

INVOLVE

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

Conference
supported by



A report on
INVOLVE's 4th national conference
10th & 11th November 2004, Nottingham

**People
at the heart of research**

Contents

	Page
Contents	2
Introduction	3
Older people researchers	7
I came from a land down under	7
Thoughts	9
INVOLVE & national programmes of research and development ..	9
Three minute marathon	11
Communication - past and present	11
Nowt about me without me	13
INVOLVE conference - November 2004.....	14
Breakfast of champions?.....	15
Involve me	18

You can access more information about the conference from our web site:

<http://www.invo.org.uk/Conference.asp>

This includes a database of abstracts and presentations from the parallel sessions.

Introduction

Kate Sainsbury

Chair, Conference Planning Group & Vice Chair, INVOLVE

The purpose of a conference report is to remind people who were there and to tell people who were not there, a bit about what went on.

This year, we are doing it in an informal and participatory way. We asked everyone at the conference to give us snapshots, poems, descriptions of what they heard or what they felt, notes, quotes ... these form the bulk of the record. I, as Chair of INVOLVE's Conference Planning Group, outline how we planned this conference and share my thoughts about future events.

The conference in 2004 was our fourth one. We had comments from the earlier ones to guide us. People had told us what they liked:

- The vibrancy of the event
- The atmosphere
- Sharing of values
- Mutual respect between participants
- Good organisation
- It was good to hear so many "user voices" at the conference
- Being inspired by other people's successes
- Dealing honestly with the problems encountered in consumer involvement
- Being treated with respect
- Very worthwhile, excellent, extremely friendly, extremely useful

We tried to build on these.

People had told us what they disliked:

- There was too much to do
- There was not enough time in the day. Consumer involvement needs time and consumers need time to prepare for involvement
- An imbalance between "professionals" and consumers
- The Harrogate venue was too big, it was too easy to get lost and too far from main rail line connections
- Lack of opportunity to network
- Too many workshop sessions to choose from
- Lack of hot food
- Too much - need to spread the content over two days

We tried to improve on these.

A short word about words. INVOLVE stopped using the word 'consumer' when we widened our work to include social care and public health. Nowadays we talk about 'the public' and 'people who use services'. The trouble is that these terms don't describe individuals and, due to diversity, there isn't a single word to describe all the ways people like to refer to themselves, such as 'self-advocate', 'service-user', 'patient', 'carer', 'citizen', 'advocate', 'survivor'. It's a feature of language that words get replaced by other words - sometimes for accuracy, sometimes for variety - so I hope we can be tolerant about the way in which the language of names works.

The Conference Planning Group is a sub-group of INVOLVE and its work is extra to other group activities. Members come from INVOLVE, and from outside if we need wider expertise. There was a majority of service users this time, covering cancer, mental health, long-term medical conditions & arthritis, severe learning disability & autism, pesticides and skin conditions together with a representative from the Research & Development Directorate at the Department of Health and a public health research specialist. Planning began eighteen months ahead of the event.

Accessibility was very important to us, in all the following ways:

- We listened to what people said last time and made changes
- We chose the venue very carefully. We selected one for comfortable size, public transport connections, disabled access, one that was out-of-London
- We organised transport from the conference centre to hotels to get round the lack of on-site accommodation
- We set aside money for free places and bursaries
- Anybody could send in a proposal to present at the conference. You didn't need an academic qualification or a certain position. We offered help to anyone who needed it in order to take part
- We planned to have the soapbox event, which offers a place for anybody to speak in public for three minutes. The soapboards offer a place for anybody to 'say' something who doesn't want to, or cannot, speak out loud
- We offered poster space and poster sessions to give more chances for people to show their work in public
- We tried to create lots of opportunities for informal networking

- We tried to make our paperwork accessible. We had it checked by our readers' panel. We offered large print and audio tape versions, and other help to anyone who needed it.

For our theme of the conference, we chose 'the research cycle'. Our idea was to identify the different stages that make up research and to show the many kinds of public involvement that are possible. We hoped it would help people to think about the different ways service users can join in at different stages and the different reasons for involvement. (In conferences before, we had not done this; we had mainly grouped sessions by the subject matter, e.g. pregnancy and childbirth or older people.)

We looked at the locality of Nottingham and at current events, to choose suitable performances for the conference. The Orpheus group linked in with the third part of the Disability Discrimination Act coming into force in October. Diwali started the day after the conference. The musicians reminded us that research still has to demonstrate an impact on policy and practice that benefits black and minority ethnic communities.

About 300 people attended the conference. There was an overall impression of energy and friendliness. It seemed that service users felt greater confidence than ever before to participate and to speak up and I think this comes from a culture that the Department of Health and INVOLVE have supported, which was seen as an inspiration by overseas visitors.

But there was also a perception of personal hostility towards researchers and professionals and clinicians at the conference. This presents INVOLVE with a challenge. How do we enable everybody committed to public involvement in research, to meet and work together, in comfort?

Individuals within academic institutions or clinical practice or parts of the Department tell us that they can feel isolated from professional colleagues, because of their support for public involvement in research. They look to INVOLVE's conference for a community of like minds. They need our support. It makes no sense to alienate them. This reflects back to INVOLVE's multiple roles as an advisory body to the Department of Health and in more broadly supporting and promoting public involvement in research to the public, researchers and clinicians.

By the next conference, INVOLVE has to work out how to provide safe spaces for discussion of issues and information that are important to different groups, without diminishing the energy of service user participation throughout. We will have to develop and work with ground rules to help us recognise and continue to work with differences. We will respond to needs and at the same time, we will expect people to state their needs so we can respond to them.

Thank you to everybody who came to the conference and participated through being there or through any other means. I'd like to close with the quote, which several of you remarked on, from Alice Hicks, a service user researcher at the Royal College of Nursing Institute. She said, 'We make the path by walking it.' I look forward to walking with you again, in 2006.

Older people researchers

Audrey Lax, Mick Williams & Glenda Cook

Off to Nottingham we set,
With some apprehension and regret.
With a poster under arm,
The audience we aimed to charm.
Co-researchers We!

To be involved was our intention,
Not quite sure what we should mention.
So Audrey and Mick spoke from their hearts,
Of experiences of taking part.
Co-researchers We!

The older persons' view we set.
Pleased with the reaction that we met.
Our contribution made at last,
Though the issues will never pass.
Older researchers are We!

I Came from a Land Down Under.....

Anne McKenzie

Consumer Research Liaison Officer
School of Population Health, University of Western Australia
& Telethon Institute for Child Health Research

"Surely you didn't come all that way just to attend this conference" was the common comment I received when I said I was from Australia. When I explained that yes, I had travelled half way around the world, and how pertinent the conference was to my work, then the response from one and all was immediately so warm, welcoming and hospitable that it still amazes me.

Attending the INVOLVE Conference was personally a totally wonderful experience. For the first time I set off overseas on my own, a bit daunted by the prospect, but determined to use the opportunity and privilege of being able to attend the conference to its fullest. From the moment I

arrived at the conference I found myself part of a large group of people with a common aim of improving public involvement in research. This was certainly inspiring and gave me an exciting insight into what we in Australia might achieve in the future. On a smaller, local scale it also gave me a sense of hope that the work I am currently doing as a Consumer Research Liaison Officer can actually result in researchers and consumers (we still call them that here) working together and being excited, honest and positive about the journeys being undertaken to improve consumer involvement and participation.

Listening to the many and varied presentations made me realise how similar the issues facing researchers and consumers are on both sides of the world. The vexed question of funding and payment for consumers seems to be high on the UK agenda as much as it is here in Australia. It was a wonderful opportunity to be able to speak to such a wide range of people and get some fresh perspectives on this and other ongoing issues surrounding consumer input in research settings.

All in all the conference was a fantastic two days - weather aside, my only disappointment was that I couldn't attend all of the sessions as there was so much on offer. I was especially impressed with the amount and quality of poster presentations, which reflected the deep commitment that seems to be part the culture to improve user involvement in research in the UK. The questions and interest that followed the presentation on the work being done in Australia in consumer and community participation in medical research was also heartening, as it again reflected the keen interest by many to learn about everything and anything that will improve participation and partnerships.

To all those who I spoke with and who willingly offered me such great ideas and the opportunity of further contact, I sincerely thank you and to the INVOLVE Conference organisers, congratulations on a fantastic job. To fit so much into a few short hours is really an amazing feat and I am looking forward to reading all the conference papers and hopefully being given the opportunity to attend another INVOLVE Conference in the future.

Thoughts

Pauline Ong

Professor of Health Services Research, Keele University

The conference was great democratic experience, starting with the legible name badges that did just identify you as a person without a label (user, clinician, researcher etc). This helped in talking to people as people, and to engage with their interests. I particularly liked the soapbox event because the honest statements from users helped me, as a researcher, to focus on what is important: to continually ask what contribution research makes to improving people's quality of life. I admired many of the contributors who spoke up and obviously had overcome many personal difficulties as well as tackling the barriers that health care and research organisations had put in their way.

INVOLVE &

National Programmes of Research and Development

Kay Pattison

Research and Development Directorate, Department of Health

As National Research Programme Manager for the Department of Health I would like to begin by making a somewhat self interested observation about this years conference - it was well attended by NHS R&D Research Programme Managers. All of the major programmes were represented - Health Technology Assessment, Service Delivery and Organisation, New and Emerging Applications of Technology, Forensic Mental Health and Research Capacity Development ... I could go on. In addition, those attending on behalf of National Programmes made significant contributions by presenting parallel and poster sessions and joining in debates. I am extremely pleased that this was the case because National Programme Managers have a tale to tell. Progress has been made.

In the early days of National Programmes there was a desire to involve the public in research but concern at exactly who to involve and how - a feeling that we, as a research commissioning community, lacked the where-with-all to get it right. Indeed, the feeling that we have much to learn is still with us but is now counter balanced by a body of knowledge built up over recent

years. We have examples of good practice and a desire to learn and to share learning experiences. This is a very significant development facilitated by all of those contributing to the work of INVOLVE and those National Programme Managers concerned.

So ... how has public involvement in research commissioning developed and how has INVOLVE contributed?

Department of Health funded R&D programmes have taken active steps to involve patients and the public. For example, in the Health Technology Assessment, Service Delivery and Organisation, New and Emerging Applications of Technology and Forensic Mental Health Programmes, patients and the public contribute variously by:

- suggesting topics for research,
- choosing which topics should become research priorities,
- helping to formulate research questions and
- reviewing and disseminating research outputs.

The work of INVOLVE has been central to the development of patient and public involvement within programmes. Those who manage the programmes meet with the INVOLVE Support Unit via the Public Involvement Collaboration Group to make links with others and discuss best practice. Recognising the importance of continuing dialogue the Health Technology Assessment Programme (HTA) website states:

"In order to contribute to the broader work of integrating public perspectives in the NHS R&D Programme, National Co-ordinating Centre for HTA staff will strengthen links and encourage dialogue with other research programmes. In particular collaboration with INVOLVE will continue through links with the Support Unit".

I am pleased to report a similar level of ongoing commitment across the piece and am confident that National Programme Managers will have an even better tale to tell at the next conference!

Three Minute Marathon

Mitzi Blennerhassett

I'm a user involvement pioneer
No, not the wild and woolly West
But breaking new ground in the NHS

And the thing I liked best
Was bending your ear in the Soapbox session
A platform, without fear of hecklers, rotten tomatoes
Or arrest
No purple powder from the gallery
Just Harry's bell, setting the test

No 'ethics approval' or 'signed consent', however well-meant
The only criterion: 'keep it short!'
So, with excellent audience participation
The 'ordeal' became just fun and sport

But if you were boring, or exceeded your limit
(And you'd have to take this in the right spirit)
You'd soon be deafened by Harry's bell, sounding your death knell!

Communication – past and present

Dr. Louise Nadim

Crawley Cancer Contact

'A picture says a thousand words' this is nothing new. Cave drawings show us what was on our predecessors' minds, and the stained glass windows and sculptures in religious buildings were put there not only as decorations but also as visual teachings for a largely illiterate congregation that didn't understand Latin. Somewhere along the line research has lost the 'art' of highlighting its work in this way.

Those with learning disabilities are not alone in finding it hard to understand what is presented to them. It affects us all when we are taken out of our area of familiarity: be it understanding your income tax,

deciphering legal litigation or delving into the world of medicine or computers etc. We can read the words but can't speak the language.

I am a visitor to social research, coming from the 'dark side'- traditional science. I felt very aware at this conference that 'I didn't quite fit in!'. I had trouble grasping what some presentations were about and what the studies had shown yet my fellow delegates didn't seem to have this problem. Hmmmmm.

On reflection I think this was due to three things:

- 1) The use of jargon and assumed knowledge in a field that I am less familiar with.
- 2) The need for clear, concise, simple communication, preferably with pictures and examples to illustrate the points. (as outlined by several of the presentations at the conference).
- 3) I am not used to information being presented to me in this way

You see it all seemed a bit 'woolly', there were innumerable variables, no real controls, massive assumptions and few if any, clear facts and figures . . . **and you call this research?** Well, yes you do and you have every right to. The quality of peoples' lives doesn't fit into neat tables of data, the numbers have no value and the 'means' are meaningless, so why use them?

We all need to recognize and accept that quantitative analysis and qualitative research are both equally valuable tools of investigation **when they are used for the right job**. I can see that some aspects of involving consumers in research could be analysed numerically and yield helpful information, but for most situations it would be inappropriate, and qualitative assessment would be the better tool to show the true effect of using people at the heart of research.

Nowt about me without me

Heather Goodare

To be sung to the tune of
'Allnächtlich im Träume' from Schumann's Dichterliebe

'Nowt about me, without me' -

That's my song.

Patronize me, ignore me

You'll get it wrong.

For if you don't consult me, your
research will be quite useless.

Not object, nor subject

But equal player

With something to offer -

It's only fair.

And also, you might find that your
project could be **better**.

Don't abuse me, but **use me**

For I know what heals.

I know more than you can

About how it feels.

And when it's done, please tell me
what we've found out together.

Involve Conference - November 2004

Stuart Eglin

Chair, Strategic Alliances Sub-Group, INVOLVE

Head of Evaluation, NHS Modernisation Agency

Nottingham, November 2004. 300 people in a conference centre for two days, working together to bring focus to the issue of public involvement in the research process.

It struck me early on day one that people attending must have a set of very different objectives - looking for very different things from the event. It would be very difficult to please all people all of the time!

What was I hoping to gain from the event?

- to meet up with old friends
- to make some new friends
- to learn about projects and initiatives which were new to me

Did the event achieve this? I think it did - I met a number of people who I hadn't seen for a while; I met some interesting people for the first time; and I was stimulated into new ways of thinking about things. I facilitated one of the poster sessions at the start of the conference, and became aware of the buzz and energy from the outset. The sense of democracy of the event was unusual and well received. This was an event where all attendees could feel that they were taking part, rather than just passively sitting in the audience.

High points of the event included the Keynote presentation by Richard Smith (past editor of the British Medical Journal), which was provocative and thoughtful. The Soapbox session was delivered with real passion bringing issues to life, and the closing performance by people from the Orpheus Centre was powerful. I guess the low point would be the realisation in one of the Soapbox presentations that there is still so much to do to be truly accessible. Discrimination and closed access can often be created by lack of thinking rather than by anything deliberate. It was important, though, to have this brought to our attention.

My lasting memory from the conference would be the way I felt part of a social movement of people who helped me feel that however small my own contribution is, it's part of a greater thing that is changing the way research is being done in the UK. The event was a celebration of things achieved, and a generation of the energy needed to tackle the huge challenges that still exist to move us to real public involvement in all aspects of research. I really enjoyed myself - and look forward to the next conference in two years.

Breakfast of champions?

Philippa Yeeles

INVOLVE Support Unit & Conference Planning Group

Ken Blanchard coined the phrase that 'feedback is the breakfast of champions'. But, not all of us like breakfast. No matter how well intentioned, offering or receiving feedback can sometimes feel uncomfortable or perhaps unimportant. So why do we do it? Feedback is a two way street. As an organisation I think you want to know if what you have done has matched up with your own and other people's expectations and also how you can improve on things in the future. As an individual I think you want to share your experiences because you have been encouraged to think that they matter.

So I would like to begin by warmly thanking the seventy two people who returned their feedback forms and tell you that the Conference Planning Group is already starting to use the information that you have given us in planning our next conference. I know that these seventy two people are a self selected rather than a representative sample. I understand that people who are either extremely happy or unhappy are more likely to complete a feedback form. And I have not analysed people's comments using any particular methodological framework. However, despite this lack of scientific robustness I'm pleased to say that we have been given some interesting anecdotal insights. For the purposes of this 'snapshot' I have made a subjective choice of just ten comments about people's likes and dislikes.

'What did you enjoy least about the conference?'

"Acoustic problems with poster sessions were very difficult for me. Standing up around poster presenters after presentation – too crushed. Long queue for buffet. Some things rushed. Public transport difficult to use. Think some people got dropped off by coach and didn't know where hotels were. Seemed not very diverse ethnically, which I missed."

"As a clinician researcher (passionate about public participation involvement in research) I found the conference very challenging. I felt that just as people have accused the medical professions as making generalisation about how people are and what people want, I felt marginalised and stereotyped. I have had to fund my attendance to this conference myself, take time out of work I will have to make up etc. I am unsure whether I will attend the next conference. I worry that support is not there for people who are working within medical research who are championing involvement as integral to research and there is a risk of alienating people. I felt that my fire for involvement had been dampened."

"Nowhere near enough opportunity for small group discussion. Only able to be part on one workshop that allowed this and it was terribly rushed. Other small groups in main hall – far too little time. This does not enable people to contribute as much as they could. Need to recognise what participants bring to the conference."

"Over the two days perhaps too much information to take in. Left feeling quite overloaded!"

"I wanted to attend more than one of the presentations in each session, 1½ days seemed too short for all planned."

'What did you enjoy most about the conference?'

"The atmosphere of enthusiasm, energy and encouragement, feeling of shared values and common purpose."

"Variety of people and presentations, Balance between 'professional' and 'public' attending. Networking. Corridor/seating very good. Appreciated quiet space although didn't use. Accessible printed info from INVOLVE."

"Really excellent stimulating, interesting. Loved the soap-box. Question time was interesting. Loads of choice on parallel sessions. Good main speakers. The Orpheus Centre performance was outstanding (but next time give them the

opening slot!). It was a crying shame that most of the delegates had gone home by the time this performance was on.”

“Ease of navigating around conference rooms. Poster presentations. Seeing how things have developed and moved on in involving people in research over the last 3yrs and the range of methods for effectively ensuring this happens.”

“Chance to spend time with people from many different fields. Very high standard of speakers. Timings – excellent, space and time to chat to people and network. Workshops – variety and QA sessions worked very well. Met some great people, learned a lot, and renewed my enthusiasm.”

If you didn't get around to filling out a feedback form we are still interested to learn from your views and experiences. For example, perhaps you know of a particularly good conference venue or an interesting method of running sessions? We are open to your ideas and suggestions in planning for our conference in 2006. You can contact us by phone 02380 651088 or email pyeeles@invo.org.uk and there is a feedback form on the 'conference' pages of our web site http://www.invo.org.uk/Conference_Feedback.asp.

Involve Me

Lyrics by The Orpheus Centre

Please involve me
Don't ignore me
I'm a person with a beating heart
To see me be realistic
I'm a human not a statistic

There's a world beyond your facts and figures
How it feels cannot be explained like this

Please involve me
Don't ignore me
I'm a person with a beating heart
To see me be realistic
I'm a human not a statistic

There are pieces missing from your puzzle
If you want to find them let me help

Please involve me
Don't ignore me
I'm a person with a beating heart
To see me be realistic
I'm a human not a statistic

I'm a goldfish in a bowl
Swimming round without a goal
From the outside looking in
Looks like I could never win

Please involve me
Don't ignore me
I'm a person with a beating heart
To see me be realistic
I'm a human not a statistic

Thank you to everybody who sent in a contribution for this report. You can see more of Geoff Barr's photographs on INVOLVE's web site - www.invo.org.uk

- This report is also available in large print and plain text format
- You can download copies of this report from the INVOLVE web site http://www.invo.org.uk/Conference_Report.asp
- You can request a hard copy of the report from the Support Unit:

**INVOLVE Support Unit
Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD**

**Tel: 02380 651088
Email: admin@invo.org.uk
Web: www.invo.org.uk**