

## newsletter

Welcome to the INVOLVE newsletter. We have some interesting articles from the 2008 Inclusion and Exclusion Conference as well as an update on the work INVOLVE and the National Research Ethics Service have been carrying out.

### Inclusion and Exclusion

The Fourth Inclusion and Exclusion Conference took place in London on 20th November 2008. It was organised by the Race Equality Foundation, Social Services Research Group (SSRG) and INVOLVE. Presentations at the conference explored research on racism and ethnicity and the messages for policy and practice in key areas of public services, including housing and health and social care for adults and children.

Several of the presentations had actively involved service users and/or carers in the research and a key highlight of the conference was the panel of service users who spoke of their experiences of being involved in research. Two presentations have articles in this newsletter and we hope to publish others throughout the year. Copies of the presentations are available on the Race Equality [Continued →](#)

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**Jabeer Butt, Deputy Chief Executive  
of the Race Equality Foundation**

If you would like a copy of the newsletter in an audio or large print version, or if you would like it in another format, please contact us. Printed on recycled paper.

Foundation website: [www.raceequalityfoundation.org.uk/news/previous/index.asp](http://www.raceequalityfoundation.org.uk/news/previous/index.asp)

The following is a reflection of the conference from Jabeer Butt, Deputy Chief Executive of the Race Equality Foundation:

A casual observer of the social (and health) research community might conclude that the argument for involving users in research has been won. Certainly, if we look at the application processes of a number of the major funders of research in these fields, a question on how users are to be involved is invariably asked. We may indeed be seeing a 'golden age', as these days funders often ask about black and minority ethnic or other disadvantaged groups too.

But scratch the surface, as we did at the 2008 Inclusion and Exclusion Conference, and the picture that emerges is more complex. The majority of those who delivered papers and those who contributed from the audience emphasised the importance of user involvement in research. However, this was also accompanied by continuing evidence of token involvement, difficulties in securing adequate funding to aid user involvement, as well as securing ethics committee approval.

Thankfully, there were a number of inspirational contributions from users who had been involved in research such as Mark Fearon, a young black man involved in research on fathers. Similarly from Salma Iqbal, who talked of the journey from user involvement to being a researcher. This was accompanied by a range of presentations that demonstrated that 'hard to reach' groups such as Gypsies and Travellers or Asian women or young black men, could not only be reached, but could be actively engaged in the research process itself. The pitfalls and the challenges

were often highlighted, but these were accompanied by practical steps that could aid the process of involving users, even those who appeared to be particularly marginalised such as newly arrived migrants.

Our discussions perhaps did not answer the question of how cost effective user involvement was, but it certainly went along way to demonstrating how valuable user involvement is.



**The Inclusion and Exclusion Conference organisers: Elijah Collins, Martin Stevens, Jabeer Butt (L-R back row); Jenny Wilding and Tracey Bignall (L-R front row)**



**At the Inclusion and Exclusion Conference: Lucy Simons, Public Involvement Adviser, INVOLVE**

# INVOLVE

## Coordinating Centre News



### INVOLVE Conference 2010

A date for your diary: the INVOLVE 2010 Conference will be held in Nottingham on 16/17th November 2010.

The 2008 Conference Report is now available along with the conference abstracts and available presentations, on the INVOLVE website [www.invo.org.uk/Conference2008.asp](http://www.invo.org.uk/Conference2008.asp)

We also have a limited number of hard copies of the 2008 Conference Report. If you would like a copy please contact us.

Email: [admin@invo.org.uk](mailto:admin@invo.org.uk) Tel: 02380 651088



### Ethics survey

We have recently completed a survey of lay members of Research Ethics Committees (REC) on behalf of the National Research Ethics Service (NRES) NHS Service Users and Ethical Review Advisory Group. A report of this survey is now available on the INVOLVE website and will soon be available in hard copy. The main findings of the survey can be summarised as follows:

- Despite changes to the appointment procedures, there was limited diversity amongst lay members. In comparison to the general population, Research Ethics Committee lay members were more likely to be older and educated to degree level or above.
- Nearly half of lay members reported

experience of either long term use of health or social care or caring for someone who uses services. However, respondents had mixed views on whether this perspective should contribute to the ethical review process.

- Overall, lay members felt they were adequately supported in the Research Ethics Committees and their views were taken into account. Around one third of respondents thought that lay members should be paid an allowance.

The full report of the findings are available on the INVOLVE website [www.invo.org.uk](http://www.invo.org.uk) – if you would like a hard copy of the report please contact us.

Email: [admin@invo.org.uk](mailto:admin@invo.org.uk) Tel: 02380 651088



### invoNET

On 12th February 2009 we held our fourth invoNET event. invoNET is a network of people interested in building evidence, knowledge and learning about public involvement in research <http://www.invo.org.uk/invoNET.asp>

The aims of this workshop were firstly to share information and ideas about making public involvement in research more visible, either in peer review journals or in the general media. The second aim was to explore the opportunities for service users and carers involved in research, once their contribution has finished on a research project.

Some of the suggestions from the day included:

- making public involvement an integral part of reporting research whether there has been active involvement in the research or not
- clarification and agreement on a common language and common search terms and

key words for public involvement to make articles easier to find and categorise

- consideration of alternative ways of communicating public involvement in research
- recognition of the value of networks to support service users involved in research and the signposting to new opportunities
- the need for larger research organisations to have an organisational approach to long term support for people involved in research projects.

The full report of the day is available on the INVOLVE website [www.invo.org.uk](http://www.invo.org.uk)



**At invoNET: (L to R) Sarah Buckland, Maryrose Tarpey, Sophie Petit-Zeman, Sally Crowe.**



**At invoNET: (L to R) Tracey Williamson, Sue Hinder, Kristina Staley.**

# Interesting articles and publications

## • **Putting People First – Working together with user-led organisations**

This document outlines the benefits that local authorities and their residents enjoy when they work with user-led organisations.

Published March 2009

Available on the Department of Health website: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_096859](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096859)

## • **Social Care Institute for Excellence (SCIE) Position paper 10: Seldom heard – developing inclusive participation in social care**

Paul Robson, Alice Sampson, Nnamdi Dime, Louisa Hernandez and Rachael Litherland.

Ensuring that the voices of seldom heard service users are not marginalised is a key challenge for practitioners and managers. SCIE's Position Paper 10 shows how through an integrated way of working the participation of people from seldom-heard groups can be enabled.

Published September 2008

Available on the SCIE website:

[www.scie.org.uk/publications/positionpapers/pp10.asp](http://www.scie.org.uk/publications/positionpapers/pp10.asp)

## • **Handbook of Service User Involvement in Mental Health Research**

Editors: Jan Wallcraft, Beate Shrank and Michaela Amering

The book describes the relevant background and principles underlying the concept of

service user involvement in mental health research, providing relevant practical advice on how to engage with service users and how to build and maintain research collaboration on a professional level. It highlights common practical problems in service user involvement, based on experience from various countries with different social policies and suggests ways to avoid pitfalls and common difficulties. ISBN: 978-0-470-99795-6  
Published: 2009 Wiley

### • **The health of Gypsies and Travellers in the UK**

Better Health Briefing 12  
A Race Equality Foundation Briefing Paper  
November 2008  
Available on the Race Equality Foundation website: [www.raceequalityfoundation.org.uk/health/index.asp#papers](http://www.raceequalityfoundation.org.uk/health/index.asp#papers)

## This is Survivor Research

**Edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose.**

‘This is Survivor Research’ marks the coming of age of service user research in mental health. Survivor research in mental health can be traced back to two programmes of work in Non Governmental Organisations (NGOs) – Strategies for Living at the Mental Health Foundation, and User-Focused Monitoring at the Sainsbury Centre for Mental Health. These were established in 1996, the same year that INVOLVE was founded as Consumers in NHS Research. ‘This is Survivor Research’ demonstrates the huge progress that has been made since then and the lively nature of

the field. The book brings together a wide range of contributions spanning step-by-step advice on how to get started in service user research through to accounts of specific projects, descriptions of personal experiences of research, both positive and negative, as well as more theoretical and philosophical pieces.

We have also included a chapter where we reflect on what brought us to survivor research and you will find that this shows the very different histories that the contributors have.

‘This is Survivor Research’ is aimed at a broad audience including mental health service users who want to get started in research, seasoned service user researchers, students, academics and policy makers. The book should also be of interest to consumer researchers and their collaborators in other parts of the health and social care arena as one model of how to develop and progress consumer research in the NHS, social care and public health as well as in the wider research community.

ISBN 978 1 906254 14 8

‘This is Survivor Research’ is available to order online at:  
[www.pccs-books.co.uk/](http://www.pccs-books.co.uk/)

If you have written or know of any publications or articles relevant to public involvement in research that might be of interest to readers, please contact Helen Hayes at the Support Unit with details: [hhayes@invo.org.uk](mailto:hhayes@invo.org.uk)

# Involving Gypsies and Travellers in research – an example from Bristol

**By Rosie Davies**

This article describes how Gypsies and Travellers were involved in a piece of research in Bristol. The conference presentation from the 2008 Inclusion and Exclusion Conference, on which the article is based, was done by Rosie Davies of Bristol Mind and Ian Holding of the Gypsy and Traveller Team at Bristol City Council, with the help of Annie Crocker, a Romany Gypsy working for the Gypsy and Traveller Team. The presentation included a broader perspective on involvement of people from Gypsy and Traveller communities than is discussed here.

## **Background to the research project**

Bristol Mind has completed a study called 'Effective involvement in mental health services: the role of assertive outreach and the voluntary sector.' It aimed to explore in detail how both NHS and voluntary sector services could best work to promote effective access to, and engagement with, services for people with serious mental health problems who get labelled as 'hard to engage.' There was a focus on people from black and minority ethnic groups, including Gypsies and Travellers. All the researchers on the project had used mental health services.

It was mainly a qualitative study which took place in Bath and North East Somerset, Bristol, North Somerset and Gloucestershire

from 2005-2008. It was supported by the Big Lottery Fund.

As part of this study the researchers wanted to find out if people from Gypsy and Traveller communities, including Show People, got the help they needed.

## **Anxieties, prejudices and fears**

The researchers had no experience of working with people from the Gypsy and Traveller communities, as a result they were not sure what to do and felt rather lost. There was some fear of going onto sites and anticipation of hostility and suspicion. It was important that the researchers became aware of their own anxieties and prejudices.

Equally, researchers often want to study Gypsy and Traveller communities but people may not feel respected. There may be concerns about what will be done with the information gathered. For example, will it really be kept confidential or might it be used by the council for eviction? Privacy is also important and it is easy to overhear things being said in caravans. There has also been a long history of discrimination against people from these communities.

## **What helped?**

What helped was to find out more about Gypsies and Traveller communities, this included looking at community magazines and relevant research.

The most important thing was to make contact with local staff working with Gypsies and Travellers. They generously gave time to discuss plans and gave feedback/advice. One staff member was a Romany Gypsy who agreed to help with the research project. Two staff also

became members of the research project's Advisory Group. Finding local allies with contacts in the community was key.

## Research issues

The study intended to recruit participants from outreach services, however, there were no Gypsies or Travellers using any of the services included. Therefore, researchers had to get permission from the Bath Research Ethics Committee to change recruitment plans and materials.

Following advice given, the new materials simply asked about 'stress, depression and trouble with nerves.' This meant it was difficult to focus on severe mental health problems or on people with a diagnosis. Packs of new information were produced and distributed. However, all recruitment came from personal contact via visits to sites. Researchers were introduced by a member of the Romany Gypsy community; no one was recruited by distributing packs.

Researchers gave information about the project and people who were interested were asked to participate in interviews which were held later.

## How to make a difference

As well as undertaking a piece of local research the project aimed to make a difference to services.

The implementation phase of the project evolved mainly through the contacts and networks that the researchers had made in earlier phases of the work. The findings, including an easy-to-read version, were sent out to all participants with a thank you card.

Staff from the Gypsy and Traveller Team at Bristol City Council circulated the findings to community members. Findings were shared at meetings with other local authorities and commissioners in the study area. Researchers have spoken at conferences and made contact with a regional Gypsy and Traveller network.

Strong relationships had developed between the lead researcher and staff at the Gypsy and Traveller Team at Bristol City Council. This was very important in making the project work. Sharing findings has meant that mental health issues have been raised and discussed more within the communities. The research also influenced the appointment of a specific Community Development Worker for Gypsies and Travellers.

A summary of findings relating to Gypsies and Travellers is available on Bristol Mind's website [www.bristolmind.org.uk](http://www.bristolmind.org.uk). The summary and full report for the whole study (Davies et al. 2009) will shortly be available on the same site and from Bristol Mind.

Davies, R., Shocolinsky-Dwyer, R., Mowat, J., Evans, J., Heslop, P., Onyett, S., Soteriou, T. (2009). Effective involvement in mental health services: the role of assertive outreach and the voluntary sector. Report by Bristol Mind, 35 Old Market Street, Bristol BS2 0EZ. [www.bristolmind.org.uk](http://www.bristolmind.org.uk) Tel: 0117 980 0370

Deadline for contributions for our next newsletter: **19th June 2009**

We welcome contributions about any aspect of public involvement in NHS, public health and social care research. Please ask us for information about submitting an article.

Email: [newsletter@invo.org.uk](mailto:newsletter@invo.org.uk)

# Participatory approaches in researching violence against women: Domestic violence and South Asian women with no recourse to public funds<sup>1</sup>

By Sundari Anitha<sup>2</sup>; Priya Chopra<sup>3</sup>; Waheeda Farouk, Qamar Haq and Saliya Khan<sup>4</sup>

This research was conducted by Saheli (which provides refuge spaces for South Asian survivors of domestic violence) in 2007 with the aim of understanding the needs and experiences of South Asian women with insecure immigration status, to work towards a change in the existing policies which prevent this group of women from accessing refuge spaces and to make the process of the research an empowering one for all its participants.

This research was conducted using the community engagement model of action research. The research team consisted of a principal researcher, three service users of Saheli who were the community researchers and the co-ordinator of Saheli. In addition, the research was guided by a multi agency steering group which gave ethical guidance and provided feedback on the policy and political relevance of the findings and enabled an ongoing dialogue with the commissioners and other statutory and voluntary services during the process of the research.

## The role of community researchers

The three community researchers were self-

selected service users of Saheli and survivors of domestic violence, two of whom had insecure immigration status when they left the abusive relationship. The need for adequate support in order to enable service user involvement in action research has been frequently emphasised by researchers. In this study, the community researchers were supported through the provision of training on qualitative research methods, on the problem of domestic violence, and on service provision in the UK for survivors of domestic violence. The researchers were supported during the process of interviewing through regular supervision, both on a one-to-one basis, through group meetings and phone conversations.

Thirty qualitative interviews were conducted with South Asian survivors of domestic violence who had insecure immigration status. The community researchers were particularly successful in using word-of-mouth and snowballing techniques to access women who were living with family, friends or strangers. Though conventional researchers often struggle to access these groups of women, the community researchers had no difficulty in making these connections, which points to the alternate perspective that it is services which remain 'hard to access' instead of potential service-users being 'hard to reach.'

## Some issues arising from the involvement of community researchers

While engaging community researchers as 'insiders' can enable access to a wider range of participants, the privileged position of the researchers can also create certain difficulties. These include the fear that researchers who are known to the respondents may not maintain confidentiality, or that where details about the research participant's lives are

already known to the researcher, this may make it harder for the researcher to respect the level of disclosure the participant is prepared to make in the context of the research. These fuzzy boundaries had to be managed through adequate training and ongoing support to ensure that all research participants were given the space to fully articulate their own experiences of services, which may have been different from the researchers' perspectives.

Listening to women recount traumatic experiences can be distressing, and this process took all of us involved in the study through terrains that were distressingly familiar yet new, distanced yet too close for comfort. Despite their distress at recalling the traumatic events, the women we interviewed urged the community researchers to take their voices to policy-makers so that the silence on their plight could be broken. Saheli made the services of counsellors available for the researchers and the research participants were also given information about existing services. For two women who participated in this study, this was their first source of information, and an immediate benefit of participating in this research.

## Conclusion

The use of community researchers not only enabled the research to include the voices of previously unheard groups of women, it also altered the very nature of the research. Having lived through the experience themselves, the researchers were able to understand the perspectives of research participants and thereby enhanced the disclosure of abuse. Their participation in the research also enabled more inclusive and equal research relationships by bridging the distance between the so-called

'experts' and 'non-experts' – the researcher and the researched – and redressing the power imbalance between them that often exists in conventional research. Listening to survivors is crucial to ensure that services meet women's needs, and where adequate training and support is provided, the use of community researchers can enable their voices to inform policy and service development.

## Notes:

- 1 This research was funded by Oxfam, with additional contributions from Care Services Improvement Partnership (North West), the Manchester Partnership and the University of Huddersfield. The report is available at: [www.oxfam.org.uk/resources/ukpoverty/downloads/forgottenwomen.pdf](http://www.oxfam.org.uk/resources/ukpoverty/downloads/forgottenwomen.pdf)
- 2 Research Fellow, POLIS, University of Leeds LS2 9JT;  
Email: [s.anitha@leeds.ac.uk](mailto:s.anitha@leeds.ac.uk).
- 3 Co-ordinator, Saheli Ltd, Manchester.
- 4 Community Researchers, Saheli Ltd.

## Patient and public involvement in research and research ethics committee review

### Purpose

This statement has been developed by the National Research Ethics Service (NRES) and INVOLVE to provide clarity and guidance on patient and public involvement in research and the requirements of research ethics review. The statement has been approved by the NRES Advisory Group on NHS Service Users and Ethical Review. Continued →

## Active involvement vs. participation in research

Involvement in research as a research participant comes with the protection afforded by research governance arrangements that include research ethics committee (REC) review to protect the rights, safety, dignity and well-being of research participants.

However, when we talk about 'involvement' in research, in this statement, we mean getting actively involved in the research process itself, rather than being participants or subjects of the research.

### Active involvement

Many people describe public involvement in research as research that is done **with** or **by** the public, and not **to**, **about**, or **for** them. The public have been involved in research and development for a number of years and in a variety of different ways. For example this includes:

- identifying and prioritising research topics;
- being part of research advisory groups and steering groups;
- undertaking research projects and;
- reporting and communicating research findings.

### When is ethical approval required for active involvement?

The active involvement of patients or members of the public does not generally raise any ethical concerns for the people who are actively involved, even when those people are recruited for this role via the NHS. This is because they are not acting in the same way as research participants. They are acting as specialist advisers, providing valuable knowledge and expertise based on their

experience of a health condition or public health concern.

Therefore ethical approval is not needed for the active involvement element of the research, (even when people are recruited via the NHS), where people are involved in planning or advising on research e.g. helping to develop a protocol, questionnaire or information sheet, member of advisory group, or co-applicant.

Research requires ethical approval as determined by the Governance Arrangements of Research Ethics Committees (GAfREC) and legislation including the Clinical Trials Directive and Mental Capacity Act. The NRES website provides guidance on the requirements for ethical review. [www.nres.npsa.nhs.uk](http://www.nres.npsa.nhs.uk)

The ethics committee will not need to consider within its review the active involvement of patients and members of the public in carrying out research that involves no direct contact with study participants e.g. helping to analyse survey data, postal surveys etc. However, where people's involvement results in direct contact with study participants, the ethics committee will need to give specific consideration to the involvement as an element of the ethical consideration and approval. A REC will need to check that the person carrying out the research has adequate training, support and supervision appropriate to the circumstances in the usual way. Here there are two ethical issues to consider in addition to the usual concerns about the safety of researchers and the researcher/participant relationship:

- The well-being and safety of the people who are actively involved as researchers. They may find that talking to other people reminds them of their own negative experiences. This can cause distress, in which case the

patient/member of the public who is carrying out the research may need additional counselling/support. A REC will need to check this additional support is available.

- The well-being and safety of the people who are taking part in the research as study participants. It is important to ensure that there are no additional risks to people taking part in a study. The REC will also need to consider any additional issues or sensitivities that may arise for those taking part in the research.

### **What is the relevance of active involvement to the role of research ethics committees?**

If patient and public involvement in research is carried out to a high standard, it is more likely to result in ethical research. This is because the research is more likely to be:

- Relevant to the people it is trying to help;
- Beneficial in terms of delivering meaningful outcomes for patients and/or;
- Conducted in a way that is sensitive to the needs of the participants – through better patient information, recruitment processes and general management of the project.

It is therefore in the interest of RECs to promote and support high quality active involvement in research.

Further information on research ethics and copies of the full statement including supported reading are available on the NRES website: [www.nres.npsa.nhs.uk](http://www.nres.npsa.nhs.uk)

Full copies are also available on the INVOLVE website: [www.invo.org.uk](http://www.invo.org.uk)

## **Patient and public involvement in UK Clinical Research Collaboration (UKCRC) advisory groups**

In September 2006 the UKCRC Board agreed to pilot patient and public involvement within some of its advisory groups and subgroups. Recruitment of patient/public members to UKCRC groups took place in early 2007. During the pilot period, 10 patient/public members have been involved in five of the UKCRC Boards.

An evaluation of this pilot project was carried out in late 2008 and sought different stakeholder perspectives on:

- The process of involvement
- The contributions made by patient/public members of advisory groups
- The impact of those contributions
- What could be done in future to improve patient and public involvement in UKCRC advisory groups.

The evaluation report, which summarises findings and makes recommendations for future activities, is now available.

The full report and an executive summary are available on the UKCRC website: [www.ukcrc.org/patientsandpublic/ppi/ppiinukcrcgroups.aspx](http://www.ukcrc.org/patientsandpublic/ppi/ppiinukcrcgroups.aspx) or by contacting Philippa Yeeles  
Email: [philippa.yeeles@ukcrc.org](mailto:philippa.yeeles@ukcrc.org)

# noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in R&D. If you would like to put an article on our notice board please contact the Coordinating Centre.

## National Primary Care Patient and Public Involvement Forum at the University of Manchester

This recently established group of lay people with an interest in health care research meets every six weeks for training sessions and to discuss research topics and projects, current and potential, in primary care.

The forum brings different insights to the research process. We are a friendly and informal group with varied interests and experience from both carer and service user perspectives.

We hope to become a more diverse group representing a broader range of health needs. Anyone in the North West of England interested in the wide and developing field of primary care research is welcome to come to our meetings. If you are interested in attending please contact: Annette Barber Tel: 0161 275 7636  
Email: [annette.barber@manchester.ac.uk](mailto:annette.barber@manchester.ac.uk)

## Authenticity to Action: Involving service users and carers in Higher Education

This conference will take place on 4-6 November 2009 at the Grange Hotel, Grange over Sands, Cumbria, UK. For further information about the conference, please visit the website at:

[www.uclan.ac.uk/health/about\\_health/health\\_bdu/conferences.php](http://www.uclan.ac.uk/health/about_health/health_bdu/conferences.php)

or contact:

Liz Roberts

Business Development Unit

Faculty of Health and Social Care

University of Central Lancashire

Preston PR1 2HE

Email: [healthconferences@uclan.ac.uk](mailto:healthconferences@uclan.ac.uk)

Tel: 01772 893809

## INVOLVE

**Wessex House**

**Upper Market Street**

**Eastleigh**

**Hampshire SO50 9FD**

**Telephone: 02380 651088**

**Textphone: 02380 626239**

**E-mail: [admin@invo.org.uk](mailto:admin@invo.org.uk)**

**Website: [www.invo.org.uk](http://www.invo.org.uk)**

INVOLVE is a national advisory body 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 receive a copy of the newsletter or find out more about INVOLVE please contact us.

**Friendly disclaimer:** The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of INVOLVE or the National Institute for Health Research. Articles are selected for the sole purpose of stimulating ideas and debate on public involvement in research.