INVOLVE

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

NHS
National Institute for
Health Research

6th National Conference
Public involvement in research
Getting it right and making a difference

A unique forum for people who are interested in active public involvement in research

Conference Report

November 11th and 12th 2008
East Midlands Conference Centre
Nottingham

www.invo.org.uk

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Introduction: An overview of the conference

INVOLVE's national conference is held every two years and aims to bring together people with a common interest in public involvement in research and encourage the sharing of knowledge and learning and the building of networks. This report provides an overview of the 6th INVOLVE conference which took place on the 11th and 12th November 2008. It summarises the presentations, posters and discussions that took place and the main themes which arose.

The programme was designed to focus on: knowledge about, and future directions for, public involvement in research. The conference began with opening presentations from three speakers: Kate Sainsbury, Chair of the Conference Planning Group; Nick Partridge, Chair of INVOLVE; and Joan Saddler, National Director for Patient and Public Affairs for the Department of Health. These were followed by over 50 presentations ('papers') and 42 posters. Delegates were also provided with a number of opportunities to raise issues for discussion. In addition to question and discussion sessions at the end of presentations and posters, people were invited to note down 'burning issues' and a 'soap box' session gave individuals a further opportunity to take the floor and share their views. The conference provided a specific 'making links' session to facilitate networking amongst delegates. Peter Beresford then concluded the main conference with a closing plenary, reflecting back over the two days. The programme finished with an opportunity to attend one of seven single issue workshops. The strength of these workshops lay in the opportunities they provided to delegates to focus on specific issues, sharing their experiences and learning from one another.

This conference successfully brought together nearly 390 people over the course of the two days. Delegates were drawn from a range of backgrounds which added to the richness of the presentations, discussions and networking. A number of themes recurred throughout the event. These included: evaluating influence and impact; evaluating collaborative working; organisational approaches to user involvement; the work of charitable organisations; personal experiences and sharing

good practice; involving young people / parents; setting research agendas; and, learning and training. In all, the conference enabled delegates to learn from one another, prompted discussion and debate, and provided valuable networking opportunities.

Summary

INVOLVE's national conference is an event for everyone who is interested in public involvement in NHS, public health and social care research to discuss, reflect, network and socialise. This includes members of the public, service users, researchers, research commissioners and representatives of voluntary sector organisations. It is held every two years. This, the 6th INVOLVE national conference, took place at the East Midlands Conference Centre on the 11th and 12th November 2008.

The conference aims were to:

- Bring together people with a common interest in public involvement in research
- Encourage the sharing of knowledge and learning
- Make links and create networks with others involved in similar issues or activities around involvement in research
- Provide a platform for research on public involvement in research
- Explore issues raised before and during the conference

The programme was designed to focus on the following themes:

Knowledge about public involvement in research
- experiences of involvement in research projects or initiatives
- involvement in particular stages of research, such as prioritising or reviewing research applications, getting ethics approval, presenting research information and findings
- partnership working, such as between service users, researchers and/or practitioners
- involving communities in research including black and minority ethnic communities, children and young people, people with learning difficulties
- learning from user researchers

Debating future directions
- via a soapbox session – enabling individuals to voice issues

- taking stock more generally, reflecting on where we have got to
- developing strategies for involvement
- policy or practice changes as a result of public involvement in research
- building knowledge and evidence of public involvement in research
- researching the impact of involvement
- planning future directions

Conference delegates

This 6th national INVOLVE conference attracted more delegates than ever before with 387 people attending over the course of the two days. Delegates were drawn from a range of backgrounds as the list below illustrates.

How conference delegates described themselves	Number
Researchers	82
Research managers	44
User researchers	35
Members of the public	75
Voluntary sector	35
INVOLVE Group members and Support team	42
'Other' (including public involvement leads, practitioners, clinicians)	64
Not given	10

Opening session

The conference began with opening presentations from three speakers: Kate Sainsbury, Chair of the Conference Planning Group; Nick Partridge, Chair of INVOLVE; and Joan Saddler, National Director for Patient and Public Affairs for the Department of Health.

Welcome

Kate Sainsbury, Carer, Chair of the Conference Planning Group

Kate Sainsbury began by welcoming everyone to the conference and emphasised the diversity of delegates attending, including approximately a third researchers and research managers; a third user researchers and members of the public; and the remaining third a mix of public and patient involvement leads, policy makers, clinicians, and people from the voluntary and community sector. She encouraged people to be open to new ideas and acknowledge others' perspectives. She talked of the different opportunities to network and emphasised that attendance at the different sessions was optional and individuals should join in as they wished. She highlighted impact as a major theme of the conference and encouraged delegates to ask questions about the impact of patient and public involvement in research on individuals, on research and on health services.

The work of INVOLVE

Nick Partridge OBE, Chair of INVOLVE, Chief Executive of the Terrence Higgins Trust

Nick Partridge also welcomed delegates and in particular thanked Kate Sainsbury for her work as Vice-Chair of INVOLVE, a role she has recently stepped down from. Reflecting on the work of INVOLVE since its inception in 1996, he suggested that there is currently much opportunity for change, with increased funding for health and social care research, increased opportunity for active patient and public involvement and influence in research, and a shift

beyond consideration of whether to involve people in research towards reflection on how to involve people and deliberation over the influence involvement might have. He talked of the ongoing developments within INVOLVE and the increase of patient and public involvement in activities such as peer review and research commissioning. Nick illustrated the changes in patient and public involvement by sharing a recent reflection: when attending a meeting at the Medical Research Council only twenty years earlier, he had not been welcome inside the building but was instead outside taking part in a demonstration demanding increased funding and community involvement in HIV trials.

Keynote speech

Joan Saddler OBE, National Director for Patient and Public Affairs for the Department of Health

Joan Saddler's role as the National Director for Patient and Public Affairs for the Department of Health focuses on the inclusion, involvement and engagement of all people in the commissioning and delivery of health and social care services.

As an experienced campaigner, manager and Chief Executive within the public sector Joan established a number of ground breaking initiatives involving the public in multi-agency partnership initiatives. As Chairman of Waltham Forest NHS Primary Care Trust for seven years, Joan managed a corporate board of executive and non-executive members with responsibility for the governance of an average annual budget of £300 million. Additionally, Joan led the development of a successful local public and patient involvement strategy. Joan was the founder and co-Chair of the National NHS Black and Minority Ethnic Leadership Forum supported by the NHS Confederation and Royal College of Nursing.

Joan began her presentation by acknowledging the date, 11th November, Armistice Day. She highlighted the value of remembering the past in order to move forward and of bringing together individual stories in order to reflect on the collective. In doing so she stressed the value of these activities for patient

and public involvement and encouraged us to reflect back on the development of the movement in planning the strategic direction for the future. She acknowledged that attempts to shape health services can feel like 'a person versus the system'. Furthermore the public do not always want to take up the task of working for change: when people in Haringey in north London were asked how their lives might be improved they didn't talk about services but instead said they wanted to leave the area.

Joan discussed the challenge of language in describing patient and public involvement activities and referred to the distinction between involvement and engagement. She felt the former described 'doing', whereas the latter was more about working with communities to build sustainability. She also suggested that the word empowerment doesn't actually exist and couldn't be found in her dictionary. With respect to the challenges of language, she referred us to the recently published National Institute for Health and Clinical Excellence (NICE) Public Health Guidance on Community Engagement.[*]

She referred to the work of NICE and INVOLVE in defining community development and public involvement within this and talked of the draft NHS Constitution which was currently out for consultation. She stressed the importance of including patient and public involvement within this Constitution, which will in time become a statute, and welcomed the positioning of patients', local communities' and the wider public interests, needs and preferences within the draft Constitution. She talked of the importance of NHS accountability and stressed that this needs to be achieved through high quality information for patients, meaningful patient and public engagement, measuring quality through the eyes of service users and embedding strategic systems.

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[*] NICE Public Health Guidance: PH9 Community Engagement (2008) London.
http://www.nice.org.uk/Guidance/PH9#summary

In discussing the strategic direction of patient and public involvement and engagement within the Department of Health, Joan talked of the importance of addressing a number of key questions. These included: what we mean by qualitative information and how it might contribute to measures of quality in health care, and how joined up thinking can be encouraged in both research and healthcare delivery. She explained the encouraging developments of new reporting requirements for NHS Trusts about the quality and accountability of their services, and also of increasing availability of patient support structures. Lastly, she closed by welcoming Department of Health commitment to patient and public involvement and stressed the importance of going beyond good intentions.

Presentations and posters

The conference included over 50 oral presentations ('papers') and 42 posters. A number of themes recurred in both the presentations and posters, each of which is outlined below:

INFLUENCE AND IMPACT

A main theme of the conference was the impact of patient and public involvement in research. INVOLVE member Angela Barnard presented ideas exploring what effect 'lay' representatives were having when they take part in research. Colleagues from St George's at the University of London also asked about whether who we are makes a difference to the research that we do.

We heard about the influence of patient and public involvement on individual projects, for example within the POPPY Project which explores the needs of parents with premature babies. Influence and impact were also considered when patients and the public were involved with research programmes, such as Asthma UK's research programme and the Nottingham Primary Care Research Partnership. Phil Cotterell and colleagues explored the impact of patient involvement in research about cancer and palliative care, specifically focusing on the impact on service users. On a slightly different note, a team

from Mersey Care NHS Trust including nurses and patients, considered how their involvement in designing and evaluating a new mental health building had impacted on services. Reflecting on evaluations such as these, Rosemary Barber presented her work with her colleague Jonathan Boote at the University of Sheffield about the feasibility of evaluating the impact of public involvement.

A number of initiatives drew together information about patient and public involvement in research. In some cases the aim was to draw together research evidence, for example Carole Mockford from the University of Warwick presented work pulling together the evidence base for user involvement as a whole. In a related initiative, Kristina Staley of TwoCan Associates presented her work for INVOLVE which aims to review research into the impact of public involvement in health and social care research. A further paper by Glyn Everett from the University of Bristol presented the findings from a survey for INVOLVE to identify examples of public involvement in social care research in England. In order to better facilitate public involvement in research, the UK Clinical Trials Gateway, presented by Iain Chalmers from the James Lind Initiative, will aim to provide a one stop access to patient friendly information about ongoing clinical trials in the UK.

EVALUATING COLLABORATIVE WORKING

As well as considering how to evaluate the impact of patient and public involvement on research, there are a number of projects which are trying to unpack how researchers and patients and the public work with one another. Ruth Stewart from the University of London presented a systematic review of the literature exploring the extent to which clinicians and patients contribute to identifying research priorities. This was complemented by a presentation by Janneke Elberse from Vrije University in Amsterdam which explored in detail how clinicians and patients interact when discussing their research priorities. In a similar way, Jennie Fleming and colleagues from 'Standards We Expect' described how service users, practitioners and academics worked together and how their collaborative and inclusive approach might be improved. Nick Emmel and Andrew Clark from the University of Leeds reflected on the nature of user

engagement with research, exploring issues such as control and competing interests.

ORGANISATIONAL APPROACHES TO USER INVOLVEMENT

Another theme at the conference was the development of organisational approaches to patient and public involvement. This was touched on in many of the presentations and posters as well as being the main focus of three papers. Simon Denegri from the Association of Medical Research Charities presented the development of the UK Clinical Research Collaboration's (UKCRC) strategic plan. Anne McKenzie from the University of Western Australia described her work in increasing consumer and community participation within the School of Population Health at her university and at the Telethon Institute of Child Health. Ruth Sayers and colleagues talked about their experiences at the University of the West of England.

Roger Steel presented current involvement activities of the UK Clinical Research Network and its strategies for future patient and public involvement; Martin Lodemore described the involvement of patients in the Diabetes Research Network. Melanie Knetsch and colleagues presented the Economic and Social Research Council's (ESRC) public engagement strategy with examples from their funded projects.

THE WORK OF CHARITABLE ORGANISATIONS

The charitable sector has played a significant role in patient and public involvement in research, and their work was reflected at the conference. Amongst others, there were presentations from David Buglar, Shirley Nurock, and U Hla Htay of the Alzheimer's Society and Gabby Ansems from the Multiple Sclerosis (MS) Society introduced their rejuvenated public involvement scheme. Liddy Davidson and colleagues from Age Concern talked about a research programme 'designed by older people for older people'. Members of TwoCan Associates and the mental health charity Rethink talked about guiding voluntary organisations about how to judge when to support researchers in finding people to take part in their research. In addition, there were presentations in the area of cancer research, including work by Macmillian

Cancer Support, Cancer Research UK, the National Cancer Research Institute and the National Cancer Research Network.

PERSONAL EXPERIENCES AND SHARING GOOD PRACTICE

As well as hearing about research projects in the area of patient and public involvement in research, delegates were able to hear and read about individual experiences of being involved in research. This included hearing about Christine Allmark's experience as a user researcher at the University of Leeds, Shirley Nurock's story from being a service user and carer to becoming a researcher, and Chris Houston's experiences of being a research bid partner alongside Tracey Williamson from the University of Salford. Joan Brogden talked of her and her colleague Elaine Jones' experiences with the University of Salford on a project called Saying Hello and discussed what happens after the research is finished. In some cases presenters drew together experiences of others involved in research. Louise Locock and Sue Ziebland reflected on the work of the Database of Individual Patient Experiences (DIPEx) Health Experiences Research Group sharing experiences of involvement in research and in particular in clinical trials. Vicky Nichols from the Social Perspectives Network presented a national survey of user controlled research projects.

Other presentations shared wider experiences of collaborative work, for example in mental health research and in stroke research. Gemma Cooper and colleagues from Turning Point shared their experiences of developing community led commissioning and service delivery in Bolton and Julie Barnes and Jill Guild discussed their work with service users and carers in creating a vision for adult social care in Lincolnshire County Council. Lessons were also drawn from the Leeds Clinical Trials Research Unit's experiences of involving patients and the public in their work and the Tower Hamlets Primary Care Trusts work with disabled people.

INVOLVING YOUNG PEOPLE / PARENTS

An ongoing theme in patient and public involvement in research is how to involve young people. Hugh McLaughlin from the University of Salford discussed the ethical issue of involving young service users in research. Others presented examples of the successful involvement of young people in research, including a lively and insightful presentation about involving young care leavers in a systematic review, which Kristin Liabo from the University of London facilitated with the help of two of her young researchers. Darren Sharpe, from the National Youth Agency also presented with the support of young researchers who have contributed to a programme of young people led research in health and social care. On a slightly different note, Jenny Preston and Claire Callens from the Medicines for Children Research Network presented their work with young people which aimed to encourage them to ask questions and voice their opinions about medicines. Two other papers presented at the conference outlined how other family members and community members have been involved in research about young people. Neil Small, from the University of Bradford, presented a new study which will track the lives of 10,000 children born in Bradford between 2007 and 2010. Community members have been key in guiding this study which includes a large number of children of Pakistani origin. Kirstie Coxon from the University of Kent, presented a collaborative project working with parents in the development of a research study about the care that children with physical disability receive in primary school settings.

SETTING RESEARCH AGENDAS

Reflected in some of the presentations already referred to is the theme of patient and public involvement in setting research agendas. The work of the James Lind Alliance (JLA) in working with patients and clinicians to identify research priorities and of the Database of Uncertainties about the Effects of Treatments (DUETs) was referred to in a number of posters and presentations, including Judy Birch's presentation on identifying research priorities for the Pelvic Pain Support Network. In addition Sally Crowe from the JLA and Kristina

Staley from TwoCan Associates ran a workshop on how to make patients' and carers' priorities for research count.

LEARNING AND TRAINING

The atmosphere of the conference was very much one of sharing experiences and of mutual learning with formal and informal opportunities to learn from one another. This was reflected in some of the presentations which explored topics about what genuine service involvement might look like, and an entertaining illustration of involvement in the form of a pantomime, 'Jack and Jill's beanstalk'.

In addition, the need for high quality training for all involved in research was highlighted in a number of posters, by keynote speakers and other delegates as well as being the focus of two presentations. Dawn-Marie Walker and colleagues ran a workshop on the training needs of the public involved in research, drawing on the work of the Trent Research and Development Support Unit. Similarly, Diane Thompson and colleagues from the University of Hertfordshire presented the evolution and content of a training programme designed for lay members involved in primary and community care.

In all, the posters and presentations at the conference enabled delegates to learn from one another, prompted discussion and debate and provided valuable networking opportunities. The conference also provided a specific 'Making Links' session to facilitate networking amongst delegates.

Making links

This session invited delegates to join one of six regional groupings. These were:

- The North of England and Scotland
- The West of England, Wales and Northern Ireland
- The South of England
- The East of England
- London

- A national and international group

Delegates could choose between joining others from their own region, or take the opportunity to meet with another regional group. The groups were structured in such a way as to encourage people to get to know one another, with a brief 'speed dating' session and discussions on the opportunities and challenges for public involvement within that region.

Feedback from these sessions showed that delegates welcomed the opportunity for regional networking, something which they highlighted as important. Many regionally specific issues which arose in discussion have relevance for other regions as well as nationally and internationally.

These included:

- The need for more training on public involvement in research.
- The need to work with ethics committees to develop their understanding of and attitudes towards public involvement in research.
- The need for a specialist library for user led research.
- The need to share information about patient and public involvement activities amongst researchers.
- The need to be aware of the diversity in our communities and ensure public involvement and research reflects this diversity.
- An acknowledgment that getting involved in research is not everyone's priority.
- Practical barriers to involvement especially when people have to travel to participate. Travel to London, and outside London present problems.

Within the groups individuals also exchanged information on useful and interesting organisations, projects and people. Delegates were encouraged to exchange emails and to continue the networking process following the conference.

'Burning issues'

Delegates were provided with a number of avenues to raise issues for discussion. In addition to question and discussion sessions at the end of presentations and posters, people were invited to note down 'burning issues' and post these on a specially provided noticeboard. A 'soap box' session gave individuals a further opportunity to take the floor for 3 minutes and have their say on public involvement in research.

A wide range of issues were raised including those about:

- The need to listen to patients and the public in order to understand and meet their needs.

- How to identify, motivate and involve the 'right' patients and the public.

- The potential role for carers in research, as well as patients, or even, in some cases, instead of patients.

- Whether there are instances in which patients or the public might refuse to be involved in research because they consider it unethical, for example research which aims to identify and terminate pregnancies which would result in disabled people being born.

- Concerns about aspects of health service delivery, from poor communication skills of doctors to controversial treatments for specific conditions.

- The importance of funding for a range of activities from building relationships between patients and the public and research organisations, to facilitating patient involvement in research projects through resources and training.

- The idea that public involvement in research should be a requirement of securing research funding.

- The idea that service users should be named co-applicants in research.

- Objectivity: whether it can be achieved and how people need to be transparent about their backgrounds and their position in relation to health services.

Closing session: Reflections and future directions

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

To conclude the main conference Peter Beresford reflected back over the two days and took a 'trip down memory lane', thinking back over the years of INVOLVE's work. He talked of how different things were since early meetings between researchers and patients in which individuals' differing experiences were met with suspicion and doubt. He referred to how this tension had been replaced with a keenness to collaborate.

Peter encouraged us all to work together to provide training and capacity building for everyone involved in research; training which is co-produced and co-provided. He talked of the value of developing regional networks and praised the inclusion of the 'making links session' in the conference schedule. He also highlighted the importance of ensuring diverse involvement in research and welcomed the variety of delegates taking part in the conference whilst stressing the need to address discrimination. He talked of the importance of ethics and emphasised the principles of shared commitment, honesty and respect.

Peter expressed a concern that infrastructure for patient and public involvement in research were lacking at local level and suggested that new change requires new levers. In considering the whole spectrum of involvement activities he highlighted the importance of user controlled research and thanked INVOLVE for their role in promoting this.

Peter identified impact as one of the main themes of the conference. He talked of the importance of acknowledging the complexity of measuring impact and called for ongoing, high quality inclusive evaluation of patient and public involvement in research. Peter also acknowledged that patient and public involvement requires years of investment and research into the impact of involvement will take time.

Reflecting on what the next steps are, Peter referred to the need to bring the benefits system in line with patient and public involvement to allow those on benefits to take part. He also talked of the need for researchers to offer payment to those involved in research and to properly address issues of access taking into account cultural, communication and physical needs. Looking more broadly, Peter highlighted the need to develop and clarify concepts, language and methodological frameworks and to report all activities to a range of audiences, including 'believers', 'non believers' and 'agnostics'.

Peter's closing comment to the conference was that as a pessimist by nature, he was pleased to say he was seriously optimistic about the future of patient and public involvement in research. He considers there to be a strong and critical body of work in this area, indeed there is not only a future for this work, but he considers it to be **the** future for research.

Single issue workshops

The conference closed with an opportunity to attend one of seven single issue workshops. The strength of these workshops lay in the opportunities they provided to delegates to focus on specific issues, sharing their experiences and learning from one another. Whilst the networking and sharing that took place is hard to capture in a report, a brief overview of each workshop is provided below. Where available, slides and/or resources from these sessions are available from the INVOLVE website.

Writing a research question: 'get it right and the rest just follows!'

Led by Virginia Minogue and John Hiley from West Yorkshire Mental Health Research and Development Consortium, this workshop covered what makes a good research question, and how to turn a topic into a question for research. Key points which were raised during the session included the fact that topic areas in the field of involvement are very broad, and can be difficult to narrow down to specific research questions. The group discussed the tension between narrowly focused and potentially meaningless questions, and very broad but unanswerable questions. Despite this challenge, they recognised the importance of getting the question right before choosing the most appropriate methods to address it. Framing a research question in terms of the Population, Intervention, Comparison and Outcome (or 'PICO') was proposed as a useful way to refine a research question.

'Hot tips' for researchers

Led by Tracey Williamson, Research Fellow in Older People User Involvement at the Salford Centre for Nursing, Midwifery and Collaborative Research, and Sophie Staniszewska, Strategic Lead for Research and Principal Research Fellow at the NHS Centre for Involvement, this workshop focused on a selection of mini case studies. These highlighted different scenarios that might occur in a collaborative research project involving patients and the public. The delegates divided into three groups and discussed the case studies and the questions raised. The key issues identified by the groups are listed below:

- Respecting each other and valuing different skills and perspectives
- Creating a safe environment
- Communication, clarity and transparency
- Planning and training
- Confidentiality
- Accessibility
- Recognition of different expectations and managing these sensitively
- Ground rules or framework for mode of operation
- Reflection on the involvement – if it is working and the balance of power

- Recognition that the impact of involvement is an issue for all members of the research team
- Acknowledgment that public involvement takes time and effort
- Closure following patient / public involvement.

Payment for public involvement in research: negotiating safely the benefit and tax system

This key workshop session was led by Judy Scott and Alison Faulkner. Alison started the session by describing her experiences of developing a payment policy for a small organisation. She highlighted some of the issues in developing a policy. The main difficulties were related to working with the existing finance systems of an organisation as well as the benefit system. For example: how much people should be paid, how and when payment could be made (cash, payment in kind, speed of payment, etc), the need for flexibility versus organisations systems and procedures, and the complexity and restrictions for people on benefits.

Judy Scott then outlined some general principles for payment including: people are valued, no one should be out of pocket as a result of their involvement, all expenses should be covered, payment should be at the rate for the job, the manner of reimbursing expenses is important, and people need to be given the opportunity to make a considered decision about whether or not to get involved in research after getting advice and information about available payments. Judy highlighted some of the myths about payment as well as some of the pitfalls and helpful benefit rules. Throughout the presentation Judy invited the participants in the workshop to ask questions and share their experiences. Two short papers were available for people to take away at the end of the session. One was produced by Judy Scott outlining advice on some of the benefit rules and problems to avoid. The other was produced by INVOLVE and gave details of a couple of useful references about payments. Both papers are available on INVOLVE's website www.invo.org.uk

Other important information shared during the workshop is listed below:

- Frontline staff within benefit agencies are often not familiar with the rules and can give conflicting advice.
- All methods of payments will count as earnings for benefit purposes whether they are paid as vouchers, in cash, or if paid to a charity instead of paying someone.
- People should always get advice in writing about payments for getting involved in research and keep a copy of any correspondence.
- Employers are required to keep a record of all payments. If this is not done then the organisation could be liable for the tax.

Judy finished the session by informing people of an advice line that has been established by Milton Keynes Citizens Advice Bureau, where organisations can buy into the service to support service users and carers who are getting involved in research. She also said that she had been involved in meetings with the Department for Work and Pensions and Ministers to try to resolve some of the difficulties related to payments and benefits.

Getting involved in peer review

This workshop was led by Jean Cooper Moran, Senior Manager for Patient and Public Involvement at the National Institute for Health Research's Central Commissioning Facility, and INVOLVE member Angela Barnard. They were supported by two lay reviewers from the Research for Patient Benefit programme, Kath Maguire and Lesley Roberts. The workshop began by considering two vignettes describing individual patients' experiences of getting involved in research. These real life examples helped the group to identify features of meaningful involvement, such as thoughtful and timely communication and support for those getting involved. Two further case studies, this time in the form of research funding applications outlining planned involvement of patients and the public, provided further fuel for discussion about how research teams might be encouraged to plan and prepare for involvement. These discussions provided a valuable illustration of what is involved in peer review and the facilitators finished by answering questions about the process of peer reviewing funding applications.

Young voices: how can we make the participation of children and young people in research meaningful?

Led by Louca-Mai Brady, Hugh McLaughlin, Sue Banton, Suryana Mohammad and Emrys Green this workshop focused on the meaningful participation of children and young people in research, exploring the challenges for young people, adult researchers and the research process. In addition they sought to demonstrate the outcomes of children and young people's involvement.

This workshop included a survey of the delegates in the workshop and their involvement activities as well as some more general discussion. Those who had undertaken research with young people (9/17) had done so mostly with 11-15 year olds or those over 15, although 3 had worked with children under 5. Of the 8/17 who had not conducted research with young people, 4 were planning to in the future. The focus of the research included health conditions such as mental health and diabetes, and broader social issues such as access to schooling and the emotional support services available in secondary schools. Young people had been involved in research advisory groups, designing questionnaires, conducting interviews, analysing data, writing up the research and dissemination. Training issues were also listed including: ethics and child protection issues, effective communication, the cost of involvement and in particular payment for young people, the challenges of working with particular groups of children such as school aged children and those with complex disabilities, recruitment of children and young people and how to sustain their involvement, and support and training for young researchers

Two young researchers from within the workshop also reported their experiences of taking part in research; both had been involved in the same project looking at health issues for looked after children and young people in a Local Authority. They had taken part in the project advisory group, selecting the research topic, conducting interviews and in dissemination. Their response to being involved in future research was positive.

The workshop went on to discuss: why involve children and young people in research; what the barriers are to involvement; what is needed for meaningful participation for those involved, including children, young people and

researchers; and how we can best demonstrate what works. The one issue that stood out in the discussion was the desire to know more and the wish that INVOLVE set up a study day specifically focused on involving children and young people in research. This day should include children and young people in the planning.

The support and development needs of public involvement leads and champions

Led by Bec Hanley, Roger Steel and Liz Philpots, this workshop was designed for people whose role in their organisation was to lead, facilitate, or champion the agenda for patients and public involvement in research. Through discussions the delegates identified key challenges for those involved in this role. These included issues related to the context in which people work: the baggage which research professionals, service users and carers bring, knowing the research 'system' and getting access to it; and the need to change the culture of research and research organisations. There were also challenges relating to the introduction of patient and public involvement activities: the level of researchers' understanding as to what patient and public involvement means; how to gain respect and recognition for this work; the need to experiment with approaches and take risks; and how best to share good practice. Additional challenges relate to facilitating involvement itself including: identifying, recruiting and retaining individuals to be involved, particularly those from black and minority ethnic groups; gaining acceptance for service users as partners in research; making the most of the skills and experiences that people bring; how best to start user led research; and how to evaluate patient and public involvement activities. Lastly, communication and funding arose as key challenges. The workshop delegates suggested a number of changes that might help enable them in their work. These suggestions ranged from a recognition of the time and resources that are needed, to calls for a revolution in research with the establishment of patient centred research centres in which everyone works in partnership. Some more practical ideas included: establishing common definitions to enable systems to share best practice internationally; an email group which people can join to share experiences and ideas; the development of local networks in a

grassroots approach; and recognition from those in senior positions that patient and public involvement is important and must be funded and facilitated.

How should Research Design Services support public involvement in healthcare research?

This workshop was led by Kirstie Coxon, Athena Christoferou, Val Hall and Natalie Lambert from the South East Research Design Service. The session started with an introduction to the Research Design Services (RDS), each of which cover a Strategic Health Authority and will support the NHS and social care research in terms of study design, specialist areas such as statistics and health economics, funding applications, research ethics applications and public involvement. The delegates discussed the available activities to support public involvement which will be offered by RDS. They then split into two parallel group activities, the first of which focused on developing an evaluation strategy for public involvement in the RDS and the second looked at the different ways in which the RDS might finance public involvement in designing research studies before they are submitted to funding streams. Both discussions provided valuable information for the RDS on how to shape their services to provide effective advice on public involvement in research.

Conclusions

This 6th INVOLVE national conference successfully brought together nearly 390 people over the course of the two days. Delegates were drawn from a range of backgrounds adding a depth to the presentations, discussions and networking.

A number of themes recurred throughout the event. These included: evaluating influence and impact; evaluating collaborative working; organisational approaches to user involvement; the work of charitable organisations; personal experiences and sharing good practice; involving young people / parents; setting research agendas; and, learning and training. Certain topics were highlighted as key future directions. In particular, there was enthusiasm for ongoing work to understand better the impact of patient and public involvement on research. The other main issue was that of payment of individuals for their involvement, something which INVOLVE are already taking forward.

Lastly, in concluding the conference Peter Beresford observed that the tension of early meetings between researchers and patients had been replaced with a new keenness to collaborate. There is not only a future for patient and public involvement in research, but patient and public involvement represents the only valid future for research.

The conference successfully enabled delegates to learn from one another, prompted discussion and debate, and provided valuable networking opportunities.

Further information

The full conference programme and presentations can be downloaded from http://invo.org.uk/Conference2008.asp

More information on INVOLVE is available from the website at www.invo.org.uk

INVOLVE

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

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

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