
**INVOLVE Awayday
10 and 11 September 2008
Latimer Conference Centre, Chesham, Buckinghamshire**

SUMMARY REPORT

Participants:

Members:

Nick Partridge (Chair)
Ade Adebajo
Richard Baker
Angela Barnard
Rosemary Barber
Louca-Mai Brady
Ann-Louise Caress
Chris Caswill
Karen Collins
Simon Denegri (day 2)
Stuart Eglin
David Evans

Ray Fitzpatrick
Poonam Jain
Hugh McLaughlin
Mary Nettle
Maria Palmer
Diana Rose
Laura Serrant-Green
Patsy Staddon
Sophie Staniszewska
Michael Turner
Tracey Williamson

Observers:

Kay Pattison (day 1)
Tony Williamson (day 1)

Roger Steel (day 1)

Support Unit:

Sarah Bayliss (Support Unit)
Sarah Buckland (Support Unit)
Barbara Dawkins (Support Unit)

Helen Hayes (Support Unit)
Maryrose Tarpey (Support Unit)
Gill Wren (Support Unit)

Apologies:

Sue Banton
Peter Beresford
Sarah Carr
Jim Elliott
Alison Faulkner

Susie Parr
Hala Patel
Mark Petticrew
Vanessa Pinfold

DAY ONE: 10 September 2008

1. Welcome and introductions

Nick welcomed everyone to Latimer and then went on to advise the Group that this would be Michael Turner's last INVOLVE meeting as he would be joining the Parliamentary and Health Service Ombudsman as a caseworker investigating complaints – 4 days per week. Due to his new job he would have to cut down many of his other commitments. Nick expressed his thanks and best wishes to Michael and said that the Group would be really sorry to see him go.

Nick congratulated Laura Serrant-Green on her recent appointments as Professor of Community and Public Health Nursing at Lincoln University starting in October, and Visiting Professor at the University of West Indies.

2. Business meeting

The awayday started with a brief business meeting.

Minutes of the meeting held on 03 June 2008

No corrections were noted.

Matters arising – paper 1

Nick highlighted the opportunity for Group members to transfer to different working groups. Nick requested that anyone wishing to transfer should complete a transfer request detailing which working group they would like to transfer to and why. He reported that there was a need to maintain equal numbers and mix of members in each working group.

Nick reminded the Group that the next meeting would be 20 January 2009 and not 16 December 2008 as previously advised.

Action: Support Unit to let Group members know if their transfer request had been successful.

Directors Report – paper 2

Sarah Buckland reported that Karen Postle who was going to join the Support Unit at the end of September, would not now start until later as she was undergoing hospital treatment.

3. Jonathan Nicholls, Research Director – Health and NHS Ipsos MORI Social Research Institute

Jonathan Nicholls Ipsos MORI gave a powerpoint presentation titled 'Engaging in involvement: what do we know?'

He explained that the aim of his talk was to share with us a perspective on NHS research as experienced by his commercial organisation Ipsos MORI over the last few years. He spoke about:

- the types of research that the NHS have commissioned them to work on (e.g. patient satisfaction surveys, local priority setting)
- the changing and growing nature of that demand within the NHS
- the issues and debates that their clients in the NHS are engaging them with (e.g. the development of patient-centred care).

The presentation was followed by a wide ranging discussion on the definitions and research approaches used by Ipsos MORI. Jonathan emphasised that their research focus was governed by their client base, primarily NHS Trusts who were mainly commissioning large scale quantitative patient satisfaction / opinion surveys intended to feed in to the formal commissioning process of NHS services.

Action: the slides used in the powerpoint presentation to be circulated to all Group members.

DAY TWO: 11 September 2008

4. World Café discussions

The World Café approach was used to debate three key areas of INVOLVE's work. During day two, Group members moved between tables to discuss the following three areas or 'courses'.

a. Building knowledge (starter)

What do we know and what do we need to know about public involvement in research?

- What has been achieved / works well and where
- What do we know about how best to influence, and what support people need
- What are the unanswered questions, and gaps in our understanding and knowledge

b. Making alliances and influencing others (main course)

Who do we most need to influence, and support and about what?

- Individuals, organisations, groups
- How are priorities changing
- What are we hoping to achieve
- How best to influence

c. Supporting and empowering others (dessert)

How can we best support others (researchers, service users, carers, commissioners)?

- researchers, service users, carers, commissioners
- different types of support needed

Below is a summary of the key points raised on each of the three topics. See **paper 12** for a full list of the points raised.

a. Building knowledge (starter)

Terminology

- 'evidence' is too narrow a term – need to widen or change our notion of evidence

Mapping and monitoring

- We need to pull together and monitor all of the information and data around public involvement in research e.g. from research application forms and research reports
- What do we know about the people who get involved and if they are individuals or organisations?
- Different areas have evolved in different ways e.g. cancer, mental health so important to situate public involvement in context
- Need a review of patient and public involvement (PPI) role in commissioning and funding groups – scoring of research bids does not fit with PPI questions / PPI is often not a decision criteria

What do we need to know or find out about public involvement in research?

- Need to consider if the different models and approaches work for different disciplines or areas of involvement. Are there particular features or types of involvement that work better than others in specific areas?
- Are there different challenges for public involvement in different disciplines or within the research process e.g. young people, older people and priority setting?
- How do we match the patients and the professionals priorities for research and ensure that each understands the others perspectives? Is there a

- shared view within different groups and individuals as to what is important?
- How can we assess/measure what is good public involvement in research and what effect it is having?
 - We need to know the interventions that change research culture to ensure real involvement

What do we know about how best to influence, and what support people need?

- Personal experience stories and examples of user involvement working can be used in a strategic way
- Money can change behaviour but does it change culture?

Ethics

- Ethics overrides the need for evidence

b. Making alliances and influencing others (main course)

Influencing – individuals, organisations, groups

- Important to promote the role of public involvement ‘champions’ in working with sceptics

How are our priorities changing

- The need to plan for a changing political climate and the implications this may have for both research generally and public involvement in research specifically

What are we hoping to achieve

- Need more clarity on who to influence in social care given the lack of a social care research structure. Need to develop a coherent body to influence social care research – as for public health
- Issues to consider related to the capacity of INVOLVE and all the changes in health and social care (practical and research)

How best to influence

- Need to follow up on opportunities to work with other relevant initiatives – for example UK Clinical Research Network’s training programme and the developing role of Research Design Services
- INVOLVE can influence most effectively by communicating with a variety of different audiences and formats whilst maintaining the integrity of the message

c. Supporting and empowering others (dessert)

Nature of support

- Not one size fits all

- Need to explore more diverse ways to provide support / be more creative
 - different resources and support needed e.g. training, tool kits, mind maps, support
 - need to map a grid of the different types of support needed
 - there is a lot of material and research available that could be used and developed (important not to reinvent the wheel)
 - diversity of what and how people wish to contribute
 - what support do people need (not one way)
 - support needs to be local
 - lack of support in Universities
- Develop a network of people who could give support around the country - need to recognise potential for burn out
 - Important to avoid being paternalistic - need to listen to what people need
 - Role for INVOLVE as a broker in relation to providing support

Who needs support

- Service users
 - supporting involvement or choice to be involved
 - look at type of support services users need – most is currently not interactive
- Researchers
 - develop mechanisms for buddying researchers

d. Other issues raised in discussion

- Encourage research funders to have budget lines in grant applications for patient and public involvement
 - Need for a debate around payment and the implications of payment
 - How to make best use of the capacity of INVOLVE and the Support Unit.
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