
**Notes of the forty second meeting of INVOLVE
held at the
Thursday 14 December 2006
The British Library, 96 Euston Road, London NW1**

Present: Nick Partridge (Chair)
Kate Sainsbury (Vice Chair)
Sue Banton
Peter Beresford
Chris Caswill
Stuart Eglin
Mary Nettle
Maria Palmer
Susie Parr
Mark Petticrew
Deborah Tallis
Tracey Williamson

In attendance: Kay Pattison (Department of Health)
Dr Jonathan Tritter Executive Director, The National Centre
for Involvement

Sarah Buckland (Support Unit)
Sarah Bayliss (Support Unit)
Barbara Dawkins (Support Unit)
Sofie De Broe (Support Unit)
Helen Hayes (Support Unit)
Jane Royle (Support Unit)
Roger Steel (Support Unit)
Maryrose Tarpey (Support Unit)

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

Declarations of conflicts of interest

No new conflicts of interest were reported.

Introductions and welcome

Nick welcomed Mark Petticrew from the University of Glasgow (Associate Director of the Medical Research Council Social and Public Health Sciences Unit), who had joined Strategic Alliances as a new temporary member.

He also welcomed Dr Jonathan Tritter, Executive Director, of The National Centre for Involvement, who would be giving a presentation.

Apologies

- Sarah Carr
- Karen Collins
- Alison Faulkner
- Carol Lupton
- Marianne Miles
- Morton Philipps
- Rachel Purtell
- Bob Revell
- John Sitzia
- Sophie Staniszewska
- Simon Wilde

2. Notes of the meeting held on 12 October – Annex A

No corrections are to be made.

3. Notes of actions taking since the meeting and any other matters arising – annex B

Sarah Buckland reported on the progress of the Accessibility Strategy. A draft strategy is planned for early January.

Sarah reported that the Support Unit had checked the INVOLVE website usage statistics and according to the producers of the statistics, they do reflect the level of access from America.

Sarah outlined the timetable for developing the Strategic Plan. Group members were invited to email any suggestions for the content of the plan. A draft plan produced with Nick Partridge and the chairs of the sub-groups would be presented for discussion at the March meeting.

Sarah reported that the Support Unit will be inviting Group members for suggestions for future agenda items and speakers, as well as volunteers from Group members to talk about some of the work they are involved in.

Actions:

**Group members to email Sarah with any input to the Strategic Plan
Support Unit to invite suggestions for future agenda items and volunteers
to give presentations at future meetings.**

4. The National Centre for Involvement, Dr Jonathan Tritter, Executive Director

Dr Jonathan Tritter gave a powerpoint presentation, the key points of which and subsequent questions are detailed below.

- The Centre was launched in November 2006 and it is a consortium of the University of Warwick, the Long Term Medical Conditions Alliance, and the Centre for Public Scrutiny. It is funded by the Department of Health for three years with a budget of 2million pounds per annum.
- The Centre will be working with NHS staff and organisations to engage with patients and the public to integrate user involvement systems into everyday working as well as working with the Healthcare Commission.
- The Centre promotes the value of patient and public involvement, creating a one stop shop for information, advice, practical resources etc... The work of the Centre is divided into 5 areas: research and best practice, organisational development, learning and support, the People Bank, and the Patient Citizen Exchange.

Question: How will the Centre reach out to practitioners?

The centre will show practitioners what has worked and the need to adapt this over time. The Patient Citizen Exchange will help to share difficulties as well as 'notable' practice.

Question: What are the plans for learning pathways?

The Centre wants to establish patient and public involvement key competencies as part of practitioners' career pathways.

Question: Will the Centre be looking at the issue of payments?

Yes, although the complexities of payments and benefits issues are well understood.

Question: What about the voice of minority groups?

There are problems with democratisation and skills in facilitating of these groups. The Centre can support organisations to do things to promote participation according to the express needs of the local population.

Question: What about the governance of the Centre - to what extent do the public have a say in its governance?

The Centre reports to the vice chancellor of the University of Warwick. Their business plans are available on the website and they will be performance managed. There is no public involvement in the governance of the Centre. It does not serve the public directly.

Question: There are tensions between local accountability and the drive towards centres of excellence – how will the Centre engage with non NHS providers for example?

This would be about identifying gaps in the service. There is a duty on provider organisations to show they are doing patient and public involvement.

Question: It was noted that the Centre has been working with the other 'Involve', what are their future plans?

The Centre is committed to work in ongoing partnerships with INVOLVE (National Institute for Health Research INVOLVE). The work with the other 'Involve' was to produce a particular document.

5. Feed Back from Involve Conference 2006, Kate Sainsbury – annex C

Kate reported back on the comments from the feedback forms from the INVOLVE Conference.

- The average score by delegates, for satisfaction with the event was 79%.
- The accessibility strategy will incorporate comments about the conference and will discuss the ground rules on accessibility needs.
- The conference report should be disseminated to key stakeholders to encourage discussion of the issues raised.
- The conference planning group needs to recruit new members.

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

Kay Pattison gave a presentation on the Cooksey review. Please see the next agenda item for details.

7. Cooksey Review – Kay Pattison

Kay's presentation focused on summarising the findings and recommendations of Sir David Cooksey's review of the best institutional arrangements for the new single fund for health research. The key points are detailed below:

- The Department of Health (DH) welcomed this report and the endorsement it offers to the continued delivery of the Government's strategy Best Research for Best Health and the National Institute for Health Research (NIHR) as being a key plank of the strategy.
- A key element of Cooksey is the Office for Strategic Coordination of Health Research (OSCHR). This will be a powerful and influential body and will sit above the National Institute for Health Research (NIHR) and the Medical Research Council (MRC). OSCHR will offer a tangible mechanism to facilitate translation of health research into health and economic benefits for the UK.
- Applied research is a key theme of the Cooksey report. Kay stressed that the greater emphasis on applied research will be through the NIHR and that this is a very important point. Future increases in funding will be weighted towards translational and applied research.
- The NIHR will become an executive agency of the DH from 2009. This will be an arms length agency. INVOLVE will be one of the managed outstreams of the NIHR. The DH Policy Research Programme will not be affected by the changes to NIHR.
- INVOLVE is not mentioned in Cooksey however it is 'part of the fabric'. There are 48 references to patients and additional references to users and carers. Patient and public involvement in the Health Technology Assessment and Service Delivery and Organisation Programmes is noted.
- It is also good news for the Central Commissioning Facility (CCF) to take forward work. Jane Royle is working with the CCF and making a big impact on involving patients and the public throughout the research programmes.

There was a brief discussion following the presentation. Key issues raised included:

- whether the report goes far enough in changing the status quo
 - the importance of ensuring that public involvement is included at the early stages of the new funding opportunities
 - the Department of Health's view on the relationship between INVOLVE and industry
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8. Directors report – annexes D,E and F

Sarah highlighted the following points.

- We are continuing our ongoing work with the UK Clinical Research Collaboration (UKCRC) to develop a website 'People in Research', which draws on information from INVOLVE's Public Information Pack to explain about public involvement in research. The centre of the website is a database which signposts members of the public who are interested in getting actively involved in clinical research to the websites of research organisations who are looking for people to get actively involved. The website is being developed and piloted collaboratively with service users and it should be available in January 2007.
- There were two current Department of Health consultations that group members may be interested in contributing to. Any comments in relation to the Houses of Parliament Health Committee inquiry into Public and Patient Involvement in the NHS (PPI's) could be emailed directly to Sarah.
- A reminder of the forthcoming invoNET event on the 9th February, to which Group members were invited.
- The final draft of the Public Information Pack would be with the designers by Christmas.
- The Netherlands organisation for health research, ZonMw, would be visiting in March to share knowledge and learning about public involvement. Group members were invited to contact the Support Unit if they were interested in joining the meeting. Sarah would email further details in the New Year.
- Mary Nettle reported that she was currently on the personal uses of secondary data working group for the Care Records Development Board.

Actions:

Group members to email the Support Unit with any comments on the House of Commons Health Committee inquiry.

Group members to complete the booking form if they wish to attend the invoNET event.

Sarah to circulate members with details of the planned meeting with ZonMw.

9. Reports from sub-groups

Verbal reports were received from the following:

Empowerment	Kate Sainsbury
Strategic Alliances	Stuart Eglin
Evidence, Knowledge and Learning	Tracey Williamson

Please see the individual sub-group minutes for notes of these meetings.

The following two points were raised:

- It was suggested that as part of developing the Strategic Plan and in the light of the proposed changes within the Department of Health, it was a good time to review INVOLVE's Terms of Reference.
- It was suggested that INVOLVE should make contact with the new Innovation Hubs.

10. Plans for 2007/2008

Sub-group Chairs fed back their proposed plans for 2007/2008.

Strategic Alliances

A very successful joint session with Evidence, Knowledge and Learning had generated discussion and new ideas around developing the work in social care.

The Operational Grid developed to collect information on the work Group members carry out on behalf of INVOLVE is currently being piloted by Strategic Alliances.

The sub-group discussed their plans for 2007/2008 and the future with a three year strategic plan in mind.

Work in the following areas was highlighted as important:

- INVOLVE Conference in 2008

- Central Office for Research Ethics Committees (COREC)
- social care
- communications
- industry
- young people
- public health research

Evidence, Knowledge and Learning

Evidence, Knowledge and Learning are currently developing a 'Position Paper' outlining their views on the development of an evidence base for public involvement in research. The 'Position Paper' should be ready in time for the invoNET event which is to be held on 9th February 2007.

The following plans and priorities for 2007/2008 were put forward by the sub-group:

- To develop and build on the bibliographic work being carried out in 2006/2007 to develop an evidence base for public involvement in research. This work would include the identification and study of examples of good practice around public involvement in research and lead on to the development of guidance. It was suggested that this learning could then feed in to the next INVOLVE conference in 2008. It was suggested the Support Unit could employ a member of staff to carry out this piece of work.

Costs:

£25,000 - £30,000 for 2007/2008

£25,000 - £30,000 for 2008/2009

- invoNET
Annual event for 2007/2008
Costs:
£6,000
- Dissemination of publications
Costs:
£5,000

Dissemination costs have been funded by Evidence, Knowledge and Learning for the past few years and it was questioned as to whether these costs should be shared amongst all three sub-groups.

- A seminar for social care research to include the sharing of good examples was felt to be a priority for 2007/2008. It was recognised that Evidence, Knowledge and Learning would not have the funds to take this work forward themselves so it was hoped that it would be considered for funding by another sub-group.

Two further suggestions were felt to be within the remit of other sub-groups: The development of a core curriculum for the training of public involvement in research and the sponsoring of an award by INVOLVE, perhaps through a category on the health and social care awards.

Empowerment

The following areas of work had been identified by Empowerment as possible ideas for 2007/2008.

- Accessibility – this work should continue to be funded
- Dissemination of new Public Information Pack due to be published March 2007
- Development of work and building of capacity within Black and Ethnic Minority communities, through working with the Race Equality Foundation and through recruitment of more people to INVOLVE from black and ethnic minority groups
- Produce a clear statement outlining the work of INVOLVE, who we are, and the historical context, to improve communication
- Work to empower health and social care practitioners
- Bring together examples of good practice of user controlled research
- Commission a piece of work to explore what difference research makes to communities who don't have a 'voice'. To explore if research has had an impact on practice.
- To identify and understand the barriers and enablers for research findings being put into practice.

11. Any other urgent business not included on the agenda

No items were discussed.

12. Dates of future meetings:

21 March 2007

14 June 2007

9/10 October 2007

13 December 2007
