
**Notes of the thirty sixth meeting of INVOLVE
held at the
Royal College of Nursing, London W1
7th June 2005**

Present: Nick Partridge (Chair)
John Sitzia
Kate Sainsbury (Vice Chair)
Peter Beresford
Ruth Sinclair
Vinod Kumar
Stuart Eglin
Mary Nettle

In attendance: Tony Stevens
Chris Caswill
Sue Banton
Lester Firkins
Maria Palmer
Carol Lupton
Morton Phillips
Susie Parr
Peter Sneddon
Sophie Staniszweska
Grace Wise
Karen Collins

Sarah Buckland (Support Unit)
Barbara Dawkins (Support Unit)
Helen Hayes (Support Unit)
Roger Steel (Support Unit)
Jane Royle (Support Unit)
Maryrose Tarpey (Support Unit)
Philippa Yeeles (Support Unit)

1. Introductions, welcome and apologies, declarations of conflicts of interest

- Introductions

Nick welcomed Peter Sneddon, Head of National Programmes to the meeting. He would be providing an update on Department of Health R&D under item 4 of the agenda.

- Apologies

Nick reported that the following had given their apologies:

David Johnstone
Derek Stewart
Sarah Carr

- Farewells

Catherine Law – Nick explained that Catherine had had the role of public health advisor to INVOLVE since 2001. This was envisaged as a pump priming role and she felt it is now appropriate for the role to finish.

Derek Stewart – Nick advised that Derek had been a member since 2001 and had not been able to make the last few meetings. He wished to stand down from INVOLVE; however he still hoped to stay in touch with the Group and is willing to assist with workshops and training events etc. Nick reported that Derek had asked him to pass on his farewells and thanks to the Group.

John Sitzia – Nick explained that John had asked to stand down from being chair of the Monitoring and Evaluation sub-group, and would stand down after the October awayday. However he is keen to continue to be a member of INVOLVE.

Nick thanked him for all he had done as chair and asked if anyone was interested in becoming chair of this sub-group, to let Nick or Sarah know.

2. Notes of the meeting held on 08 March 2005 - annex A

Karen Collins should be added to those in attendance. No other amendments were requested and the notes were agreed as correct.

3. Notes of actions taken since the meeting and any other matters arising - annex B)

Freedom of Information Act

Nick reported that we had received some overheads from Kay Pattison regarding the Freedom of Information Act which could be circulated if members would find that helpful.

Action: Members to let Barbara Dawkins know if they were interested in receiving overheads about the Freedom of Information Act. If there were any other issues or queries around the Freedom of Information Act, to contact Nick or Sarah

Conference update

Nick invited members to let Kate know if they were interested in joining the Conference Planning Group.

4. What's new in the Department of Health (NHS R&D and PRP)

Peter Sneddon reported that his post was a new post at the Department of Health (DH) which oversaw two areas in the DH's work in research. One was the Policy Research Programme, headed by Susan Lonsdale and the other the National NHS Research Programmes. He reported that this was a wide and diverse portfolio and involved a large number of stakeholders.

He advised that all programmes were interested in the patient perspective and that was evident at the Service Delivery and Organisation (SDO) board meeting which had taken place that morning, where Derek Stewart and Harry Cayton had spoken about how patients could become involved in research.

He informed the Group that he was impressed by the effort people had been making, but he suggested we needed to be aware of the political dimension, and much of this would depend on the new Minister, Patricia Hewitt. He advised that the new R&D portfolio was the responsibility of Jane Kennedy.

He reported that he had attended a meeting the previous day where Patricia Hewitt gave a clear direction on the public involvement agenda. He suggested that the number one workstream would be improving health insight, where the challenge is to understand what patients want. He advised that it was about how to put patients at the centre of what we are doing.

Peter reported that from the patient perspective, it was positive that the NHS R&D programme under Sally Davies, was keen to make changes. He advised that this included more transparency of funding from the £150m R&D programme. He reported that with a patient centred strategy he was fairly confident that INVOLVE would be one of the priorities for funding.

The following questions / issues were raised by Group members:

- After nearly 10 years in health services, hearing about patients being at the heart of health services whether this time there would be real changes
- Whether the proposed workstreams will look at diverse involvement in health and social care
- Many academics see the term 'patient centred' as tokenism and meaning targets. It's treated as a buzz word that will one day go away. It is important to get patients to view research applications to make sure it is being applied
- Patient centred needs authenticity and constituency
- Gathering data about patients views ought not just to be quantitative, it should also be about qualitative data, and patient experiences
- The evidence base is poor in respect of accessing information on what people actually want. Need to recognise that some of the instruments designed to measure satisfaction and quality of life, do not address the issues that are important to people. Many of the scales are no good at measuring quality of life from a patient perspective.

5. Horizon scanning re. public involvement in research - Discussion

Nick asked the Group to consider what they feel are the driving and inhibiting forces for achieving effective public involvement across NHS, social care and public health and whether they felt they were different. He also asked the Group to look to the future to see how things might and should develop?

He informed the Group that we could then use this discussion to take to the awayday to start to think about how we can encourage / support the driving forces and overcome some of the inhibiting forces.

The members were divided into four groups and their responses were as follows:-

Group A

Driving Forces	Restraining Forces
<ul style="list-style-type: none"> • Policy environment – Moved from fringes to central – impact on NHS • Developing confidence/examples of good practice eg Cancer Research Network leads to developing critical mass • Peoples juries – continued improvement • Growing evidence base linked with dissemination • Public interest in research and access to research but • Public Health White paper and action plans. Public engagement – health literacy positive move • Fluidity of public involvement • Changing environment. Work to reduce restraining forces and add driving forces 	<ul style="list-style-type: none"> • Rhetoric without resources (need to compensate/reward people for participating) - diversity • Little reward/credit for public involvement • Low priority for researchers and managers • Lack of compelling evidence base • Lack of public understanding about research • Academic research culture - lack of imperative to involve public • Huge cultural shift required • Research fatigue of those who do get involved.

Group B

Driving Forces	Restraining Forces
<ul style="list-style-type: none"> • Time, money, commitment • Strategic whole systems approach. Can't talk about involvement without doing it • Rewards for doing involvement – career paths - points 	<ul style="list-style-type: none"> • Time, money, commitment. • Confidence that getting involved makes a difference - to spend the time – stress circumstances • Motivation from personal experiences • If basic needs aren't being met you have very limited capacity to get involved • System arbitrary in the way it categorises people – not user driven • Private/public provided NHS – patient sensitivity ? • Confusion of meaning of involvement (involvement in trials or involvement in determining what needs researching) • Opportunities to influence research agenda

Group C

Driving Forces	Restraining Forces
<ul style="list-style-type: none"> • Senior level influences e.g. Primary Care Trusts, INVOLVE, Department of Health • Education of professionals – integration • Champions of consumer involvement • Public and Patient Involvement Forums 	<ul style="list-style-type: none"> • Transferring a suitable model of consumer involvement to other disease areas • Needs a sustainable infrastructure for consumer involvement • Lack of practical knowledge and know how • Evidence base/need to demonstrate outcomes

Group D

Driving Forces	Restraining Forces
<ul style="list-style-type: none"> • How long is the horizon? • Ministerial interest • For Human Rights and general information access - IT literacy (esp. research) • Invest in research manager capacity and training grants • System and organisational development (e.g. in field champions DH application forms) • Building confidence 	<ul style="list-style-type: none"> • Will this translate will anything change • Instability e.g. Commission for Health Improvement in Patient and Public Involvement • Professional interest groups – power of vested interests • Competing political imperatives • Research Assessment Exercise/ Research Governance Framework and & ethics committees – paternalistic role • Extension to hard to reach groups • Elite mind sets • Too many sticks and not enough carrots • Limited public involvement in services

It was also suggested that a system of 'Public Service Time' could be considered. This would allow people who work full time or who are on benefits to get involved, either by a) employers allowing them time or b) provision made for it not to affect the receipt of benefits.

6. Director's report - annex C

Sarah reported that she was very pleased that Maryrose would be staying on at the Support Unit to undertake two rapid reviews for the Monitoring and Evaluation sub-group, one is looking at sources for publishing articles on public involvement in research and the other is around public motivations for getting actively involved in research.

She advised the Group that the Support Unit contract expired in January 2007. She reported that she and Nick would be meeting with Noreen Caine and Peter Sneddon on 22nd June to discuss the possibility of an extension to the contract to 2009.

She informed the members that in May the Support Unit co-ordinated a training day for the public involvement leads in the National NHS R&D Programmes.

Budget: update annex D

Sarah explained that the budget for 2004/05 had been fully spent. It was noted that the costs for the main Group had risen since increasing membership of the Group. It was suggested that this could be raised with the Department of Health with a request for additional funding to support these increased costs.

Action: INVOLVE to raise with the Department of Health the possibility of an increase in the INVOLVE Group budget to cover the increased costs of attendance and travel for Group members (as a result of the increase in the size of the Group).

Summary of Operational Plan 2005/2006 – annex E

Sarah reported the following:

- Annex E is the main part of the plan (previously agreed), with the 2 new job sheets for the UK Clinical Research Collaboration (UKCRC) and the James Lind Alliance.
- The job sheets have been updated and will be put on the INVOLVE website (an email version will also be sent to members).
- Members to contact the Support Unit if they would like a hard copy (they are very similar to the ones distributed in March with minor updates)

Monitoring the work of INVOLVE – annex F

Sarah advised that the Group could see Annex F for statistics on the numbers of presentations and meetings attended during 2004/2005 as well as enquiries to the Support Unit and website use. The average number of visits to the website have increased over the year, with over 15,000 in March 2005.

7. Public Health Action Plan Report 2004/2005 – annex G

Philippa briefly introduced a discussion on the report. She reported that it had been very useful to have the structure of the strategy and action plan as a framework against which to systematically develop INVOLVE's public health agenda over the previous year. She acknowledged the invaluable expertise and guidance she has benefited from over the past eighteen months from her mentor, Catherine Law and her Support Unit colleague, Jane Royle.

In the ensuing discussion the following points were made:

- Nick reported that he had been in touch with Jennie Popay re. taking on the role of mentor for Philippa. Jenny is Professor of Sociology and Public Health at the Institute for Health Research at Lancaster University. Amongst other things, she is also Director of Health R&D North West and Director of the National Collaborating Centre for Community Engagement.
- The spectrum of public health research is so broad that it is not possible to generalise on public health researchers' attitudes to public involvement in research. There are some areas, such as research with children and young people where public involvement is being strongly supported. However in other areas, for example in secondary public health research, there appears to be little evidence of public involvement.
- INVOLVE would benefit from the inclusion of some more members who come from a public health background.
- The development of a three year public health strategy and action plan needs to be undertaken in conjunction with work on updating INVOLVE's overall Strategic Plan. Any strategy development would benefit from the support of an advisory group and broad consultation with stakeholders.
- It was suggested that if there was to be a strategy for public health the Group should consider a parallel strategy for social care.

Philippa suggested that it would be good if more work could be done with grassroots public health researchers.

Nick gave a summary of a memo sent from Catherine Law to Carol Lupton, and copied to INVOLVE, regarding how she felt INVOLVE had progressed regarding public health.

She felt that INVOLVE had made great progress and her concerns reflected the large scale of the task rather than INVOLVE's progress.

Achievements in making public health research part of core business:

- a) changing its name and strap line
- b) recruiting more members with public health expertise to the Group

- c) two consultations with public health researchers and commissioners (2001 and 2004) to inform its public health strategy
- d) Hosting a seminar on public health research
- e) Revising some of its resources to make them applicable to public health
- f) Including public health articles in its own publications and writing them for the publications (e.g. newsletters) of others
- g) Producing a leaflet for public health researchers
- h) Making alliances with public health organisations
- i) Responding to public health consultations
- j) Developing and starting to implement a public health strategy

Some of her concerns:

- Few members on the Group who would say public health is their first concern
- Pressure of time means that PRP is often not represented at meetings
- Other (often better funded) developments in clinical research

Opportunities:

- Number of new policy and research initiatives e.g. choosing health, Public Health Research Consortium, Public Health initiatives being planned by UK Clinical Research Collaboration (UKCRC)

8. Prioritisation of activities 2006/2007 – annex H

Nick gave a summary of discussions and plans agreed at the Chairs meeting for improving the prioritisation process for the Group.

A checklist of criteria to assist in assessing the priority of ideas was proposed. These would be used in developing initial ideas at the awayday, and then in prioritising activities at the December meeting.

Action: The checklist of criteria presented to the June Group meeting to be used at the INVOLVE awayday to assist in developing ideas for activities for 2006/2007.

9. Reports from sub-groups

Verbal reports were received from the following:

Empowerment
Strategic Alliances
Monitoring and Evaluation

Kate Sainsbury
Stuart Eglin
John Sitzia

Please see the individual minutes for notes of these meetings

10. Any other urgent business not included on the agenda

There was no further business.

11. Dates of future meetings:

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Awayday: 05/06 October 2005, Weetwood Hall Conference Centre, Leeds.

Group meeting: Tuesday 29 November 2005, Royal College of Nursing,
London
