
**Notes of the forty sixth meeting of INVOLVE
held at the Kings Fund, Cavendish Square, London
Thursday 13 December 2007**

Present: Kate Sainsbury (Vice-Chair)
Peter Beresford
Stuart Eglin
Mary Nettle
Susie Parr
Jim Elliott
Ray Fitzpatrick
Angela Barnard
Anne-Louise Caress
Sophie Staniszewska
Diana Rose
Poonam Jain
Patsy Staddon
Michael Turner
Ade Adebajo
Louca-Mai Brady
Hugh McLaughlin
David Evans

In attendance: Penny Cole and colleague (Dovetail Communications)
Kay Pattison

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

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

Declarations of conflicts of interest

Peter Beresford and Michael Turner expressed a conflict of interest as they had both applied to undertake work for the Examples of User Controlled and Social Care Research.

Introductions and welcome

Kate Sainsbury welcomed Penny Cole from Dovetail Communications and David Evans as the new chair of the Empowerment working group.

Kate thanked Jane Royle, who was leaving the Support Unit, for all her hard work at INVOLVE and wished her well in her new role.

Apologies

- Sarah Carr
- Vanessa Pinfold
- Tracey Williamson
- John Sitzia
- Carol Lupton
- Hala Patel
- Nick Partridge
- Sue Banton
- Laura Serrant-Green
- Mark Petticrew
- Richard Baker
- Chris Caswill
- Simon Denegri

2. Notes of the meeting and awayday report 09/10 October 2007

Clarification was sought on page 9 of the awayday report, as to whether it should read: 'There had been subtle changes from patient led to clinician focused provision'.

Action: Support Unit to check the minutes and amend statement on page 9

3. Notes of actions taken since the meeting and any other matters arising

Kate requested that Group members should complete the form that was sent out and return it to the Support Unit. This form is to let the Support Unit know when members give presentations or talks where they refer to INVOLVE.

4. Developing a communication strategy for INVOLVE – annex C Penny Cole, Dovetail Management Consultancy

Dovetail Management Consultancy have been commissioned to carry out a piece of work on communication for Strategic Alliances working group. Penny Cole a consultant with the company attended the meeting to seek members' views on the best ways for INVOLVE to approach and communicate in a meaningful way with the research community.

The work entails developing a strategy for INVOLVE to improve our communication with researchers. The work will have two stages. Phase 1 will involve identifying short and long term options and Phase 2 will involve implementing some of the options identified in Phase 1.

Outlined below are the questions Penny asked Group members and some of the responses:

i) Two years from now, what would you like people to know about INVOLVE that they don't know now?

- full range of activities
- full breadth of work
- INVOLVE to be recognised as part of the National Institute for Health Research (NIHR) programme
- people know the range of expertise that is available through INVOLVE
- implementation of good practice
- strategic vision and practical help
- it practices what it preaches
- more ordinary people to hear about INVOLVE
- work INVOLVE has done over last 10 years – claim credit for what it has achieved and the difference it has made
- it doesn't cost you to get involved

ii) Who are your key audiences to communicate and influence, within the research community

- people who use services
- academics, clinicians, medics
- National Institute for Health Research (NIHR)
- ethics bodies
- journals and journal editors
- social care top level and downwards
- charities, Non Government Organisation (NGO's)
- research commissioners
- industry
- researchers
- practitioners
- nurses and allied health care professionals
- champions of public involvement in research
- opinion formers eg. Presidents of Royal Colleges

How do we prioritise amongst these audiences?

The following questions were identified by Group members:

- Is the way forward to reinforce success or are we trying to influence those who are reluctant or slow to involve?
- Should we have a bottom up or top down approach – with top down there is a risk of becoming a tick box exercise

It was recognised that there is also a need to offer support and recognition to develop and build on success.

iii) Practical approach to the work – what media should be used to effectively reach the audiences?

Face to face and 'warm' contacts were identified as a very important method of influencing others.

It was recognised that different approaches will influence the media used however the following suggestions were made as key media to use in the communication strategy:

- electronic: digital, web based
- INVOLVE website has a significant role
- a big idea eg. Awards

iv) Barriers to achieving communication goals

- resources
- large range of audiences
- wanting to do everything
- look at INVOLVE strategic plan and how communications can help to achieve objectives
- addressing opinion formers who don't want public involvement
- those with no understanding of public involvement or who see involvement as negative or something they are doing already (even if not)
- getting the message across is a challenge in itself

v) On a scale of 10 where would you place communication in relation to other objectives

It was agreed by Group members that communication runs through everything that INVOLVE does and that it is the method for the delivery of their objectives.

Penny asked Group members to describe INVOLVE in no more than 50 words - refining their key messages and to send their descriptions to the Support Unit.

Action: Penny Cole to take suggestions from Group members to assist in developing a communication strategy for INVOLVE.

5. Social Care Research – Poonam Jain

Poonam gave a talk on social care research and highlighted the points below:

- There is confusion about what social care research actually is. The definitions tend to be different from health.
- There is a relatively low level of funding for social care research. The Department of Health spend £10m on social care research, but £650m on health research. Only 0.5% of social services spending is on research, whereas in health it is 5.4%.
- In social care they are not good at sharing research even with other social services directorates. This is partly because there is very little research infrastructure in Social Care, although recently a Social Care Research Register was established, and there are discussions on the possibility of a social care journal with the status of the BMJ or Lancet and establishing centres of social care research excellence.

- Social care has twice as many practitioners as primary care and yet, unlike primary care, few are involved with research.
- However, there are developments being suggested by organisations such as the Social Care Institute for Excellence (SCIE) whereby social care research can be more easily accessed and shared so that practice can be more based on evidence. The Platt report recommended the setting up of a social care skills academy.
- There are other organisations like RIP (Research in Practice) (children), RIPfA (Research in Practice for Adults), and MRC (Making Research Count) (children). Also the Social Services Research Group. All these are networks but not substantial infrastructure.
- The type of research in social care is more commonly qualitative, but there is more quantitative research now being done because it attracts more funding. There are epistemological issues about what sort of information 'counts'. The methods used should follow the question being asked, but this is not always the case where limited funding is available. There is a move to funding more large scale quantitative research and this could be a threat to small scale qualitative social care research.

Kate thanked Poonam for her presentation.

6. Involve Conference update 2008 – Kate Sainsbury

Kate Sainsbury gave an update as chair of the Conference Planning Group which is supported by Strategic Alliances Working Group.

- The next INVOLVE conference will take place on 11 and 12 November 2008 at the East Midlands Conference Centre in Nottingham (the venue we used in 2004).
- The title of the conference will be: 'Public involvement in research: getting it right and making a difference'.
- The conference 'call for presentations' will be widely disseminated in January with a deadline of mid-April for people to submit their summaries of what they propose to present at the conference. People are being given a variety of options for presentations from posters and talks through to workshops and 'other' formats for example, using theatre, a DVD or music.
- All proposed presentations will be sent to volunteer members of the Conference Planning Group for review and a decision on whether they

should be selected or not. People will be notified of whether or not they have been invited to present at the conference by mid-May.

- The full Conference programme will be finalised and publicised in June.
- Nearer the time of the actual conference we will be asking all members of INVOLVE to 'volunteer' their time during the conference. We always need members to chair sessions, cover the stand, take photos and generally help make sure the conference runs smoothly.

7. What's new in the Department of Health and Policy Research Programme

Kay Pattison's update focused on the National Institute for Health Research (NIHR) news – see <http://www.nihr.ac.uk/news.aspx#181>. Kay felt that the NIHR news was a good way to run through new developments. Group members could then go and look up more information if they were interested. It was also an opportunity to see how INVOLVE could link with the NIHR branding.

Kay circulated a handout which had NIHR news dated from 3 October 2007 until 5 December 2007. She highlighted the following news items:

- **NIHR Faculty membership**
Anyone who is funded by the NIHR or the Department of Health or Policy Research Programme (PRP) is automatically a member of the Faculty. This would also include members of the public who were co applicants.
- **Joint Medical Research Council MRC-NIHR Methodology Research Programme.**
This programme has recently been launched and is the programme through which you can get methodological research funded.
- **NIHR Research Design Service (RDS)**
The old Research and Development Support Units (RDSUs) role was to support researchers develop well thought through research designs. A paragraph was included from INVOLVE in the brief for the new RDS. A briefing event was held in December for applicants. INVOLVE's input has been gratefully received.
- **Roll out of the Research Passport system for streamlining honorary research contracts,** Kay recommended that Group members look at the website for further information.

8. Directors Report

Sarah reported that she was sorry to be losing Jane Royle from the team and we would all miss her.

Sarah advised the Group that the Support Unit had attended an interesting conference run by the University of Central Lancashire around public involvement in higher education. The Support Unit had also been working with the UK Clinical Research Collaboration (UKCRC) Patient and Public Involvement Strategy Development Group.

Sarah explained that the main Group budget had an overspend on travel and expenses for Group members attendance as they hadn't fully anticipated the level of costs for recruiting and supporting new Group members.

Sarah reported that we were continuing to get many hits on the website. It was queried as to why the website hits had been sliding recently and whether it was seasonal? Sarah advised that we would be doing everything we could by linking to other's websites eg. the NHS Choices website.

9. Reports from working groups

Post card reports were given by

Stuart Eglin	Strategic Alliances
Sophie Staniszeweska	EKL
David Evans	Empowerment

Please see the separate working group minutes.

10. Plans for 2008 / 2009

Strategic Alliances

The following were identified as potential areas of work for 2008 / 2009:

- INVOLVE Conference (committed)
- Social care examples work
 - Phase 1 will run into 2008/2009 (committed)
 - Phase 2 - more in-depth work based on the examples gathered
- Social care workshop (committed)

- Development work with ESRC
- Communication strategy – eg. a ‘big idea’
- Support to the Research Design Services

It was noted that we may need to apply for additional funding from the Department of Health related to:

- a) the communications strategy – if it recommends taking forward a ‘big idea / initiative’
- b) the role of the Support Unit in providing the support ‘hub’ for the Research Design Service in relation to public involvement

Evidence, Knowledge and Learning

Evidence, Knowledge and Learning, have three ongoing pieces of work which need to be continued for 2008 / 2009:

- invoNET (ongoing)
- Dissemination of publications (ongoing)
- Review of evidence on the impact of public involvement (committed)

Empowerment

The following were identified as potential areas of work for 2008 / 2009:

- Accessibility (ongoing)
- User controlled examples (ongoing)
 - Phase 1 will run into 2008/2009 (committed)
 - Phase 2 - more in-depth work based on the examples gathered
- Empowerment issues for researchers (committed)
- Outcomes for groups whose views are often ignored or overlooked
- Development of BME work
- Promoting and supporting best / better practice

Action: Support Unit to develop the INVOLVE Operational Plan 2008/2009 in discussion with the chairs, based on the suggestions raised by Group members at the meeting.

11. Any other business

Peter Beresford advised the Group of a new publication called ‘We are not Stupid’. This book is about the experiences of people with learning difficulties, how they are treated and what needs to change. It is based on research controlled by people with learning difficulties. It tells us how they did the research,

what they found out and what needs to be done. This is available to download from the Shaping our Lives website.

12. Dates of future meetings

Please note the dates of future meetings (some of which have changed from the original dates circulated).

Thursday 06 March 2008

Tuesday 03 June 2008

10 and 11 September 2008 – awayday

Tuesday 16 December 2008

INVOLVE Conference: 11 and 12 November 2008.
