which service users were trained and supported to participate as researchers; and one undertook a clinical study coordinated by the group. A variety of methods included focused events in which people shared their experiences, and the more conventional use of questionnaires, interviews, and focus groups. Common to all of the projects was a shared identity between the researcher(s) and the research participants.

The extent of control by service users varied across the seven projects. Absolute control depended on service users having independent funding (and having control of that funding) as well as a user-controlled organisational base. Having control over the research was seen as vital by all of them. Many of the people interviewed spoke passionately about the significance of having control, both to themselves and to their organisation and their wider community of service users.



It just wouldn't have happened if we hadn't had that level of control.

**Rainbow Ripples**



### 3. The benefits of user-controlled research were identified as:

- Making change happen
- Access and trust
- Improved research quality
- Empowerment
- Credibility

Amongst these seven case studies are some powerful examples of user-controlled research making a difference. As stated earlier, all of the projects were committed to making change for the benefit of their community of service users. What is perhaps surprising is the degree to which they achieved this, given their scale and the size of their budgets.

A shared identity between the researcher and participants meant that trust could be established, particularly when conducting face-to-face interviews and focus groups, leading to improved access to participants and to open and honest accounts about the issue under investigation.



It's people who know asking people who know.

**Connect Works**



People take us more seriously. That's what empowerment is. Empowerment: you know you can do it.

**Young Researcher Network**



The value of a shared identity was also demonstrated when it came to designing the research, deciding upon the questions and analysing and interpreting the findings. The 'insider knowledge' ensured that the research would address the right questions, and be interpreted by people with an understanding of the nature of that lived experience.

For some projects, the increased accessibility that this shared identity brought with it was central to the success of the research. For example: a Deaf researcher who could communicate with Deaf participants using British Sign Language, young people in care talking to other young people in care, and the value of people with learning difficulties seeing a person with learning difficulties facilitating and leading a group.

Empowerment has been identified as a key principle of user-controlled research. These projects help us to understand empowerment and how user-controlled research can bring about empowerment for the service users involved. It was most often mentioned in connection with the two projects that involved supporting service users without previous research experience: the young people's projects and Connect Works. The young people talked of the opportunity the research had given for them to learn new skills and gain confidence. Empowerment reached out beyond the research and into people's lives.

#### **4. The challenges of user-controlled research encountered by these projects included:**

- Resources
- Discrimination
- Dilemmas surrounding identity and power
- Distress

In nearly all of the projects, individuals and organisations had contributed additional resources over and above the funding they had received. Some contributed their time and skills for free because of their commitment to the research. Others subsidised the available funds, whether in terms of actual money or staff time or both, in order to ensure their success.

Many of these projects represented people facing multiple discrimination. For at least two researchers, this became a very real part of the research process; one experienced abuse as he left one of the interviews and one researcher received abusive emails in response to publicity about the research.

Having control over the research did not necessarily mean that issues of control and power were predetermined or unproblematic. Sharing key aspects of personal identity or experience with research participants could give rise to some dilemmas on the part of the researchers. It could lead to people asking more of the researcher than they could perhaps offer, or to some discomfort on the part of the researcher about their role and the power they had adopted in relation to their interviewees. In addition, this shared identity could at times lead to distress on the part of researchers who shared difficult experiences.

All of these challenges highlight the importance of building in good supervision and support for service user researchers and ensuring that lone workers in particular have adequate opportunities for de-briefing and supervision.

#### **5. The impact of user-controlled research demonstrated by these projects can be seen in relation to their:**

- Impact on service users
- Impact on the research
- Impact on services
- Impact on policy

Nearly all of these projects had achieved what they set out to do, in making change happen. Some directed their findings towards people in decision-making positions within local services with the aim of making changes through policy and service development.

Service user/researchers involved in these projects talked passionately about gaining new skills, gaining in confidence and feeling empowered. Some had gone on to develop their skills further or to do more research. Many of the projects resulted in tangible outputs which aimed to extend their impact to their wider community of service users. Examples of these include: training packs, information packs and dedicated website, a training programme, DVDs and an improved pathway through mental health services.

Several projects were able to make use of their relationships with powerful allies to impact upon change. The Vision Sense project worked closely with a Deaf commissioner, who was able to understand the issues and politics surrounding the culture of Deaf people; Thyroid UK had a medical ally to assist them with their research as well as a wealth of expertise amongst their members; the National Youth Agency's Young Researcher Network acted as an ally in enabling the successful dissemination of the two Young Researcher Network projects.

Some of the projects also achieved an impact on national policy, whether by virtue of their efforts at disseminating the findings, or through support from their funding body. Recommendations from the Rainbow Ripples report entered the Commission for Social Care Inspection inspection guidelines. Connect Works, through dissemination via the Skills for Care website may have had an impact on personalisation policy in relation to people with learning difficulties. The young people's projects were enabled to disseminate their findings at a national level through support from the National Youth Agency's Young Researcher Network, including taking part in a House of Lords' debate.



It wasn't just the research, it's opened lots of doors for us, we got involved in all sorts of other stuff...go to all sorts of places you wouldn't ever have gone to, like the House of Lords.

**Young Researcher Network**



# Conclusions

**This section contains the key messages from this detailed exploration of seven user-controlled research projects.**

**1) These seven projects powerfully demonstrate what can be achieved by small organisations or groups of service users on sometimes very small budgets:**

- most had found creative ways of ensuring that the findings reached the people that mattered, some through obtaining additional funding and some through their relationship with powerful allies.

**2) The projects were motivated by the desire for positive change:**

- to improve the lives of service users
- to improve services or influence policies that will affect the lives of service users.

**3) These seven projects highlight the potential of user controlled research to raise awareness of the needs of groups and people often ignored or overlooked by mainstream society, creating opportunities to:**

- describe and account for their lives, and to
- identify and explore specific needs not addressed by mainstream research.

**4) The projects highlight the potential of user-controlled research to create the conditions for empowerment through:**

- equalising the relationship between researcher and researched through a shared identity
- establishing trust with research participants
- enabling service users to participate in the research process with training and support
- leading to positive change.

**5) The challenges they faced were common to many research projects involving service users:**

- issues of identity and power, personal distress and inadequate resources
- however, a few of them also faced incidents of direct discrimination during the course of the research
- these challenges indicate the need for user-controlled research projects to establish support strategies to sustain them through difficult times.

**6) The things that helped them to succeed included:**

- passion and commitment
- funding
- good support and training
- support of powerful allies.

# Further information

This summary report is supplemented by:

The full report: Faulkner A. (2010) **Changing our worlds: examples of user-controlled research in action**, INVOLVE, Eastleigh.

An easy version of Example 3: Faulkner A. and Connect in the North (2010) **Easy read version: Connect Works – Connect in the North**, INVOLVE, Eastleigh.

We have also produced a series of short films available on DVD and our website. These include one film about user-controlled research and four short films presenting the examples of user-controlled research.

This publication is one in a series. Other titles available are:

Blackburn H., Hanley B. and Staley K. (2010) **Turning the pyramid upside down: examples of public involvement in social care research**, INVOLVE, Eastleigh.

These and other useful INVOLVE publications are downloadable (free) from: **[www.invo.org.uk](http://www.invo.org.uk)**

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## Key references

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Hanley, B. et al. (2004) **Involving the public in NHS, public health, and social care research: Briefing notes for researchers**. INVOLVE, Eastleigh.

Turner, M. and Beresford, P. (2005a) **User Controlled Research: Its Meanings and Potential. Eastleigh: Shaping Our Lives and Centre for Citizen Participation**. Brunel University.

**Disclaimer:** The views and opinions expressed in this publication are those of the authors and do not necessarily reflect those of INVOLVE or the National Institute for Health Research.



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