
**INVOLVE Awayday
09 & 10 October 2007
Latimer Conference Centre, Chesham, Buckinghamshire**

SUMMARY REPORT

Participants:

Facilitator:

Derek Stewart

Members:

Nick Partridge (Chair)

Kate Sainsbury (Vice Chair)

Ade Adebajo

Richard Baker

Sue Banton

Angela Barnard

Rosemary Barber

Louca-Mai Brady

Ann-Louise Caress

Sarah Carr

Chris Caswill (day1 and morning day 2)

Karen Collins

Simon Denegri

Stuart Eglin

Jim Elliott

David Evans

Poonam Jain

Hugh McLaughlin

Mary Nettle

Maria Palmer

Susie Parr

Mark Petticrew

Diana Rose

Laura Serrant-Green

Patsy Staddon

Sophie Staniszewska

Michael Turner

Observers:

Kay Pattison (day 2)

Morton Phillips (day 2)

Support Unit:

Sarah Bayliss (Support Unit)

Sarah Buckland (Support Unit)

Barbara Dawkins (Support Unit)

Helen Hayes (Support Unit)

Jane Royle (Support Unit)

Roger Steel (Support Unit)

Maryrose Tarpey (Support Unit)

Gill Wren (Support Unit)

Apologies:

Peter Beresford

Alison Faulkner

Ray Fitzpatrick

Carol Lupton

Marianne Miles

Hala Patel

Vanessa Pinfold

John Sitzia

DAY ONE: 09 October 2007

1. Welcome and introductions

Nick invited brief introductions from all present and welcomed Derek Stewart who would be facilitating the awayday. Derek was introduced as a cancer patient, advocate, activist and also a member of the National Cancer Research Institute Consumer Liaison Group (NCRICLG) plus an ex member of INVOLVE.

2. Business meeting

The awayday started with a brief business meeting.

Minutes of the meeting held on 14 June 2007

No corrections were noted.

Matters arising – Annex C

Nick requested that Group members send back completed forms for any activities undertaken in connection with INVOLVE.

Action: Support Unit to send out forms to all members

Directors Report – Annex D

Sarah Buckland reported that Jane Royle would be leaving the Support Unit at the end of December to take up a new role as Consultant in Public Health based in Cornwall.

Involve Strategic Plan – Annex B and the Report of the work of INVOLVE – Annex B (i)

Nick advised that the Strategic Plan had been revised as a result of the feedback from the consultation (18 people had submitted comments and suggestions). He asked the Group to recommend that the plan should be signed off. This was agreed.

The following two comments were made about the Strategic Plan:

- The hope that INVOLVE could fulfil as much of the Strategic Plan as possible.

- That it is important to communicate how INVOLVE operates to ensure there are no misunderstandings.
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3. What's in the future: an introductory activity

Derek facilitated a short introductory activity, where participants divided into small groups and considered the approach and issues that might be covered by an **INVOLVE conference in 2015**.

DAY TWO: 10 OCTOBER 2007

4. Considering our own mental health

A short exercise where Group members were invited to discuss in pairs how they looked after their own mental health.

5. Sally Davies, Director General, Research and Development Department of Health

Sally Davies reported on current progress within the Department of Health, in delivering the strategy Best Research for Best Health, as well as progress with the establishment of the Office for Strategic Coordination of Health Research (OSCHR). Sally also reported that the comprehensive spending review has increased the budget for health research from £550 million to £1.7 billion by 2010. In relation to patient and public involvement, Sally highlighted how the Department of Health is committed to patient and public involvement at every stage of the research process, however the challenge for all those involved should not be underestimated.

The following questions / issues were raised by Group members in discussion:

- Whether there is the possibility for a league table or award that recognises effective public involvement in research
- Where does social care research fit into the health research agenda
- Concerns that bureaucracy and governance is stifling research
- We have the evidence for health care; we need the evidence base for involvement and funding is an issue for research in this area

- What about other funders and the scope for support from the UK Clinical Research Collaboration (UKCRC)
- Major challenges are how we maximise impact; how we make sure that public involvement is main stream and how we focus our current limited resources

Sally Davies indicated that if a good case was made, then more money was available for public involvement and INVOLVE.

6. Issues of Access – Susie Parr

Susie Parr presented the draft Accessibility Strategy and Annual Plan on behalf of the Empowerment working group. The INVOLVE Accessibility Strategy is broad. It covers making activities, events and products welcoming and easy for everyone by creating the conditions that will enable a wide range of different individuals and groups to contribute to and benefit from the organisation. The strategy aims to make accessibility integral to INVOLVE.

The underpinning values are that: everyone should be valued and treated with respect; there should be continuous work towards identifying and removing any barriers that prevent stakeholders from taking part in what INVOLVE has to offer; accessibility is a shared responsibility that will benefit everybody, and; it is a process rather than a fixed state.

INVOLVE's approach should:

- be responsive to external influences and internal issues;
- be implemented in planned annual phases, with specific goals;
- be transparent and sustainable;
- build on successes and learn from mistakes;
- take place in a continuous cycle of action, reflection, and revision.

There will be an annual review of information gathered from a range of sources, including; events (conferences, seminars); group meetings; communications; publications; and internal processes.

This year, information was gathered from a survey of Group members, informal feedback from members, a survey of Support Unit staff, the Central Office of Information audit of INVOLVE documents and national conference, and feedback from events. The review identified INVOLVE's strengths and possible weaknesses in respect of accessibility. It then identified a number of targets which would help improve INVOLVE's accessibility.

Following the presentation there was a comment from a Group member commending the strategy particularly in respect of how it approached accessibility within a continuous learning framework. Nick asked if there were

any other issues to be raised before the strategy and the annual review report were endorsed by the Group. There were no other issues raised, so the strategy and report were approved.

7. Discussion of key priorities for INVOLVE

On day one, the three working groups were asked to identify key priorities for INVOLVE. Derek introduced the priorities raised. It was noted that developing the evidence base around public involvement was raised by more than one working group as a priority.

Evidence Knowledge and Learning (EKL)

- a) Need for evidence to influence and change policies
- b) Building relationships and communication, including influencing journal editors
- c) Developing the evidence base

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- c) Improving evidence and championing and disseminating the evidence to influence policy
- c) Evidence – sharing and increasing awareness of
- e) Developing champions of good practice for public involvement

Strategic Alliances (SA)

- d) Developing capacity to support public involvement around the country through hubs
- b) Review methods for how to prioritise alliances
- b) Decide on which Strategic Alliances to prioritise

Members then divided into mixed groups to discuss the priorities. The following points were fed back:

a) Influencing policy

This was perceived as an important area for all of the working groups with the following roles:

Evidence, Knowledge and Learning to find and develop the information base, Empowerment to disseminate the work and Strategic Alliances to determine and prioritise the different approaches for influencing policy.

Discussions took place around the different ways policy is expressed and the difference between something being written into policy and being 'essential'. It

was considered important to map out the pathways for researchers within the National Institute for Health Research (NIHR) and how they are managed.

One suggested way forward was to contribute to the development of the Department of Health indicators and metrics.

b) Communication

A broad strategic approach was considered important which would cover:

- identification of who to talk to, why they should be contacted and to what effect
- facilitation of organisations to talk to each other
- pathways to achieve an 'end'

It was felt important to ensure that as well as health, the approach included social care, academic publications and individuals who are not 'aware' of INVOLVE. It was considered important to support good practice 'champions'.

One suggestion was whether INVOLVE should set up a training or workshop programme.

c) Evidence

The following questions were raised:

- What types of evidence should we look at
- What does this mean for INVOLVE

To explore the possibility of INVOLVE working with the Department of Health to develop thinking around building an evidence base for public involvement in research as well as the financial contribution

Suggestions put forward were:

- Development of a research commissioning brief with the Service, Delivery and Organisation programme (SDO) around requirements for generating evidence
- Development of metrics to begin to show the difference public involvement makes
- How can public involvement in research be measured in studies and built in as integral to grant applications. What information can be collected?
- Consideration of going to a group of projects and assessing the impact of public involvement either in ongoing work or retrospectively
- How can INVOLVE lobby for the appropriateness of different forms of evidence
- Evidence also required to: identify gaps and challenge the hierarchy of evidence

d) Hubs and capacity

Key question do we need to use what currently exists to better effect or is there a capacity issue?

Two main groups to serve:

- Researchers are looking for advice
- Members of the public actively involved in research are looking for more support

Regional R & D Support Units (RDSUs) were identified as potential spokes to deliver public involvement support, with INVOLVE as a national hub. This discussion moved rapidly to checking whether the tender document currently being finalised by DH for the new Research Design Service (the replacement to RDSUs), included reference to providing advice on public involvement. The Department of Health were contacted and it was agreed that the final tender document should have a paragraph included which spelt out that applicants should have a named person with responsibility for public involvement and they should be required to outline how they envisage working with INVOLVE. Draft text was sent to the Department of Health, for inclusion in the tender documents, during the meeting.

It was recognised that social care research would still require capacity development and that the new Research Design Services did not cover social care research.

The Department of Health were approached to include working with INVOLVE to promote public involvement as part of the remit for the new Research Design Service.

e) Good practice 'Champions'

The following points were raised in this discussion:

- Need to develop 'champions' to promote public involvement in research
- Difficulty of isolation for 'lone' champions.
- Support would be required on how they can influence structures. They need the knowledge and evidence to support their case including examples of public involvement.
- Lessons to be learnt from community development
- Important to identify different types of champions including those from within the Department of Health
- Need for both top down and bottom up champions
- Service user champions also need support on how to influence

- People who supervise researchers can be important champions
 - Need to understand the motivation for people getting involved
 - A role of champions is to develop and support others
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8. Solutions to key priorities

Group members were asked to look at a summary of many of the other priorities identified in the working group meetings on day one, and vote on which they felt were priorities for further discussion.

The text in brackets, refer to the numbers of votes given to items, and the number of the strategic priority in the Strategic Plan (eg. SPi = Strategic Plan priority: Influencing policy)

Resourcing public involvement and developing infrastructure (16 votes) (SP ii)
 Raising public health and social care agenda (12 votes) (SP i)
 Influencing DH and other Departments (7 votes) (SP vi)
 Ethics and morals of involvement (5 votes) (SP v)
 Good practice guidance (5 votes) (SP vi)
 Develop international links (4 votes) (SP vii)
 Support for involvement (3 votes) (SP ii)
 Help users / carers to understand (2 votes) (SP v)
 Create and use group networks / grids (2 votes) (SP vii)
 Addressing information for specific groups (1 vote) (SP iii)
 Use stories and narratives (1 vote) (SP v)
 Review infrastructure (1 vote) (SP vii)
 Clarity about involvement as opposed to engagement (1 vote) (SP vi)
 Peer recruiting of participants (SP iii)
 Recognising changing environment (SP iii)
 Further understanding (SP iv)
 Need to understand research environment (SP v)
 Regularly review processes (SP vii)

The following three topics were rated highest by Group members as topics for discussion. The three topics were then explored in small group discussions with members discussing possible solutions to some of the issues identified:

- Influencing the Department of Health and other departments (SP vi)
- Raising public health and social care agenda (SP i)
- Resourcing public involvement and developing infrastructure (SP ii)

a) INVOLVE's role in influencing the Department of Health and other departments

The Group noted:

- There had been subtle changes from clinician led to patient focused provision
- The Department of Health may not be the only programme to influence
- The Department of Health is not the NHS. Influence over the NHS may diminish with development of Foundation Hospitals etc. There are different audiences for INVOLVE to approach. The Department of Health may be in less of a position to command and control in the future.
- Foundation Trust membership database, provides the potential for public involvement, but will public involvement have a role?

Comments:

At a Trust level different drivers are developing – INVOLVE will need to move to influence key decision makers – for example Finance Directors at Trust level.

b) Raising public health and social care agenda

The Group noted:

Social care research

- The problems of social care research and the limited infrastructure were discussed
- The need to map who is doing social care research. This will help to identify who we need to influence e.g. Research Assessment Panel (RAE).
- To see whether there are lessons to be learnt from Scotland and Wales in relation to health and social care research

Public health

- The need to communicate the public involvement agenda via public health journals. Also to identify specific barriers e.g. ethics committees
- Opportunities in public health due to increased funding – there is the potential to influence commissioners to do public involvement
- The UKCRC are funding 5 centres of excellence on public health and all have to include public involvement. Once the centres have been announced we need to network and form alliances with these centres.

c) Resourcing public involvement

The Group noted:

- The need to resource public involvement prior to funding – need to push for pump priming at the beginning and at the dissemination stage - 'wing

funding’ e.g. small pots of money for development of research ideas with or by service users and carers (could be administered by research funders or RDSUs)

- Resourcing service user organisations to develop research involvement
- Ring fencing for user controlled research
- Need for funding of service user networks
- The NIHR Faculty – this provides the possibility of service users becoming members of the Faculty and having access to flexibility and sustainability budget.

9. Working Group Discussions

Participants then re-convened into the three working groups to discuss the issues discussed throughout the awayday and to reflect on the implications for their own working group.

Strategic Alliances

What	How	When	Who
Strategic Alliances to work with the new Research Design Services (to develop hubs to support and promote involvement)	Include responsibility for public involvement in the tenders for the new Research Design Services (RDS)	Done / soon	
Prioritisation of strategic alliances – who to prioritise and what we do with them e.g. identify a piece of work to develop a relationship around	Continue to work on the ‘grid’ to identify which organisations to make stronger alliances with - especially social care funders and academics		Sarah, Angela, Simon
	Develop a common agenda with ESRC re. workshops and working together	To draft outline and circulate	Sarah
Development of communications strategy – a brief for the work has just been advertised	Seek advice / help from Angela Barnard’s contact re. communications		Angela to discuss contact re public relations advice

Empowerment

What	How	When	Who
Training toolkits for use by involvement leads and research advisors	Need to check how this is approached by others in order to spread learning. Talk to SCIE re multi-media – etc.		Support Unit
Develop a systematic strategy for identifying champions and working closely with them	Universities, user groups, charities, RDSUs etc		
Identify who needs what evidence and how to convey it			
Getting messages from champions to people who need to hear them	Use of video, stories, vox pops		
Populate the new structures with patient and public involvement	Capacity building for user groups and other champions. Athens login, CBI schemes for employers.		

Evidence, Knowledge and Learning

What	How	When	Who
Find out who is doing work around developing an evidence on the impact of public involvement in research. Circulate information to working group members.	Via email	Soon	Helen and Maryrose and everybody to contribute

Contribute to metrics issue	Check process with Kay. By email identify and clarify metrics. Talk to Sarah	Now and soon	Maryrose to liaise with Jim, Sophie, Michael, Diana and other members
Influence key policy makers and funders	Talk to Sally and others		Nick
Developing the evidence base	Members to join invoNET Members to join discussion forum and start a thread	Now	All
Develop sub-group for evidence - to collect, distill and disseminate	Through initial discussions at next EKL working group meeting	Soon	Helen to put on agenda for December 2007
Creating and contributing to coherent evidence base (underpinning and ongoing)	Through initial discussions at next EKL working group meeting	Ongoing	Helen to put on agenda for December 2007 to ensure other members have input.