
**Notes of the forty eighth meeting of INVOLVE
held at
The Kings Fund, London
Tuesday 03 June 2008**

Present: Nick Partridge (chair)
Peter Beresford
Stuart Eglin
Mary Nettle
Jim Elliott
Ray Fitzpatrick
Angela Barnard
Anne-Louise Caress
Sophie Staniszewska
Poonam Jain
Michael Turner
Louca-Mai Brady
David Evans
Tracey Williamson
Karen Collins
Richard Baker
Laura Serrant-Green
Patsy Staddon
Susie Parr
Alison Faulkner
Simon Denegri
Sue Banton
Rosemary Barber

In attendance: Tony Williams (DH)
Roger Steel (UKCRN)
Sally Crowe (James Lind Alliance)
Kristina Staley (TwoCan Associates)
Hala Patel (MRC)
Sarah Buckland (Support Unit)
Sarah Bayliss (Support Unit)
Barbara Dawkins (Support Unit)
Helen Hayes (Support Unit)
Maryrose Tarpey (Support Unit)

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

Declarations of conflicts of interest

No conflicts of interest were declared.

Introductions and welcome

Nick welcomed Sally Crowe, James Lind Alliance (JLA) and Kristina Staley, TwoCan Associates who would be talking about the scoping exercise they have done on priority setting.

Apologies

Apologies had been received from:

- Mark Petticrew
- Ade Adebajo
- Chris Caswill
- Diana Rose
- Hugh McLaughlin
- Kay Pattison
- Maria Palmer
- Sarah Carr
- Vanessa Pinfold

2. Notes of the meeting held on Thursday 06 March 2008

No corrections to be made.

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

Nick reported that a couple of changes had been made to the revised Operational Plan to include a section at the beginning listing the activities in relation to the Strategic Objectives as follows:

- A sentence has been added about the role of the main Group
- The budget has been increased for invoNET by £2,000
- Activities have been included where no budget allocated.

4. Survey of Public Involvement in Health Research Commissioning Sarah Buckland

Sarah Buckland presented the findings of a recent survey that INVOLVE carried out in collaboration with the UK Clinical Research Collaboration (UKCRC), Association of Medical Research Charities (AMRC) and James Lind Alliance (JLA). The web based questionnaire, requesting information on public involvement in their research commissioning and funding process, was sent to research funders during November and December 2007.

Members thanked Sarah for her interesting presentation. It was agreed that the survey would be a very useful benchmark as well as identifying areas for further support and encouragement.

Members discussed the report and various points were raised:

- It was suggested that payment rates might be an additional question in future years.
- Concern was expressed that there are not clearly identified mechanisms for following through public involvement in projects that outline plans in their grant application. The Support Unit is working with the Research for Patient Benefit Programme to consider how to capture this information.
- It was suggested that there could be a link with the interim and final reports requested by ethics committees in order to help build further knowledge on how public involvement develops within funded projects.
- It was noted that few were evaluating the impact of public involvement in the research commissioning process. The Support Unit advised that the full report, currently being verified, did have information from some respondents as to why they were not evaluating the impact of public involvement in research.

5. Research priority setting in the UK: interim feedback from a scoping Exercise – Sally Crowe, James Lind Alliance (JLA) and Kristina Staley, TwoCan Associates

Sally Crowe, JLA and Kristina Staley, TwoCan Associates presented to the meeting. They explained that the overall aim of the JLA was to highlight and prioritise treatment uncertainties considered important by patients and clinicians and feed those uncertainties into the research agenda. Work in progress covers

Asthma, Urinary Incontinence, Schizophrenia, Epilepsy, Vitiligo, Eczema and Diabetes. Using PowerPoint slides their presentation outlined the initial findings of a scoping study commissioned by JLA to explore how research priorities are identified by clinical research funders and how treatment uncertainties identified by JLA could influence their research priority setting agenda.

The study mapped current commissioning processes to find out:

- which clinical research bodies identify research priorities and /or commission research;
- whether and how patients and the public are involved;
- how priorities influence funding decisions.

They reported that whilst the study is not yet finished interim findings suggest that the majority of commissioners operate in a responsive mode. Most use peer review to decide which research to fund and there is a huge variation in patient and public involvement.

Following the presentation there was a wide ranging discussion by Group members including the following points:

- the need for a change of thinking in the way research is commissioned towards a 'public benefit test'.
- commissioning agencies not well informed on importance of treatment uncertainty issues. Some research programmes tend to commission research on what we already know.
- it was suggested that commissioners would make much better use of the money if they had a proper debate with researchers as well as patients and clinicians.
- how treatment uncertainties relate to ethnicity. Perhaps this is more about decision-making issues rather than clinical uncertainties.

6. Membership of INVOLVE – induction process and current support for members

Group members were asked the following questions about their recent experiences of joining INVOLVE:

- What it has been like?
- What worked well?
- What didn't work?

- Suggestions for improvement and additional support

The following is a summary of the range of comments made and issues raised.

Comments:

- Most enjoyed the induction day
- Information pack helpful
- Induction day was excellent for understanding the context of INVOLVE – it helped new members to feel on a more equal level in the group. Good that established members came too so we could meet informally
- Friendly group
- Induction – clear and helpful
- INVOLVE has taken time to really think about how to do patient and public involvement within the group
- Good balance in the group. Clear about what is expected, but open and friendly with attention to inclusive process. Felt clear what the task was
- Interested to know why people were chosen for particular working groups
- Quality of support and paperwork from Support Unit exemplary
- Sometimes there is frustration at the tendency to agree too much. There should be more critical debate
- Recruitment – impressed by process

Suggestions:

Introduction event

- Difficult to tell who were new and who were established members. Perhaps have the first half of the induction day with just the new people?
- Would have liked an evaluation form

Attendance at meetings

- Confusion regarding whether to stay for afternoon Group meeting – emphasis to be clearer that working group members **should** stay
- Different for those who already knew people ie. it is easier to settle in. Perhaps more could be done in the working groups to induct?

Working groups

- Greater clarity about the roles and activities of the different working groups e.g. why the conference is under the Strategic Alliances brief
- Greater clarity between working groups and main Group
- Could be clearer about opportunities to move between groups and take on new roles and tasks. However, maintaining corporate memory is important. More crossover work between groups would be refreshing.

General suggestions

- Buddy/mentor scheme with existing member
- Issues such as use of acronyms should be addressed
- Didn't realise initially that members can also apply for opportunities e.g. commissioned projects – this needs to be explained
- Sometimes get stuck talking around the same things at meetings – need to make sure things move on
- Need to be more involved in decision to stay or go when time on group is up. Leaving process for members plus to let members know when their membership of the group ends
- Support Unit could develop an archive of past meeting papers
- Roles and responsibilities – members not pushed enough. What is the limit of expectation of members?
- Consider support to give to help service users through the recruitment process

Action: Support Unit to take forward recommendations for supporting new members

7. INVOLVE Conference

Maryrose reported that the INVOLVE conference is taking place on 11th and 12th November 2008 in Nottingham. She advised that nearly 160 presentations were submitted in response to our 'call for presentations', these were all reviewed by a panel drawn from the conference planning group. She informed the Group that the final selection of posters, poster talks, workshops and papers covered a wide range of topics for example, user research, developing strategies, young people and evidence. She advised that she was waiting for confirmation from presenters before working on the detailed conference programme. She reported that as well as these presentations we are also planning to run eight additional 'single issue' workshops lasting 90 minutes, these workshops would focus on a particular aspect of public involvement in research.

She informed members that they do not have to pay conference fees or accommodation costs but are required to fill in a conference registration form which would be distributed at the beginning of July. All Group members are encouraged to attend.

Action: Group members to complete and return booking forms for INVOLVE conference

8. Future development of INVOLVE

The three working groups reported on their morning agenda discussions on future development of INVOLVE.

Research Design Services – Strategic Alliances

Strategic Alliances reported that the contracts for the new services were currently being negotiated by the Department of Health. The Support Unit had had contact with some of the RDS's and plan over the summer to bring together those within the organisations who had the lead for public involvement, to discuss how we might work best together and provide support for the services.

Strategic Alliances considered working with the new Research Design Services a very important area to take forward as soon as possible. It would be essential to ensure that there is a cohesive and organised approach to public involvement within the very early stages of the new structures. They supported requesting additional funding from the Department of Health for a specific INVOLVE post to support the new services.

Champions/ Ambassadors – Empowerment

Empowerment reported that it was recognised that INVOLVE is not able to take forward all of the different work agenda's at the same time. Reflecting this it was suggested that this work should initially be linked in to the work with the Research Design Services. It was suggested that a regionally based learning set and collective toolkit could be developed with one of the regions and following piloting this could then be 'rolled out' to the other regions. Further work to develop and support ambassadors at different levels can then be considered once this work is established.

It was agreed that consideration needs to be given to competency, content and core values alongside the development of a toolkit.

Research Programme – Evidence, Knowledge and Learning (EKL)

EKL reported that discussions on the development of a one off programme of research to generate evidence of public involvement in research, identified the following areas and ideas to develop further for inclusion in a research programme:

a) A range of themes including:

- How to involve the public in research
- Methods and mechanisms for involvement
- What works for different groups

- Goals and aspirations for public involvement in research
 - Why some choose to involve the public and others choose not to
- b) Range of outputs**
- c) Pluralistic approach – wide range of methods**
- d) Focus on primary research**
- e) To seek funding for an ambitious programme of research with the aim of funding 8 – 12 diverse projects**
- Projects completed within 3 years
 - Welcome international contributions
 - Online proposals which can then be developed further for full brief
 - Encourage balanced approach outlining positives and negatives of public involvement in research
 - Public involvement within the projects a criteria for funding
 - Support for small organisations and consideration of small development grants

Evidence, Knowledge and Learning would continue working on this with a view to sending an initial proposal to the Department of Health mid July 2008.

9. What's new in the Department of Health (National Institute for Health Research and PRP)

Tony Williams from the DH gave the following update:

▪ **Government announces a National School for Social Care Research**

The new school to improve the evidence for social care practice will be part of the National Institute for Health Research (NIHR). The School will include research by social care professionals as well as academics, and encourage active collaboration with service users and their carers. It will draw on a wide range of academic disciplines and methods. Details of the call for applications for the new School for Social Care Research can be obtained from the NIHR website:

<http://www.nihr.ac.uk/>

▪ **NIHR Senior Investigators: announcing the second annual round of competition**

Applications are invited for the second annual round of the NIHR Senior Investigators competition. The competition deadline is the 28th July 2008 at 4pm. Details are on the NIHR website.

- **Professor Jim Neilson has been appointed as the first Dean for NIHR Faculty Trainees and will take up his new role in June 2008.**

Jim Neilson is Head of the School of Reproductive and Developmental Medicine, Co-ordinating Editor of the Cochrane Pregnancy and Childbirth Group and Deputy Dean of the Faculty of Medicine at the University of Liverpool. He is also Honorary Consultant Obstetrician and Gynaecologist to the Liverpool Women's NHS Foundation Trust. The Dean will be responsible for the career management of trainees and the quality of training programmes and mentoring support.

- **New Biomedical Research Units**

The 12 new NIHR (National Institute for Health Research) Biomedical Research Units will work in major areas of ill-health and clinical need which have traditionally received relatively limited amounts of research funding. Each new NIHR Biomedical Research Unit is a partnership between an NHS Trust and a university, which will enable health researchers and clinicians to work together.

- **Launch of a new patient resource which highlights the importance of diabetes research**

The NIHR Diabetes Research Network has launched a new DVD and website resource which aims to encourage patients to get involved in diabetes research. The DVD and the dedicated website (www.diabetesresearchnetworking.org) which accompanies it have been developed with patients in mind to highlight the importance of diabetes research. They focus on showing patients' perspectives of what it's really like to be involved in a clinical trial. Copies of the DVD are available by contacting info@diabetesresearch.oxdem.ox.ac.uk. Further information is available from the Diabetes Research Networking website at www.diabetesresearchnetworking.org.

10. Directors report

Sarah Buckland reported that we were currently advertising for two posts for Public Involvement Advisors at the INVOLVE Support Unit. The closing date was 02 June 2008. They had received 29 applications and would be short listing and interviewing in the next few weeks.

Sarah advised the Group that we would shortly be undertaking a survey of lay research ethics committee members to collate their experiences (NRES).

Nick thanked Sarah and her team for the high quality of the work produced, particularly considering the pressure they were under.

11. Reports from the working groups

The chairs of each working group gave a post card report from their working group:

Strategic Alliances	- Stuart Eglin
Evidence, Knowledge and Learning	- Sophie Staniszewska
Empowerment	- David Evans

Please see separate notes for each working group.

12. Any other urgent business not included on the agenda

Sophie commented that INVOLVE was no longer at the top of the Google search list. Helen replied that everything was being done within our resources to keep us at the top but it wasn't always possible.

13. Dates of future meetings

10 and 11 September 2008 - Awayday (Latimer Conference Centre)

11 and 12 November 2008 - INVOLVE Conference:

Tuesday 16 December 2008 - **meeting cancelled**

Tuesday 20 January 2009 - **new date** to replace cancelled meeting.
