

INVOLVE

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

A report on
INVOLVE's 5th national conference
6th and 7th September 2006, Hertfordshire

People in Research



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***National Institute for
Health Research***

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National Institute for Health Research.**

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Introduction

This conference report focuses on the ten themed sessions at the conference, which were areas of interest that had been identified and prioritised as being worthy of particular attention. The purpose of the report is to remind people who were at the conference of what went on. It is also to inform organisations and people who were not there, about what was thought to be important in these areas of interest and it is interesting how many overlapping themes emerge.

The report will be sent to key health and social care organisations who need to know what the public and researchers are saying. INVOLVE works in partnership with other groups to support public involvement, so we will send it to them to carry forward the issues that were raised.

The INVOLVE conference happens every two years. It aims to give a range of people, including members of the public and researchers, an opportunity to meet in comfort, to explore issues around public involvement in health and social care research, as well as to hear about many research projects in which the public are actively involved. This led to the title of the 2006 INVOLVE conference - 'People in Research'.

Judging from the overwhelmingly positive feedback from people who attended, we seem to have achieved our aims. For example, people praised:

- the huge range of presentations and time given to discussion
- the way service users and researchers reflected on their experiences of involvement
- the opportunities to meet and talk to others
- the vibrant and friendly atmosphere

There were also, of course, some critical comments focussing on:

- the layout of the venue (too spread out)
- the large number of sessions and the off-putting amount of reading material
- the manner in which tensions between service users and researchers were sometimes expressed

Tensions are inevitable and reflect the reality of public involvement in research. Not only do they exist between professionals and the public, but also between different groupings within the public. With the breadth of experience that now exists across the research community, there are bound to be conflicts of interest, differences in priorities and perspectives. It is worth noting, however, that

even on this issue, the positive comments on how people handled the tensions hugely outnumbered the negative, with descriptions such as the following:

'Sharing ideas and experiences – being challenged and inspired. (It) felt like a safe and respectful environment where people were open and honest'.

'Amazing atmosphere, very courteous....the approachability and flexibility of all concerned'.

The challenge facing INVOLVE and everybody who is committed to public involvement in research, is to move forward acknowledging the tensions, supporting each other, establishing 'ground rules' - so that everybody can work comfortably and constructively on improving the quality of research.

**Kate Sainsbury
Vice Chair of INVOLVE
Chair of Conference Planning Group
December 2006**



Overview of the conference

INVOLVE's fifth national conference 'People in Research' took place at the University of Hertfordshire in September 2006. It ran over two days and consisted of talks, workshops, posters, information stands, plenaries and themed sessions. There was also a soapbox session, where people could talk for three minutes about any aspect of public involvement in research that they felt strongly about. Nearly 400 people came to the conference over the two days and more than half were members of the public or service user researchers.

The themed sessions

There were ten themed sessions at the conference. The purpose of these sessions was to allow more time for people to share their experiences and ideas on issues of particular interest. The issues identified in these sessions will inform INVOLVE's work over the next two years.

All of the sessions had the same format – half of the time was allocated to presentations about work and ideas which related to the theme. The other half was for discussion with the audience. The sessions were co-chaired by two people, one of whom was an INVOLVE Group member.

These sessions covered the following themes:

- Children and young people**
- Clinical research**
- Commercial research**
- Communication and aphasia**
- Developing strategies for involvement**
- Engaging communities**
- Evaluating the impact**
- Identifying and prioritising research**
- Tensions of involvement**
- User led and user controlled research**

In the following pages, we give a brief summary of what was covered in each of these themed sessions – who gave a presentation, what they spoke about and the key issues that came up during the discussion. At the final plenary session of the conference, the co-chairs for each themed session outlined one key issue that they felt had come from the session, and how this should be taken forward over the next two years. This key issue is identified at the end of each section of this report.

You can find out more about what was covered in each of the presentations by looking at the conference 2006 abstracts on the INVOLVE website http://www.invo.org.uk/Conference_Abstracts.asp

Common issues

Some issues were raised in a number of different sessions. These included:

- **Payment**
This was seen as a key priority in many of the sessions. People who get actively involved in research, whether as user researchers, collaborators, steering group members or in other ways need to be paid for their time and their expertise.
- **The importance of dissemination of the results of research**
Many people talked about the importance of researchers sharing the results of their research with the people who had taken part in it, in ways that can be understood. But it's also important that the results of research are shared with a wider range of people who may have an interest in them.
- **Training**
There was a widely held view that more training about involvement is needed. This includes training for researchers, and those training to be researchers, about the benefits of public involvement, and about how to involve members of the public. It also includes training for members of the public about what research is and how to get involved.
- **We need to encourage people to share their experience of involvement**
In a number of sessions it was pointed out that public involvement in research is still relatively new. It's therefore very important that people are encouraged to share their experiences of involvement – for example what worked, what didn't work and why. This could help to ensure that the public are able to be involved in research meaningfully, and to have an equal voice in what is researched, and how it is researched.
- **The role of the UK Clinical Research Collaboration (UKCRC) and the UK Clinical Research Network (UKCRN)**
These new organisations were seen as having a key role in how public involvement in health research develops over the next few years. It's too early to say how this involvement will work out, but many people were encouraged by what has

happened to date. They wanted a watching brief to be kept on developments. INVOLVE has had a role in the development of UKCRC and UKCRN.

- **Transparency**

Lots of people at the conference talked about the need for transparency – in identifying and prioritising topics for research, in commissioning research and in carrying out research. But one person pointed out that we need a shared understanding of what 'transparency' is, and how it can be measured.

- **Collaboration**

Collaboration was talked about a lot – especially the need for researchers to collaborate with members of the public and with each other to promote public involvement in research.

Children and young people

Who were the speakers, and what did they talk about?

Sarah McCauley and Jenny Preston described how they are involving children, young people and parents in the Medicines for Children Research Network (MCRN) through setting up, training and supporting children and young person's research panels. The MCRN was set up to promote and increase the number of clinical trials and other well-designed studies of medicines for children.

Anita Franklin talked about a young people's reference group on public health, set up by the National Children's Bureau on behalf of the Public Health Research Consortium, where young people identified priorities for public health research. This project is funded by INVOLVE. Anita works for the National Children's Bureau.

Jill Turner from the University of Bristol described a Young People's Research Ethics Committee across four schools in the South West, which involved over 100 young people aged 12-13.

This session was co-chaired by **Sue Banton** from STEPS and a member of INVOLVE, and **Howard Taylor**, a young person who attended in an independent capacity.

What issues were identified by people in this session?

After each talk there was a question and answer session. There was then a wide ranging discussion. Three key issues were identified:

- This is a new developing area of research with a developing community. We need to explore the issues and ethics of young people's involvement in research and the impact on young people, in order to raise awareness of the benefit of involving young people.
- We need more focus on effective recruitment of children and young people.
- Some people in this session were concerned about the 'professionalisation' of children – we need to be clear about what the role of children and young people is in research.

How can these issues be taken forward by the time of the next INVOLVE conference?

We need to raise awareness of the benefits of involvement. We should ask children and young people who have been involved in research about how we should raise awareness.

We need to bring everyone who is involved in children and young people research together, to communicate, share experiences and support each other.

Who needs to be involved to make this happen?

We'll need to work with communities and institutions in health, social care and education, others working in children and young people research – in fact anybody who has an involvement in children and young people.

One key thing from this session was....

Working with children and young people is an emerging area so it is most important to explore the issues, impact and ethics of children and young people research. This could be achieved by creating opportunities for those involved in children and young people research to communicate, share experience and support each other.

Clinical research

Who were the speakers, and what did they talk about?

Matthew Hallsworth and Marianne Miles described the work of the UK Clinical Research Collaboration (UKCRC) and the UK Clinical Research Network (UKCRN). The UKCRC is a partnership of organisations, including the NHS, INVOLVE and the pharmaceutical industry, that are working to make the UK a world leader in clinical research – so benefiting everyone who uses the NHS. Public involvement is an important part of the UKCRC and UKCRN.

Jackie Imrie talked about the impact of a clinical trial on a small population - people with Niemann-Pick Disease, a rare condition for which there is no cure. Jackie is from the Niemann-Pick Disease Group.

U Hla Htay, a carer, described the development of a mental health clinical trials pilot website, which was undertaken by a team including mental health service users and carers.

Barbara Woodward-Carlton is a member of the Alzheimer's Society's Quality Research in Dementia Consumer Network. She talked about being part of a steering group for a trial which looked at how best to manage the challenging behaviour of people with dementia who live in care homes.

This session was co-chaired by **John Sitzia** from Worthing and Southlands Hospitals NHS Trust and an INVOLVE member, and **Roger Wilson** from the National Cancer Research Institute Consumer Liaison Group.

What are the key issues that need to be addressed?

After the talks, there were question and answer sessions and a discussion. The issues that were identified during the discussion were:

- It's really important to involve the public in clinical research. They need to be involved at all stages of the research process.
- One important stage where it's important to involve the public is in setting the research agenda.
- Other important stages are dissemination and implementation of research findings. Often researchers struggle with these stages and need help from the public. It's really important to feed back the results of research to people who took part in a sensitive way. And to tell others, especially the public, about the results of the research – in plain English. Sometimes

grants are available to help researchers disseminate the results of research (for example researchers funded by the Alzheimer's Society can apply for a dissemination grant). Some research organisations (for example the Cochrane Collaboration) already try to disseminate the results of research in plain English.

- Funding for involvement is important
- The public plays a key role in research – there needs to be greater funding of the infrastructure to support public involvement
- We need to set up systems so that researchers and the public can share information about how involvement is happening
- We need research about complementary therapies as well as traditional treatments.

One key thing from this session was....

Clinical research has many stakeholders, even within patient and public involvement. We need funding so that we can develop a joined up approach to public involvement in clinical research. Greater public ownership of research evidence will result - and the tangible benefit will be a wider understanding of how and why clinical practice changes. This issue can be taken forward by working with the UKCRC and UKCRN. To make this happen, all research funders, whether they fund infrastructure or projects, need to be involved.

Commercial research

Who were the speakers, and what did they talk about?

Jane Fiona Cumming from Article 13 described a project which looked at whether people felt they had given informed consent to take part in a clinical trial. The key finding was that informed consent should not be viewed as a one-off activity when a person is first recruited to a trial. Informed consent should be part of an ongoing communication about the research between researchers and the person taking part in a trial.

Richard Tiner the medical director of the Association of the British Pharmaceutical Industry (ABPI) talked about what is being done in the commercial sector to promote public involvement in research. For example, ABPI members will register all trials (except very early trials looking at safety) on a publicly accessible register, and will make available the results of trials about a new medicine within one year of its being given a licence.

This session was co-chaired by **Peter Beresford** from Shaping our Lives and a member of INVOLVE, and **Alan Needham** from the Institute of Clinical Research.

What are the key issues that need to be addressed?

People who came to this session identified a number of key issues. Of those listed below, the first three were seen to be most important.

- Transparency and trust are key issues. People were encouraged by the ABPI presentation, and agreed that commercial research can be good for patients. There needs to be transparency about the research and marketing of drugs. We need to check how transparent commercial research is in two years' time
- We need to monitor the effectiveness of the infrastructure for involving the public in commercial research – for example through the UKCRC and the UKCRN
- There needs to be payment for involvement
- People from Black and Minority Ethnic Communities need to be actively involved in research, and should be encouraged to take part in research
- It can be very difficult to tell the people who took part in trials about the results, because information about them is anonymised

- The public need to feel ownership of research – there needs to be public involvement in the development of new clinical trials, including drug company / commercial trials.

One key thing from this session was....

We need to monitor how the new research structures (e.g. UKCRC and UKCRN) are working to enable, support and advance effective public involvement and transparency in the commercial sector. This can be taken forward by keeping a general watching brief on what is going on in commercial research and perhaps taking forward some specific systematic monitoring. To make this happen, all of the stakeholders need to be involved, including service users, carers, researchers, commissioners, INVOLVE, managers etc.

Communication and aphasia

Who were the speakers, and what did they talk about?

Maggie Lawrence from Glasgow Caledonian University, talked about a study that she is doing to find out about the needs and priorities of young adults who've had a stroke – and how these needs are met. An advisory group made up of people affected by stroke has been involved in analysing information gathered through interviews and supporting the project.

Kate Swinburn from Connect described how she had involved people with aphasia in developing an assessment tool – a way of finding out about life with aphasia. The tool asks people with aphasia what they find easy and difficult, and what gets in their way. People with aphasia had a big impact on this project.

Ellen Townsend from Glasgow Caledonian University. She explained how she and her colleagues had developed a collaboration with members of a local stroke network. They worked together to design an aphasia friendly consent form. Research about depression was a priority for these stroke survivors, so they got actively involved in designing and carrying out a project about depression.

This session was co-chaired by **Susie Parr** and **Alan Hewitt** from Connect. Susie is also a member of INVOLVE.

What are the key issues that need to be addressed?

After the speakers, there was a lively discussion. These were the issues that were discussed:

- Researchers need to be clear about what role they want people to have in the research – you can't agree to get involved until you know what the purpose of the research is
- It's important to think about control – who has it? Who are the experts? There's a danger of tokenism.
- Resources and access are also important. Making research accessible is not cheap, and people who get involved should be paid for their time.
- Researchers need training to help them to work in partnership with people with aphasia, and people with aphasia need training to learn about research
- Support is a big issue. People with aphasia who get involved in advisory groups or steering groups often see these as very supportive. So what happens after the project has finished?

- Society's view of people with aphasia will impact on research – it's important to be aware of this wider context
- Research needs to be rigorous. People with aphasia can be involved in high quality research – and can help to improve the quality of research.
- Dissemination and implementation are very important. You need to plan for dissemination from the very beginning of the project, and especially dissemination to people with aphasia. Research should lead to change – not just to more research.
- People with aphasia will have different perspectives. For example someone who has had a stroke recently may well have a different perspective to someone who had a stroke a long time ago.

One key thing from this session was....

People with communication disability can be involved in research – however there is currently little shared knowledge about what's involved and how to do it. To take this forward, we need to set up accessible forums, training and publications to share practical ideas about how to involve people with communication disabilities at every level and in every stage of research from priority setting to dissemination. To make this happen, everyone needs to be involved - people with communication difficulties, people with support skills, researchers, INVOLVE and other organisations. They all have a responsibility to bring this about.

Developing strategies for involvement

Who were the speakers, and what did they talk about?

Di Thompson and David Grayson described how the Centre for Research into Primary and Community Care at the University of Hertfordshire developed a strategic approach to involving the public. A reference group, which involves members of the public, has helped to secure funding for research and has developed training.

Jane Stewart and Rose Clacy talked about developing public involvement in the Nottingham Primary Care Research Partnership, which has five research programmes. They have taken a 'suck it and see' approach! This has involved starting small, training members of the public and professionals in how to work to encourage public involvement.

Vanessa Pinfold from Rethink talked about developing a carer involvement strategy for the Mental Health Research Network (MHRN). Vanessa and her colleagues undertook a study to ask carers whether and how they'd like to be involved in mental health research. This study has produced ideas to help develop a strategy, and there is a clear recommendation that there is a role for carers throughout the MHRN.

This session was co-chaired by **Lester Firkins** from the James Lind Alliance and a member of INVOLVE, and **Simon Denegri** from the Association of Medical Research Charities.

What are the key issues that need to be addressed?

After the speakers, people who came to the session talked in pairs about what they felt the main issues were. Later they shared these as a group. They were:

- Funding for involvement is key
- Jargon is a real barrier - not just when people are getting involved, but also when researchers report the results of their work
- Public involvement in research needs to become the norm. Researchers should only be able to get funding and ethical approval for their work if members of the public are involved
- There is a need to manage expectations – only so much can be achieved in the limited time available
- Public involvement in research is piecemeal - we need a coherent policy on involvement

- Communication is an important issue – it's especially important to have information that gets concepts across in a way people understand
- Power is a big issue – at the moment it feels like members of the public are at the margins of research, and not really true partners
- We need more research topics that have been generated by service users and carers
- There is a need for transparency about public involvement in research - publications and talks about the results of research need to show how members of the public were involved throughout all stages of the research process.

How can they be taken forward by the time of the next INVOLVE conference?

- We need to change the way that research funding works, so that it can be responsive to user-led research
- We need 'translators' who can speak the language of researchers and 'normal' language - a team of jargon busters. They could improve communication
- INVOLVE should produce a plain English guide for writing about research
- We need to ensure that service users and carers are paid for their time
- INVOLVE should produce a good practice guide on consultation
- Service users should not get involved in a research project unless they think that the involvement is good
- INVOLVE should lobby the Central Office for Research Ethics Committees (COREC) and the National Patient Safety Agency (NPSA) to raise the profile of public involvement
- We need to address the ethical issues around sharing results of research and the implications for the clinical treatment for individuals
- There's a danger of divergence – so we must also ask researchers about their concerns. Everyone needs to be involved and to have an equal voice

- We need to offer training for researchers on how to involve the public in research, emphasising the benefits of involvement. We should talk to them about barriers to involvement, and how they might be addressed
- Ethics committees need to develop an understanding of user-led and user controlled research.

One key thing from this session was....

The barriers still need to be broken down between all the stakeholders. It is vital that no one party feels excluded as 'the enemy' – this can be as a result of 'share of voice' or language barriers. We need more transparency! This can be achieved by producing a plain language guide; training 'translators' to act as links between researchers and the public; reviewing payment or compensation issues, and developing alliances with all stakeholders so that there is equal contribution and dialogue. In order to make this happen, INVOLVE should audit and then draw together all possible stakeholders. We need to obtain the 'real' commitment of all the relevant parties.

Engaging communities

Who were the speakers, and what did they talk about?

Margaret Greenfields from Buckinghamshire Chilterns University and **Richard O'Neil** described the development of a partnership model for collaborative engagement with 'hard to reach' communities – in this case gypsies. Richard, who is a gypsy, said that this project worked because people trusted the researcher, because common sense was used and because the project was flexible. Gypsies and travellers acted as interviewers for the research, and have gone on to work on other research projects.

Angela Knight-Jackson from the Heart of Birmingham Teaching Primary Care Trust talked about community participation in a cultural competence research project for community public health nurses. Lay health advisors became members of the project steering group and attended cultural competence training. Three of the lay advisors **Tari Atwal**, **Cynthia Thompson** and **Sharda Lavingia** joined Angela to talk about this project.

This session was co-chaired by **Jabeer Butt** from the Race Equality Foundation and **Robert Nurick** from the Development Focus Trust.

What are the key issues that need to be addressed?

Three key issues were identified by people who attended this session:

- We need to use training to build capacity within communities as a way of investing in the future.
- We need to deal with organisational barriers to involvement, including the lack of cultural awareness within many organisations and the lack of a culture of involvement of service users. Middle management was seen to be a particular barrier in some organisations. Some organisations seem to use Department of Health policies and guidance to increase barriers to involvement. The Human Rights Framework might be a way that some of these barriers can be overcome.
- We need to address the practicalities of paying people – so proper funding for all projects involving service users is required. It's important not to run on 'good will' all the time - people have their own lives. Don't expect some to take annual leave whilst others are paid – cream cakes are not enough!

How can they be taken forward by the time of the next INVOLVE conference?

The people who came to this session identified four core areas to help take community engagement in research forward. These were:

- Trust
- Common sense
- Flexibility
- Funding

In thinking about funding, people suggested that we should put the 'business case' to Trusts and organisations – talk money – and stress that prevention is better than cure. We need to get across that it's cheaper in the long run to engage communities, and we need to provide evidence of why involving service users will save money. It would be helpful to develop a checking mechanism for research funding bodies to ensure that user involvement in research is not tokenistic.

Who needs to be involved to make this happen?

Community engagement is an issue for all of us and we can all do this. We all need to be and can be culturally competent.

The following agencies need to be involved in thinking about payment issues: INVOLVE, Department of Health, Department of Work and Pensions, Inland Revenue.

One key thing to be taken forward from this session was....

Appropriate payment for the participation of users (both monetary and non monetary) in research, through the production of information sheets to health related organisations. This could be taken forward by collecting and collating existing guidance or remuneration, including looking at on-going reviews of charges, tax and benefit system; raising awareness amongst professionals of the importance of remuneration and how it can be done, and identifying gaps and barriers in the existing framework for remuneration to ensure effective lobbying. INVOLVE, Department of Health, Department of Work and Pensions, Inland Revenue all need to be involved to ensure this happens.

Evaluating the impact

Who were the speakers, and what did they talk about?

Phil Cotterell from Worthing and Southlands Hospitals NHS Trust talked about an evaluation of the Consumer Research Panels pilot project. Three panels work within cancer networks in the NHS to improve the relevance and quality of research. The evaluation looked at the influence of the panels on research and researchers after one year.

Shirley Nurock and Ted Freer who are members of the Alzheimer's Society's Quality Research in Dementia (QRD) programme described the early stages of an evaluation of the impact of public involvement on this programme. So far, this evaluation has looked at the outputs and outcomes of research projects funded by QRD.

Gill Gyte who works for the Cochrane Collaboration's Pregnancy and Childbirth Group, talked about an evaluation to assess whether consumer refereeing improves the quality of systematic reviews of healthcare interventions, looking at the perspectives of researchers in the Pregnancy and Childbirth Group.

This session was co-chaired by **Sophie Staniszewska** from the Royal College of Nursing Institute and a member of INVOLVE, and **Angela Barnard** an independent researcher.

What are the key issues that need to be addressed?

- We need to focus on evaluation, because the NHS in particular places a lot of emphasis on evidence based policy. If we want public involvement in research to become more widespread, we need evidence to back this up.
- Evaluation of the impact of involvement is complex – we need to identify funding for this type of research in order to identify the different possible methods to carry out this kind of evaluation.
- Evaluation of impact can't happen too quickly in a project – the evaluation of Consumer Research Panels shows that it takes a while for involvement to begin to be effective. But we need to plan for evaluation from the beginning of a project, so that we're collecting the right information from an early stage.
- There's a need for collaboration, to bring people who are working on evaluating involvement together, so that they can share information, experience and expertise.

- One size doesn't fit all – we need to develop a range of different measures of impact
- It's also important to evaluate the process of involvement – how to involve people as well as what the impact is.

One key thing from this session was....

There's a need to develop a collaborative network of groups working on evaluating the impact of involvement. This network could be used to share learning and avoid replication. It could look at how we develop a framework or structure for evaluation of impact. This should include the key themes identified in this themed session. INVOLVE should play a key role in making this happen.

Identifying and prioritising research

Who were the speakers, and what did they talk about?

Linda Goulbourne a research associate from North Tyneside General Hospital, described a project to compare the research priorities of people with ulcerative colitis with those of health professionals, using a technique called 'q-sort'. This technique helped to identify research priorities that were shared by people with ulcerative colitis and health professionals, as well as those where there was disagreement.

David Wright from Southampton University and **Mary Sayers** a Macmillan co-researcher talked about the Macmillan Listening Study. This is a national research priority setting exercise involving people affected by cancer, who acted as co-researchers. The study found that current UK cancer research activity does not reflect the experiences and priorities of people affected by cancer. The study also identified areas where research practice needs to be improved, such as the dissemination of research findings to participants.

Lester Firkins and John Scadding from the James Lind Alliance talked about how research is prioritised, and in particular how the James Lind Alliance is supporting clinicians and the public to work together to identify areas of uncertainty and then to prioritise these for research.

This session was co-chaired by **Nick Partridge** from the Terrence Higgins Trust and chair of INVOLVE, and **Sally Crowe** director of Crowe Associates.

What are the key issues that need to be addressed?

After a question and answer session, people identified key issues which need to be taken forward. These were:

- Methods of priority setting are not always well understood – they need to be acceptable to the wider clinical/scientific community
- It's important to share the results of research with people who have taken part, as well as with those who didn't take part
- 'Professionals' and the public need training to help them work together. We need to ensure people are talking the same language to each other if they are to work together effectively
- It should be a statutory requirement to involve or at least consult the public about priorities for research

- Service users should be able to lead research as well as be consulted by researchers about projects that researchers want to carry out
- We need to ensure that research findings which have negative results are published.

How can they be taken forward by the time of the next INVOLVE conference?

These issues could be taken forward through:

- Networking
- Money
- Dedicated people in each of the research organisations to promote public involvement
- Training
- Transparency
- Regular communication between interested groups about mismatches in the research agenda
- Media interest
- Sensible incentives to involve the public in research – particularly for clinicians and managers in NHS Trusts.

One key thing from this session was....

We need more transparency about conflicts of interest, language, culture and methods in identifying and prioritising research. This could be taken forward by promoting communication and dialogue between interested groups about the mismatches that exist in their research agenda, and how these can be addressed. Health and social care organisations (e.g. Primary Care Trusts) need to get much more involved in research, to make sure that what is researched is more allied to the day to day needs of service users and service providers.

Tensions of involvement

Who were the speakers, and what did they talk about?

Jill Thompson from the University of Sheffield talked about a study of researchers' attitudes to public involvement in health research, which focused on the tensions about and barriers to public involvement. She concluded that funders should look carefully at how meaningful public involvement is in grant applications; that researchers need more training, especially in communicating; and that researchers often see people as their medical condition.

David Ardron is a carer with a wide experience of working in cancer research. He's also the vice chair of North Trent CRN Consumer Research Panel. David described a study he has begun to undertake, which is about the cost of a cancer illness. He has spent a huge amount of time trying to secure funding and ethical approval, and has ended up working in partnership with a 'professional' researcher. This has meant that the project has shifted from being carer controlled to being carer driven.

Tracey Williamson from the University of Salford talked about the realities and challenges of public involvement in research. She argued that we need to talk about tensions and problems that can occur, and why they occur, so that others can learn from this experience.

This session was co-chaired by **Vanessa Pinfold** from Rethink and a member of INVOLVE, and **Rosemary Barber** from Sheffield Care Trust.

What are the key issues that need to be addressed?

People at this session identified three key issues:

- The purpose of public involvement in research and the threats from it
- Training
- Funding – this covered difficulties of getting funding, and the importance of persuading funding bodies to recognise public involvement.

They took a vote – this showed that most people felt that training was the most important issue. The rest of the session was therefore spent discussing training. These were the main things that were discussed:

- There may be useful lessons we can learn from social care – in terms of training social workers. Could there be a similar process for researchers? It would be interesting to ask

service users what they believe to be the key skills of researchers

- Training works best when service users and researchers undergo training together. Then researchers become better at spreading good news and championing public involvement
- People who study for a PhD should receive training in public involvement, so that they learn about this early in their career as a researcher
- Training in client feedback should be extended to researchers
- Training needs to be ongoing. You should think about training needs as you go along, not just at the beginning of a project or a new job
- The main challenge is providing training for everybody – there may not be enough time or resources
- We need personal testimonies of how public involvement has made a difference to studies to use as part of training – for researchers to learn from their peers
- It's also important to understand the different cultures within research. For example, people who get involved in research need to understand the tensions between researchers who do quantitative research and those who do qualitative research - and how these tensions are dealt with. It may be easier to involve the public in qualitative research.
- We need mentoring alongside training – so it's important not just to provide training courses, but also to offer follow-up
- We also need training in the purpose and outcomes of public involvement in research.

One key thing from this session was....

We need training for researchers and the public in how to work collaboratively. This should foster shared respect and openness. The training should include being clear about the aims and objectives of research. This issue could be taken forward through funding collaborative training, embedding public involvement in training for researchers, and ensuring that involvement is firmly on the agenda of research commissioners. To make this happen, the public, patients and researchers all need to be involved, to share their experiences of collaborative working.

User led and user controlled research

Who were the speakers, and what did they talk about?

Michael Turner and Peter Beresford from Shaping our Lives talked about the first national review of user controlled research, a project funded by INVOLVE. This identified that the aims of user controlled research should be the empowerment of service users and the improvement of their lives. User controlled research should be part of a broader process of change, and should involve people working together on an equal basis. A controversial issue was whether the researcher should be a service user.

Alison Faulkner an independent service user consultant, presented a think piece based on her experiences of mental health research. She argued that we need user/survivor research now more than ever before, because it seems that nationally, there is a growing emphasis on participation in clinical trials rather than on the public getting actively involved in research.

This session was co-chaired by **Rachel Purtell** Folk.us co-ordinator and INVOLVE member, and **Patsy Staddon**, from the University of Plymouth and the Women's Alcohol Dependency Unit.

What are the key issues that need to be addressed?

After the presentations, people in the session identified a number of key issues to be taken forward. These were:

- We need to communicate the benefits of involving service users from the beginning of a research project, and the benefits of what can come out of research
- There's a lack of funding to involve service users in research. There have been cuts in R&D Managers' budgets, and there is no funding available for service user researchers
- The funding regime for research is so complex that most service users and carers are out of the loop. They need to be linked to a research establishment to apply for research funding through the NHS – so inevitably their research won't be user led or user controlled
- We need to be clear about the differences between user led and user controlled research, and collaborative research
- Payment is a barrier to user led and user controlled research. We need to pay people an appropriate rate for their expertise
- There's a need for an institute for user led/user controlled research

- Disability equality schemes need to be outlined by December 2006 – organisations will need to give a clear indication of how they are going to involve disabled people in decision making.

One key thing from this session was....

All research organisations must have anti-discrimination policies (with an implementation plan) according to the Disability Discrimination Act. These policies should include non discrimination in awarding funding to user-led and user involving projects and how they are viewed in terms of quality and rigour. It will be important to tell Sally Davies, the Director of Research and Development at the Department of Health, how important this topic is.

The final session

At the final session of the conference, the co-chairs for each of the themed sessions presented the key issue they felt had come from their session. There was then a discussion about some of these, about the questions they raised and about some of the themes that were common across many of the sessions.

At the end of the session, Kate Sainsbury, chair of the conference planning group and vice-chair of INVOLVE lit a candle with Loretta Wilson to celebrate the fact that INVOLVE had been in existence for ten years.

Kate thanked staff at the University for hosting the conference; the INVOLVE Support Unit staff, the planning group and the conference organisers Professional Briefings for organising the conference; presenters; facilitators; notetakers and chairs.

Most of all she thanked everyone for coming to the conference.

INVOLVE

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

INVOLVE is a national advisory body that is funded by the Department of Health to promote and support public involvement in NHS, public health and social care research and development.

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Snapshots from the conference

