

**INVOLVE**

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

**NHS**

*National Institute for  
Health Research*

INVOLVE is funded by the National Institute for Health Research

---

# **Social research and public involvement: colliding worlds?**

**A JOINT INVOLVE and ESRC NATIONAL CENTRE  
FOR RESEARCH METHODS SEMINAR**

**26<sup>TH</sup> SEPTEMBER 2008**

**REPORT**

---

**This one day seminar was for researchers, including user researchers, with an interest in public involvement in applied social science research. The seminar discussed the contribution that the public can make to the research process (e.g. users of public services and people directly affected by applied or social policy research). It provided an opportunity to hear from speakers about the issues and challenges of public involvement and to discuss approaches to facilitating this process.**

**This report was written for INVOLVE and NCRM by Ruth Stewart, Social Science Research Unit, Institute of Education, University of London.**

**This report should be cited as:**

Stewart R (2008) Social research and public involvement: colliding worlds? A report of a joint INVOLVE and ESRC National Centre for Research Methods seminar, INVOLVE.

# Contents

Abbreviations .....	1
Summary .....	2
Background .....	3
Delegates .....	3
Introducing the day.....	4
Three perspectives on public involvement and social research.....	4
Workshop discussions of why and how to involve the public in social research .....	8
Final reflections on the day .....	13
Appendix 1: Delegates.....	14
Appendix 2: Programme.....	16
Appendix 3: About the speakers .....	17
Appendix 4: Powerpoint presentations.....	18

## Abbreviations

ESRC	Economic and Social Research Council
NCRM	National Centre for Research Methods
NIHR	National Institute for Health Research
SPRU	Social Policy Research Unit (SPRU)

## Summary

Organised jointly by the National Centre for Research Methods and INVOLVE, this seminar brought together researchers, including user researchers, service users and carers with an interest in public involvement in applied social science research. Through the course of the day delegates enjoyed thought-provoking presentations and discussions exploring the issues around why involve the public in social research and how. Rather than providing answers, a number of issues and questions were raised providing a useful foundation for further work in this area.

The main issues arising from discussions about **why** involve the public in social research included:

- questions about ownership of research, control and power;
- the possibility of conflicting agendas;
- the pressures on researchers to conduct more traditional research and publish papers in peer-reviewed academic journals;
- the challenge of managing the expectations of those involved in research;
- the question of how public involvement might shape research itself; and
- in what ways public involvement might enhance the quality of social research.

In considering **how** to involve the public in social research the following issues arose:

- the need for common ground to ensure effective public involvement;
- the importance of attitudes to public involvement;
- differing ideas about quality in research;
- the challenge of representativeness in public involvement;
- time and resources, as well as social science methodologies,
- both as facilitators and as barriers to public involvement in research;
- the importance and complexities of incentives for participants; and
- the need to consider the long lasting effects of public involvement in a research project.

The day concluded with final reflections about the value of the day. People spoke about having learned from one another and recognised that we had built a good foundation from which to work together. Many benefits of public involvement in research were recognised, whilst acknowledging that public involvement remains challenging for all involved. It was agreed that this seminar represented the beginning of an ongoing dialogue about public involvement in social science research.

---

## **Background**

This seminar was planned and organised by the National Centre for Research Methods and INVOLVE.

The National Centre for Research Methods (NCRM) is funded by the Economic and Social Research Council (ESRC) to improve the standards of research methods across the UK social science community. It provides a focal point for research, training and capacity building activities.

INVOLVE is a national advisory group, funded through the National Institute for Health Research (NIHR). Its role is to support and promote active public involvement in NHS, public health and social care research. This is in order that research might be: more relevant to people's needs and concerns, more reliable and more likely to be used.

---

## **Delegates**

The seminar was attended by fifty people, including social science researchers, service users and carers. A full list of the delegates and their organisations is included in Appendix 1.

---

## Introducing the day

Jackie Powell (NCRM) and Angela Barnard (INVOLVE) opened the meeting by welcoming everyone and introducing the day. They explained that this day was a learning opportunity for everyone and a chance to explore the issues of public involvement and social research in a safe and supportive environment. They expressed the hope that this would be the first of many such discussions.

The programme for the day is included in Appendix 2.

---

## Three perspectives on public involvement and social research

The morning session consisted of three presentations providing different perspectives on public involvement and social research: the perspective of conventional social science; of people researching their own lives; and of bringing social scientists and communities together. Profiles on each of the presenters are included in Appendix 3 and their presentations (where available) are in Appendix 4.

### 1. Who is research for?

#### **Roy Sainsbury, Assistant Director, Social Policy Research Unit (SPRU), University of York**

**Presentation** (see appendix 4 for slides)

Roy Sainsbury introduced himself and explained that his work at SPRU is in the area of benefits, employment, sickness and disability. SPRU has a common aim, 'to reflect, and communicate, the experiences and views of the users and beneficiaries of services and policy interventions'. He then presented a number of ideas about who research is for, how the public might be involved in social research, and why.

He suggested that research projects might be for a wide range of different people who he described as 'stakeholders'. These included: the target groups who were the focus of the research, the wider public, researchers themselves, the wider research community, funders, service providers or practitioners, policy makers and the media. Using two examples (a children's hospice project, and a mental health and employment project) he illustrated how these different projects gave more emphasis to different stakeholders.

He explained how 'outsiders' (ie those not already members of the research community) might be involved in a number of roles:

- as participants of the research (interviewees etc)
- in giving advice to the research team
- being part of the research team
- in controlling part of the research project.

Roy suggested that at the very least a project's findings should be based closely on the accounts of research participants. He added that he has not had direct experience of the public taking control of part of the project, or being part of the research team.

He then discussed ideas about how the public might be involved in research: deciding the aims of the research, the design, the recruitment and data collection, data analysis or the outputs.

Roy presented two main purposes for public involvement in social research:

- ethical reasons, such as human rights and empowerment
- functional reasons, such as increased quality of research and greater impact.

He suggested that these are very different purposes, and that either or both can be relevant to an individual project.

Roy highlighted that there are no rules about who research is for and that researchers are in a very powerful position to decide. He stressed the importance of clarity about the reasons for public involvement, the need to acknowledge both the advantages and disadvantages of involvement, and the need to address barriers such as time and funding.

Lastly, he concluded the presentation with the suggestion that social research and public involvement may not be colliding worlds, but instead we should aim to continually move between two 'connecting' worlds.

## **Discussion**

The discussion following this presentation raised a number of additional issues. These included how, sometimes, it isn't possible to define in advance who research is for, but rather this evolves during the course of a project. There was also discussion about the power of funders and how it can sometimes be a challenge to stand up for any controversial findings of research. Some delegates said they did not consider being a participant in a research project (as an interviewee etc) as being the same as actively involved in the research. Others argued that being a participant could still provide some

opportunities to shape research, either when giving feedback in pilot interviews or in raising new issues in open ended questions.

## 2. Research messages from young people

### Mary Kellett, Director, Children's Research Centre, Open University

#### **Presentation** (see appendix 4 for slides)

Mary Kellett began by explaining how her centre only supports research by young people on issues they think are important, and that by working with schools and the community they are creating a body of knowledge generated by children. She presented her experiences of involving young people as well as some of their work.

She described involvement in research as a choice, with not everyone wanting to take part. She underlined how important it is not to impose participation on young people, whilst also not excluding anyone from taking part. She explained the potential benefits for young people of getting involved, including achieving better understanding amongst adults of young people's worlds. She stressed the importance of high quality training to ensure young people have the skills and confidence to contribute and the need to support young researchers, whilst not managing their activities or putting pressure on them. She highlighted the need to teach young people about ethical responsibility in conducting research as well as the need for the adults supporting them to take an ethical approach to their role. Mary presented young people's popular data collection methods, and approaches they use to analyse the information they collect (see slides for more information).

To illustrate their work, she presented two projects designed and conducted by young researchers. The first project was undertaken by the daughter of a wheelchair user, exploring the issues surrounding travelling as a pedestrian, by train and by bus. The second was a project by a group of young people with learning difficulties about their involvement in decision-making groups such as youth councils. Mary used slides prepared by the young people themselves.

#### **Discussion**

The discussion following this presentation focussed on the range of possible outcomes of such work and the challenge for young people, and older researchers, if their research

findings are surprising or ignored. The issue of funding was also raised as these types of involvement activities are rarely well financed.

### **3. A perspective from the community**

#### **Richard O'Neill, Community Campaigner, Gypsy Traveller, Fellow of Social Entrepreneurship**

##### **Presentation**

Richard O'Neill started by talking about our preconceptions of what people are like, particularly how researchers can be perceived as very clever and distant. He talked about the need for people to get to know one another and not rely on what we learn from the internet. He illustrated the need to talk a common language by reading from an INVOLVE conference abstract and reciting a builder's shopping list – both used specialist terms not widely understood, and stressed the need to communicate clearly.

As a gypsy traveller he was able to draw on examples of researchers working with his community. He highlighted some of the mistakes which have been made with researchers making assumptions, accepting rumours and raising expectations and suspicions amongst the community. One example included researchers providing Marks and Spencer's vouchers to people who never shopped in Marks and Spencer's, and attempts to run focus groups in an inappropriate venue and no-one turning up. He described himself as fulfilling the role of a 'key communicator', someone who is trusted by researchers and the community and who can therefore help both groups to build working partnerships.

Richard stressed the importance of properly funding public involvement in research and suggested that if you are unable to fund people's participation properly then you shouldn't start the project. He talked about making involvement fun, and ensuring that people are happy to be associated with the project. He expressed his wish, that when the researchers move on, he wants his community to be better off for their involvement.

Richard ended his talk by telling us that when people ask what he does, he explains that he is like the cement that joins bricks in a building – insignificant to look at, but holding everything together.

##### **Discussion**

Delegates were keen to learn how to identify key communicators within different communities; by asking around and making note of the recurring names. There was

discussion of the term 'hard to reach' groups. There was a dislike amongst some of labelling people, with such a researcher-centred term.

---

## **Workshop discussions of why and how to involve the public in social research**

In the afternoon session delegates were asked to choose between two workshop topics, with the aim of:

- Learning from each other about the challenges and the management of public involvement in the context of social science research;
- Identifying key issues for developing public involvement in social science research.

In the workshops delegates were asked to draw on their own experiences of research from researcher and/or user perspectives to explore specific questions relating to the why and how of public involvement in social science research.

### **Workshop 1: Why involve the public in social research?**

#### **Who research is for: implications for methodology & the nature research**

Working in two groups, delegates in this workshop were asked to address the following topics:

- Who or what is research for? Who is the end user in research (from the perspectives of different people -i.e., academic researchers, researchers in other settings; user researchers; service users; the public)?
- What are the aims of research from the perspectives of different people (i.e., academic researchers, user researchers, service users, the public)? What things motivate these different groups to undertake or become involved with research?
- Can the aims of and needs for research from different groups be reconciled? How?
- What are the implications for research methods of user involvement? Does user involvement imply a particular type of methodological approach? Can non-participatory methods be used and still satisfy a 'user involvement' agenda?

- What implications does user involvement have for the nature of research?

In their groups, workshop delegates raised the following issues relating to why the public should be involved in social research. In discussing the reasons **for** public involvement, the groups also chose to discuss the **challenges** facing public involvement:

- Questions about who owns research and who has the power, or should have the power, to make decisions about research were raised. Whilst it can be argued that research that uses public funding should be owned and controlled by the public, some researchers may be reluctant to allow others to take control. Indeed, there is a view among some researchers that allowing non-researchers to take control might reduce the value of the research.
- The potential for those involved in research to have different and conflicting agendas was raised as an issue. This may be an argument both for and against public involvement. Some people suggested that when members of the public control research they might have a different aim from researchers, and even that different groups, such as patients and carers, may have differing agendas. Others pointed out that both academics and service-users have their biases and may not be objective.
- Workshop delegates described the pressures on researchers to produce research for different audiences, in particular their need to satisfy their funders in order to generate an income for themselves. Arrangements for research funding for universities put particular pressure on researchers to focus on writing academic papers. Politicians and politics, as well as the media, add to the pressure on researchers to undertake particular research using particular methods for certain audiences. Who research is for may differ from those who are the final beneficiaries, and the consideration of who research is for can even change during the course of a project. It was considered an ethical issue for researchers to consider why they were undertaking research and what the benefit might be before starting the project.
- The importance of transparency, clarity and managing the expectations of all those involved in research was highlighted as a challenge. In particular, the workshop delegates stressed the need for clarity about the purpose of involvement in research. Wider communities may also need to understand what the research might achieve and that there is value, even if the research has a negative result (i.e. it finds something does not work).

- The groups discussed who to involve in research and the implications on how research is done. It was suggested by some delegates that certain research methods may not be appropriate for public involvement. Some people felt that involving members of the public in quantitative research which uses complicated study designs and statistics might be inappropriate, although others disagreed. It was also suggested that involving people particularly from the start of a project, can shape the research methods used.
- If the purpose of public involvement is to ensure that different views and perspectives are represented, a question is raised about how to ensure the research remains independent. When researchers struggle to find a way to involve the public, they need to reflect on this and be clear about why people may not have been involved. Whilst public involvement should be valued, any disadvantages and challenges should also be recognised.
- It was suggested that the involvement of members of the public in research might also contribute to the development of new research methods, such as quality of life measurements.

## **Workshop 2: How might we involve the public in social research?**

### **Modelling possibilities for involvement: the challenges of involvement**

Working in two groups, delegates in this workshop were asked to address the following topics:

- What does user involvement in research mean? What does the term user mean in this context (from the perspectives of different people -i.e., academic researchers, researchers in other settings; user researchers; service users; the public)?
- What are good models of involvement? What are poor models of involvement? How do these translate in applied social science research (which may take place in academic or other research institutions)?
- What do social science researchers view as the barriers and opportunities for user/public involvement in applied social science research? How can these be addressed? Whose role is it to address them? Is there the will to do so?
- Should there be incentives to encourage or enforce user/public involvement in research (e.g. by funding bodies insisting on user involvement in projects)?

- How can user researchers/the public influence research design and practice in Universities and other research organisation that conduct applied social science research? Should they attempt to do so?

Discussions were wide-reaching and highlighted the following issues :

- Identifying common ground was seen as fundamental for effective public involvement. It was noted that this requires recognition of the importance of public involvement in research, as well as challenging stereotypes of power and authority in research.
- Attitudes to public involvement were identified as central. In particular it was noted that user involvement requires courage on the part of both researchers and service users/the public. One view expressed was that service users have valuable information to contribute and it should not be assumed that they require mentoring; they may in fact be in the best position to mentor the researcher in certain areas. In addition it was suggested that researchers consider not only what they think the benefits of involvement are, but other people's views of what the benefits might be.
- Concern was expressed that there might be difficulty in maintaining rigour alongside public involvement in research. However it was agreed that the commitment to high quality research is one shared by both researchers and service users.
- Workshop delegates discussed issues relating to how representative public involvement should be. The importance of not over emphasising diversity and representativeness was stressed. While diversity was important, it shouldn't be used as an excuse for not involving anybody and not always the most important consideration.
- The groups discussed factors which facilitated public involvement as well as barriers to involvement. The need to highlight to research funders that public involvement needs to be properly resourced was identified as a key issue. Other important factors included time and resources, as well as existing social science methodologies and processes which can exclude the public taking part.
- Incentives for involvement, such as money or gift vouchers, were acknowledged as an important issue, including what to pay and how, and concerns about people on benefits being unable to accept payment.

- Lastly the need to follow through after research is conducted was highlighted, for example issues about what happens to those who have got involved once the project ends, and what happens to the findings of the research.
- 

## Plenary

### **Peter Beresford, Director of Centre for Citizen Participation Brunel University, Chair of Shaping Our Lives**

To conclude the day Peter Beresford shared some thoughts about the discussions of the day. He suggested that perhaps public involvement and social research are not colliding worlds but actually just worlds which miss each other altogether. In a recent speech the prime minister emphasised the importance of traditional clinical health research; more innovative research which engages with and involves the public has no such profile. Similarly social policy research text books show very little commitment to public involvement.

Peter welcomed the dialogue which this day represented. He spoke of the time given to public involvement at the ESRC methods festival earlier in the year and suggested that there is now a need to engage people in discussion in a safe and supportive environment, as this day had. He spoke of this as the first step and looked forward to further meetings and forums for ongoing discussion.

Referring back to Roy Sainsbury's point that there are both functional and ethical grounds for involving the public in research, Peter suggested that the way forward is to give attention to both of these. He suggested that whilst researchers have some power to influence the extent to which the public is involved in research, funders are even more powerful.

Referring to Mary Kettle's presentation of children's research, he welcomed the way in which Mary had shown what is possible and what the potential gains of public involvement are, both for individuals and society. He highlighted the importance of having a growing evidence-base of public involvement in research, such as the research by young people, from which to draw lessons and make recommendations. He talked about the need to engage with questions about the rigour of research and indeed what constitutes research, and suggested that we need to recognise and engage with different types of knowledge.

Referring to Richard O'Neill's presentation, he picked up on the importance of recognising and challenging expectations and preconceptions about each other. He welcomed Richard's assertion that research has to offer everyone something and stressed that if we wish to make a difference we have to go out to where people reside.

Reflecting on what the next steps are, Peter quoted from a colleague who said that we had to 'riddle the system' with public involvement – in funding research, conducting research, peer reviewing research and disseminating research. It is important to be working with 'believers' but also 'agnostics'. He promoted the need to publish on the subject of public involvement in social research, in text books, journals, peer-reviewed publications, organisational reports, training resources and so on. He warned that we should not assume that the progress which has been made in involving the public in social research will remain; it needs to be guarded and promoted in order that we can build on it.

---

## **Final reflections on the day**

When asked to give their final reflections on the day, the speakers and some of the delegates suggested the following key points:

- These discussions had been worthwhile and a great deal learnt during the course of the day.
  - The benefit of public involvement in research was recognised
  - Public involvement takes courage and we need to be ready to challenge those in powerful positions.
  - There remains an ongoing need for dialogue as there are still questions to explore and issues to discuss.
-

## Appendix 1: Delegates

<b>Name</b>	<b>Organisation (if applicable)</b>
Gabby Ansems	Multiple Sclerosis (MS) Society
Leila Baker	Independent Researcher
Angela Barnard	Independent Consultant and member of INVOLVE
Geoff Barr	St Leonard's Research Practice
Ruth Bartlett	University of Bradford
Peter Beresford	Centre for Citizen Participation, Brunel University and member of INVOLVE
Annette Boaz	King's College London
Melanie Boyce	Anglia Ruskin University
Louca-Mai Brady	National Children's Bureau and member of INVOLVE
Sarah Buckland	INVOLVE Support Unit
Verity Campbell-Barr	University of Plymouth
Kryisia Canvin	University of Oxford
Mandy Cook	Swansea University
Judy Corlyon	The Tavistock Institute
Hannah Curtis	Ecodesign Centre Wales
Kate Darlington	Brunel University
Naomi Day	The National Centre for Social Research
Nick Emmel	Sociology and Social Policy, University of Leeds
Bob Erens	National Centre for Social Research
Jennifer Evans	Welsh Assembly Government
Sandra Fitton-Wilde	University of Derby
Tony Gilbert	University of Plymouth
Louise Hardwich	University of Liverpool
Yvonne Harris	Arts Council England
Belinda Harries	South London and Maudsley Trust
Helen Hayes	INVOLVE Support Unit
Keith Holt	Comensus/ Service User and Carer Advisory Group (SUCAG)

Poonam Jain	Researcher, London Borough of Harrow and member of INVOLVE
Victoria James	Essex County Council
Jagadish Jha	Institute of Psychiatry, King's College London
Elizabeth Jones	Children's Research Network
Kairika Karsna	Shared Intelligence
Mary Kellett	Childhood and Youth Studies, The Open University
Mary Nettle	Mental Health User Consultant and member of INVOLVE
Sandy Oliver	Perspectives, Participation and Research, Social Science Research Unit, Institute of Education
Richard O'Neill	Fellow of Social Entrepreneurship
Rosemary Phillips	University of Southampton
Jackie Powell	ESRC National Centre for Research Methods
Neil Radford	University of Derby
Rebecca Rees	Social Science Research Unit, Institute of Education
Neil de Reybekill	MEL Research and Centre for Community Research
Roy Sainsbury	Social Policy Research Unit (SPRU), University of York
Juliet Scott	The Tavistock Institute
Elizabeth Smith	National Nursing Research Unit, Kings College London
Sophie Staniszewska	The NHS Centre for Involvement, University of Warwick and member of INVOLVE
Ruth Stewart	Perspectives, Participation and Research, Social Science Research Unit, Institute of Education
Peter Sullivan	Comensus/ Service User and Carer Advisory Group (SUCAG)
Maryrose Tarpey	INVOLVE Support Unit
Rose Wiles	ESRC National Centre for Research Methods

## Appendix 2: Programme

### PROGRAMME

10.00: **Registration and coffee**

10.30: **Introduction**

Jackie Powell, Co-Director ESRC National Centre for Research Methods and Angela Barnard a Member of INVOLVE

10.45: **Who is research for?**

Roy Sainsbury, Assistant Director SPRU University of York

**Research messages from young people**

Mary Kellett, Director Children's Research Centre, Open University

**A perspective from the community**

Richard O'Neill, Community Campaigner, Gypsy Traveller, Fellow of Social Entrepreneurship

12.15: *LUNCH*

13.15: **Discussion - a choice of two workshops:**

**Workshop 1: Why?**

Who research is for; implications for methodology & the nature of research

**Workshop 2: How?**

Modelling possibilities for involvement; the challenges of involvement

14.45: *BREAK*

15.00: **Plenary session: An Agenda for the Future**

Peter Beresford, Director of Centre for Citizen Participation Brunel University, Chair of Shaping Our Lives

**Speakers Panel and discussion**

16.00: *FINISH*

## **Appendix 3: About the speakers**

### **Roy Sainsbury**

Roy Sainsbury is Professor of Social Policy in the Social Policy Research Unit (SPRU) at the University of York. Over the past 20 years he has carried out research, for government and other funders, in the area of benefits, employment and sickness and disability. The Social Policy Research Unit includes in its organisational aims to reflect, and communicate, the experiences and views of the users and beneficiaries of services and policy interventions, an aspiration that has been addressed in a variety of ways but possibly not always achieved.

### **Dr Mary Kellett**

Mary Kellett has an international reputation as a leading pioneer in the empowerment of children and young people as researchers and has done much to establish this as a serious focus of study. She has published widely in this and associated fields and sits on a number of advisory panels. She is Founder Director of the Children's Research Centre at The Open University, a unique centre that exists solely to support research by children and young people. Her work has inspired many initiatives including a three year European Community funded project, 'Children as Researchers in Primary Schools in Europe' involving eight Higher Education Institutions in seven European countries. She was appointed International Expert by the United Nations Development Programme to a bi-communal young researchers' project in Cyprus and is a Visiting Professorship at the Institute of Education, Qatar, where she is developing a student research programme in Qatari schools.

### **Richard R O'Neill**

Richard O'Neill was born into a large Gypsy Travelling family in the North East, Richard followed a traditional travelling lifestyle, before settling in the North West in the mid nineteen eighties. Since the early 1990s Richard has worked as a community volunteer and a freelance trainer, counsellor, management consultant and professional speaker.

His current clients include, health authorities, local council's, education authorities, police forces, government departments, National Charities and professional sports clubs. He sits on the Department of Health Gypsy Traveller equality group. He is the founder and former volunteer director of National Men's Health week an international event. A fellow of social entrepreneurship he has been commended twice by the Beacon Fellowship for his work on community cohesion. He was advisor to the leading Gypsy Traveller health study carried out by Sheffield University and the leading Gypsy Traveller accommodation needs assessment for Cambridgeshire. He is the co-founder and lead storyteller of the Lollobal storytelling group.

Richard has an interest in the cohesion and development of all communities. He counts Hill walking, cycling and traditional wood carving and restoring the family bow top Gypsy wagon amongst his hobbies. He lives in Bury Lancashire with his wife and two daughters.

### **Peter Beresford**

Peter Beresford OBE is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is also Chair of Shaping Our Lives, the national independent service user controlled organisation and network. He has long term experience of using mental health services.

He is a Trustee of the Social Care Institute for Excellence, member of the Advisory Board of the National Institute for Health Research, member of the Standing Group of INVOLVE and Academician of the Academy of Learning Societies of the Social Sciences. He has a longstanding interest in issues of involvement as researcher, service user, writer and educator.

# Appendix 4: Powerpoint presentations

THE UNIVERSITY of York

spru Social Policy Research Unit

NCRM/Involve Seminar

‘Social Research and Public Involvement:  
Colliding Worlds?’

## Who is Research For?

---

Roy Sainsbury  
Social Policy Research Unit  
University of York

26 September 2008

### Outline of presentation

- ◆ Mapping the stakeholders
- ◆ What does ‘who is research for?’ mean
- ◆ 2 case studies
- ◆ Implications for public involvement
- ◆ (Lack of) conclusion

### Stakeholder worlds

### Children’s Hospice project

### Mental Health and Employment

### Types of ‘outside’ involvement

- ◆ As research participants
- ◆ Advice
- ◆ Control
- ◆ Part of research team (i.e. doing the research)

### Options for 'outside' involvement

- ◆ Deciding research aims/questions
- ◆ Research design
- ◆ Recruitment/data collection
- ◆ Data analysis
- ◆ Outputs – reports etc.

### Rationales for 'outside' involvement

- ◆ Functional reasons
  - ◆ Increased quality
  - ◆ Impact
- ◆ Ethics/rights/inclusion/empowerment

### Involvement in practice – the hospice project

- ◆ Discussion re scope/practicalities/sensitivities
- ◆ Recruitment
- ◆ As research participants
- ◆ Feedback on findings

Why? ... functional/budget constraints

### Involvement in practice – the mental health and employment project

- ◆ Established formal advisory group
- ◆ Information on current issues/practice
- ◆ Advice - design of research instruments
- ◆ Advice – appropriate language
- ◆ Advice – recruitment strategy
- ◆ Feedback on draft report

Why? ... functional

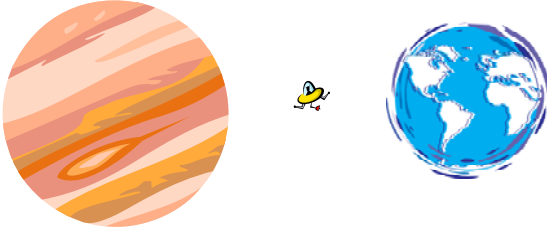
### Conclusion – so, who *IS* research for?

- ◆ No rules – researchers in powerful position to decide
- ◆ Be clear about reasons
- ◆ Acknowledge pros and cons (including tensions and conflicts)
- ◆ Address constraints (time, money, funders)
- ◆ Be transparent – tell it like it is

**Colliding worlds?**



**Connecting worlds**



## Research Messages from Young People

Mary Kellett  
Children's Research Centre  
The Open University

<http://childrens-research-centre.open.ac.uk>  
m.kellett@open.ac.uk

## Children's Research Centre at the Open University

- empowers diverse groups of children and young people as active researchers via a taught programme of research process followed by support to design and carry out a research project of their own choosing
- recognises that children and young people are experts on their own lives
- values their perspectives and promote their voice by supporting them to research topics *they* identify as important
- builds outreach links to schools and youth community organisations across the UK and beyond
- creates a body of knowledge *by* children and young people about childhood, youth and their lived experiences.

## Involving young people as researchers

- Choice
- Age
- Diversity
- Pressure groups
- The importance of quality training
- Time pressures
- Gatekeepers

## Potential benefits for young people

- Increased voice
- Increased participation
- Better understanding of YP's worlds
- Generation of knowledge
- Alternative perspectives

## Training for empowerment

### support

- enabling: training in research process
- sustaining: training in data collection skills
- supporting: paving the way with gatekeepers
- helping: transcripts, literacy; numeracy; writing frames
- empowering: dissemination platforms; presentation skills

### management

- influencing: allowing adult interests/agendas to influence what and how C&YP research
- limiting: only teaching C&YP certain skills thereby reducing their ability to make 'informed choices'
- judging: suggesting that their ideas aren't 'worthy' enough
- hijacking: content and/or ownership

## Popular data collection methods

- Questionnaires
- Interviews - focus groups
- Observation
- Participatory methods
  - diamond ranking with sticky post its
  - pasta pots
  - participant life narrative techniques
  - photographs
  - video diaries

## Data analysis - it's tough!

- Quality street
- Immersion
- Codes, categories and themes
  - Scissors
  - Colours
  - Space
  - Boxes
  - Big tent day



## Ethical responsibilities

### Young researcher's ethical responsibilities

- ethical research question
- informed / ongoing consent
- cause no harm or distress
- no deception
- disclosure of abuse
- data storage
- Share findings with participants



### Adult supporter's ethical responsibilities

- help child researchers arrive at ethical research topics/questions
- withdraw support from unethical projects
- don't make rash promises
- help child researchers to keep projects feasible
- ensuring wellbeing of child researcher
- clear the way with gatekeepers
- disclosure of abuse
- support child researchers with data storage



## Getting around as the child of a wheelchair-user

Manasa Patil  
aged 11

## Why I wanted to do this research

- People forget that some wheelchair users have children and any transport issues affecting them also have an impact on their children and on their childhood.
- I'm the child of a wheelchair user and I feel that it is important to be able to listen to the child's point of view because I see things that adults don't notice.



## How I designed my project

- I learnt a lot about observation in my research training and so one of my methods was observation.
- I also kept a research diary.
- I drew on my experiences using a life narrative technique.
- I wanted to explore 3 different ways of getting around as the child of the wheelchair user.



## Journeys I went on with my Dad

1. Bus
2. Pedestrian
3. Train



## Methodology

- I used a Dictaphone on the journeys to make notes so I could use those points later on to write a report.
- I took some photos
- I wrote my findings in a research diary.

The next slide will show what I found out on the bus journey.

## 1. Bus Journey

I went on a local bus with my dad and recorded all my observations onto a Dictaphone.

- My dad wasn't allowed onto the first bus because there was already a pushchair.
- One of the bus drivers said we couldn't come on the bus because my dad's wheelchair is battery powered.
- There are only two buses in our area with a ramp and a wheelchair space.
- All the buses that we have travelled on have a very narrow wheelchair space.

- It's hard for my dad to position his wheelchair in the space on the bus.
- My dad can't reach the machine which checks the tickets.
- I used my life narrative research technique to draw out some experiences that I'd had on other bus journeys with my dad and how this affects my childhood eg...

## Pedestrian Journey

- It was easier getting around on foot than travelling on the bus although there were a few difficulties.
- The roads weren't too bad but they were too bumpy and rocky in some places and the pavement was sometimes too high.
- My dad's wheelchair had got punctured because of a rocky footpath, so the next time, he had to take the longer route.
- There weren't enough slopes on the pavement.
- In some places, the pavement was too narrow and it was difficult for my dad to ride on it.

## Train Journey

- As part of my research I did a train journey from Oxford to Banbury and back. Here are some of the findings.
- It's not possible for me and my dad to travel by train unless we book 24 hours in advance.
- The train that we travelled on had 4 second class carriages but only one wheelchair space.
- Narrow wheelchair space...
- The wheelchair has to go into a separate place, but if the train is crowded I can't sit next to my dad.
- The staff were very kind and polite but they didn't seem to be very well informed about what it's like for wheelchair users and particularly what it's like for children of wheelchair users.
- Difficulties with access ramp.
- Here is an example from my life narrative:

## Conclusions

Just some small changes could make a big difference to my childhood because transport difficulties for my dad mean difficulties for me too and people always forget about the children of wheelchair users.

Here are some suggestions that I have concluded from my research findings:

### Bus

- All buses (not just a few) should have wheelchair ramps
- All the ramps should be electronic so that bus drivers don't have to get out of the bus to put it in place
- There should be a space for a wheelchair AND a pushchair not one or the other because too often the wheelchair can't get on because of pushchairs.
- There should be more training for bus drivers about disabled people and wheelchair users so that they might be more understanding about our difficulties particularly about trying to manoeuvre the chair into a very narrow, awkward space.
- For the future design of buses, these problems could be taken into consideration and the necessary improvements could be made. This will result in better facilities on buses for other wheelchair users in future.

### Pedestrian

- It might be easier for my dad if the pavements could be widened and not so bumpy and rocky.
- More ramps and slopes would really help.
- Getting around on foot is the easiest mode of transport for a wheelchair user but obviously this is restricting and stops children like me having exciting and fun days out with my dad.

### Train

- The train is the hardest and riskiest way to get around because there is no guarantee you'll get a ticket when you want or need to travel especially if you want to do something spontaneous.
- You might miss your stop because of poor communication about needing a ramp and this is very frightening for a child.
- This has given me a bit of a phobia of travelling on a train even when I'm not with my dad.



## Final Thoughts

I felt it was important to explore how children like me feel about getting around with parent/s who are wheelchair users and the impact of this on childhood and how this will impact on my feelings about transport when I'm older.

- The experience of being shouted at by bus drivers and felt to be a nuisance is upsetting and embarrassing and this will stay with me a long time even when I'm older and not travelling with my dad.
- The fear of missing my stop because no-one will get the ramp that will enable us to get off the train has given me a bit of a phobia about travelling on trains
- So many of my childhood treats have been spoiled by transport difficulties
- I hope that in the future, other children like me might have happier experiences getting around.



## WeCan2

- Have a say
- Be heard
- Take part

by Allan Aoslin, Ross Baines, Alice Clancy, Lizzie Jewiss- Hayden, Ryan Singh and Josh Strudwick



- We all take part in youth decision-making groups such as youth councils.
- We want to take a full part in the meetings and the decision-making of these groups.
- Sometimes this can be hard for us.
- It doesn't have to be hard if people understand what support we need in order to be able to take a full part.
- We decided to do some research to find out what the real difficulties are and what stops us joining in.



## What we did

- First of all we did some research training with Mary from the Open University. We learned about what research is and why it is important. It's not just adults who can do research, young people can too. We learned about good and bad research and how to not hurt anyone in the way we do research. We practised some research skills such as observation and interviews.



## Our data collection

- Josh and Allan listened, watched and recorded what happened at the meetings they attended.
- Lizzie collected evidence of all the big words used at meetings that she could not understand.
- Ross did some interviews about what changes need to be made to include young people with a learning disability.
- Alice helped as Ross's deputy.
- Ryan watched and made notes about the kind of things that annoyed him in meetings.



## How it went...

- We worked on our research for a year.
  - We each kept a folder to record our findings.
  - We collected over 300 pages of information and research evidence about taking part in youth meetings.
  - In total, we spent 70 hours of going to youth decision-making meetings.
  - For example
    - young people's councils
    - anti-bullying meetings
    - youth opportunity fund panels
- We did 4 interviews with
- young people,
  - a youth parliament member and
  - a youth participation worker.



## Analysing our data

- When we sorted out everything we had found out,
- some points came up again and again.
- Finding the same points lots of times shows how important these points are.



## Some of our findings

- People speak too fast.
- Minutes of meetings are not sent out in advance and have to be read during the meeting.
- Minutes and agenda papers with small print and no pictures are hard to read.
- People use too many big words: e.g. in just one youth council meeting Lizzie checked 66 big words such as 'ethnically diverse'.
- Timings of meetings are often fixed for straight from school and we are hungry and tired which affects how well we can participate.
- Places of meetings frequently do not have good disabled access.



## What we think

- Before we did this research we had a feeling about a lot of these things but we didn't have any evidence. What we have been able to do is collect the evidence to show that these things really do happen. Now that we can show this, we want to do something about it.



# INVOLVE

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

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.

If you would like to know more about what we do, please contact us:

INVOLVE  
Wessex House  
Upper Market Street  
Eastleigh  
Hampshire  
SO50 9FD

Web: [www.invo.org.uk](http://www.invo.org.uk)  
Email: [admin@invo.org.uk](mailto:admin@invo.org.uk)  
Telephone: 02380 651088  
Textphone: 02380 626239

**If you need a copy of this publication in another format  
please contact us at INVOLVE.**

**Email: [admin@invo.org.uk](mailto:admin@invo.org.uk)  
Telephone: 02380 651088  
Textphone: 02380 626239**