

# INVOLVE

## Minutes of the Strategic Alliances Working Group Meeting

Thursday 06 March 2008

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**Present:** Richard Baker, Angela Barnard, Sue Banton, Chris Caswill, Stuart Eglin (Chair), Poonam Jain, and Maryrose Tarpey.

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### 1. Welcome, apologies, introductions, declarations of conflicts of interest and ground rules

- Apologies were received from Simon Denegri, Patricia Ladly (replacing Carol Lupton), Marianne Miles, Maria Palmer, Mark Petticrew and Laura Serrant-Green.
  - There were no conflicts of interest reported.
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### 2. Notes of meeting held on 13 December 2007

The minutes of the previous meeting were agreed.

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### 3. Matters arising

- **Group members activity form:**

It was reported to the meeting that this was the form devised by Strategic Alliances to collect information from Group members on any activities they had undertaken, either on behalf of INVOLVE, or where they referred to the work of INVOLVE. The form was circulated to all Group members who were asked to complete the form for any activities carried out between 01 June and 30 November 2007. Fourteen Group members replied. Of these, eleven had not attended any events or represented INVOLVE over this period. Three members recorded sitting on various advisory or steering groups, running workshops and speaking at conferences where they referred to INVOLVE's work. Based on feedback from the last meeting this form has now been amended and will be sent to members again at the end of May to cover December 2007 to May 2008.

- **Young Peoples Public Health Reference Group (YPPHRG) – paper 1**

The Executive Summary of the final report on the YPPHRG's pilot project was provided (see Paper 1). Members were reminded that in the afternoon at the main Group meeting Louca-Mai Brady (author of the report and member of Evidence Knowledge and Learning) will do a presentation with Hugh McLaughlin (member of Empowerment) on involving children and young people in research which will include working with the YPPHRG.

A copy of the full report (29 pages) is available from Maryrose Tarpey at the Support Unit.

**Action: Maryrose to send electronic copies of the full report to Richard Baker, Stuart Eglin, Poonam Jain, Sue Banton and Angela Barnard. Sue and Angela to also receive printed copies.**

- **A members only section of the INVOLVE website**

The INVOLVE discussion forum provides a private forum where Group members can discuss issues within their working group and view the discussion points raised. It is also now possible to download documents onto the INVOLVE discussion forum by following these instructions.

- Open the Discussion forum and log in as normal
- You will see a page that shows all of the Forums that are available to you
- Click on the name of the Forum that you want to put information into
- Click on 'New Topic'
- Type in a subject
- Put all information, including the web address of any associated documents, into the Message box

**Action: Maryrose to explore the provision of email alerts when new entries are placed on the forum.**

- **Links with ESRC**

As agreed at the last meeting Stuart Eglin wrote to David Guy at the ESRC and received a detailed response proposing three actions. These three proposed actions (summarised below) were welcomed and discussed under the following headings:

- (1) Proposal to develop a joint project  
David Guy proposed that we consider the potential to develop a joint project with INVOLVE taken forward by an ESRC Knowledge Transfer Partnership (KTP)

Associate. It was agreed that this proposal should be followed up although these partnerships are more usually focused on innovation and industry and related knowledge transfer from the university to the business sector. We would need to clarify the interest KTP has in linking with INVOLVE and the public involvement agenda.

(2) Proposal to develop a joint understanding of shared interests  
We had suggested planning a series of joint meetings to develop our joint understanding of opportunities for shared projects. In his response David Guy did not want to take up this suggestion as he felt it would not be helpful. As an alternative he asked us to consider a report on health technologies that had just been completed for their knowledge transfer programme and from this report to identify topics of shared interest. This document was received and forwarded electronically to members only two days before the meeting (printed copies tabled at the meeting) so most members had not had a chance to read it through and it was not discussed in detail. Alongside this report David Guy also asked Strategic Alliances to consider ESRC's organisational objectives as contained in their documents and on their website and to identify specific areas of collaboration from these sources.

(3) Proposal that ESRC have a presence at the INVOLVE Conference  
Members warmly welcomed David Guy's suggestion that the ESRC plan to have a presence at the INVOLVE conference in November 2008. David Guy stated that he would like it to focus on the social and economic significance of health technologies which is a priority activity for the ESRC. As our conference focuses on the topic of active public involvement in health and social care research some thought would need to go into carrying this forward. Members suggested that David Guy could be asked to consider either of the following options:

- i) the ESRC could co-ordinate a conference session on the role of active public involvement in health technologies research (as distinct from engagement);

or

- ii) the ESRC could co-ordinate a session on the work of the ESRC more generally and its promotion of public involvement across other ESRC programmes as well as the knowledge transfer programme. For example Sue Banton referred to pilot work by Professor Wendy Tindale based in Sheffield NHS Hospital Trust funded by the Healthcare Technology Co-operative (HTC) Board which involve patients from the outset in the development of new technology to deliver new devices which promote dignity and innovation.

For either option it was suggested that the session would require two speakers and a chair and that ESRC sponsorship could cover the costs of the three nominees for their travel, conference fees and accommodation. As a tangible

output it was suggested that they could also sponsor a write up of the session to record both presentations and discussion. This report could then be 'badged' as a joint ESRC / INVOLVE report and significantly help inform future joint activities.

Progress on this will be discussed at the next meeting.

**Action: Stuart Eglin to write to David Guy as soon as possible outlining our discussion and responses to his suggestions for each of the three actions as follows:**

**(1) He should request that David Guy ask one of the regional KTP advisers to contact Maryrose Tarpey at the INVOLVE Support Unit to develop this first strand of work.**

**(2) A copy of INVOLVE's Strategic Plan 2007 – 2011 of INVOLVE's priorities should be attached to the letter for David Guy's consideration of where our shared interests might overlap.**

**(3) Welcome the proposed ESRC presence at the INVOLVE conference and outline our initial suggestions for an ESRC sponsored session**

**Action: Maryrose Tarpey to forward to members the website link to ESRC's organisational objectives.**

**Action: The ESRC sub-group formed at the last meeting will have a teleconference to discuss this further once David Guy has responded to Stuart's letter.**

- **Report on public involvement and the NIHR research programmes**

Maryrose Tarpey confirmed that the revised report summarising public involvement within research commissioning will be circulated to members as soon as possible.

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#### **4. INVOLVE Group Networks – paper 2**

This development of a grid is an on-going piece of work for Strategic Alliances aiming to record INVOLVE's level of contact with key relevant organisations. Since the last meeting some members have provided additional comment and updating of their organisational links. This has included additional entries from Sue Banton and Richard Baker with the suggestion that we may need yet another column to record outcomes. Richard also provided a very informative summary of his recent discussions with the Royal College of General Practitioners (RCGP).

It was agreed that entries be colour coded to indicate the priority status of each alliance using red (high priority), amber (medium priority) and green (low priority).

By doing this the priority column can be deleted and replaced by a new outcomes column.

**Action: Angela Barnard to transfer the grid onto Excel, edit the columns and colour code the priority status of each entry.**

**Action: Maryrose to update alliance details and start to produce short background paragraphs on each of the entries**

**Action: The updated grid will be placed on the discussion forum**

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## **5. Budget – paper 7**

There were no questions about the budget.

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## **6. Operational Plan 2007 – 2008**

Please note that the letters refer to those used in the Operational Plan.

### **i) INVOLVE conference 11<sup>th</sup> & 12<sup>th</sup> November in Nottingham**

Plans for the INVOLVE Conference are going well. 5000 copies of the Conference 'Call for Presentations' were printed in January 2008 and have been widely distributed by post and electronically via Professional Briefings (PB) and INVOLVE using various lists and networks.

During April and May 2008 a sub-group of the Conference Planning Group will be involved in scoring and selecting from the submitted presentations. The final conference programme and booking form will be available by the beginning of July 2008.

**Action: Maryrose Tarpey to forward to members the timeline and minutes of the most recent Conference Planning Group**

### **j) Feedback on commissioning guidelines**

Maryrose Tarpey reported that the seven commissioning guidelines continue to be a popular download from the website. A total of 667 were downloaded between December 2007 and January 2008. The most popular downloads continue to be: the Guidelines for commissioners on public involvement in peer reviewing (97); Guidelines for members of the public in getting involved in grant applications (114); and Guidelines for researchers on public involvement in grant

applications (135). Hard copies of the latter document have been most popular at our INVOLVE stands.

### **k) Involving service users in the National Research Ethics Service (NRES)**

The INVOLVE Support Unit continue to attend the NRES NHS service user advisory group. INVOLVE will shortly be piloting a survey of lay Research Ethic Committee members to find out more about who they are and the perspectives they bring.

### **l) Communications Strategy – papers 8a and 8b**

Phase 1 of the development of a communications strategy for INVOLVE is now complete. The report – papers 8a and 8b identify short, medium and long term options for implementing the strategy. The overall content of the report was commended by members as providing very useful observation and commentary. Disappointment was expressed about the report's recommendations which it was felt did not draw out the main messages contained within the report and require further work.

It was noted that this should not be seen as a research report and that the number of people interviewed was very small. There were also factual errors and misunderstandings about the role of INVOLVE and its work that should be corrected in the final version of the report. Specific comments by members included the following:

- Disagreed with the idea of developing a 'kite mark' (part of recommendation 5)
- Queried the appropriateness of INVOLVE focusing resources to work at a regional level and develop a regional communications strategy (recommendation 9)
- Wary of going for a single message approach – for example production of a PowerPoint presentation (recommendation 3). It would be more helpful if INVOLVE publicity material and talks, including a set of PowerPoint 'pick and mix' slides that could be tailored to address specific research issues or topics related to how to do public involvement in research rather than just focused on information about INVOLVE. We need to avoid bland material and a 'communications gloss' which may not convey the right message.
- It was felt that the recruitment of 'champions' (recommendation 4) was taking the wrong approach and that it would be much better to recruit 'champions' who are highly regarded in their sphere of research and include public involvement in their work.

- Agreed with the recommendation that INVOLVE should develop links with the NIHR faculty (recommendation 7) although this needs further thought.
- Agreed that we should be thinking about the INVOLVE conference (recommendation 13) in particular the recommendation to employ someone to comprehensively write up the presentations and discussions for use in a variety of formats.
- Caution was expressed about the proposal under 'communications and media expertise' (p 17) options a) and b) both of which relate to the employment of a communications person either part-time or as a consultancy. Based on their own experiences members felt that unless INVOLVE has constant PR issues this would not be good value. However, option c) proposal to employ a freelance consultant would be worth considering for specific tasks – e.g. commissioning using a science writer for the conference.
- Whilst this was not included as a recommendation in the report members suggested that INVOLVE should have a presence at more national research conferences. It was suggested that this could have as much impact on researchers as developing the INVOLVE website as listed in recommendation 11 (also see Appendix 3 of the report).

In conclusion members were keen to ensure that INVOLVE does not lose track of the useful comments contained in the main report that are not included as recommendations.

#### **m) Social Care (workshop and examples)**

Social care examples:

The meeting was given an update on the progress of a Strategic Alliance's funded project to map and gather examples of social care research where there has been active user and carer involvement. A collaboration of researchers associated with the Norah Fry Centre at the University of Bristol were appointed in late December 2007 and their work on the examples project began on 1<sup>st</sup> February 2008. A meeting was held in January to ensure there would be good cross working between this project and the user controlled research examples work (Empowerment lead), which is being undertaken by a collaboration of Shaping Our Lives and the Social Perspectives Network. The first advisory group meeting took place on 20<sup>th</sup> February. Work is due to finish by the end of May 2008 (see also Operational Plan 2008 / 2009).

Social research workshop:

It was reported that this joint one-day seminar with the ESRC National Centre for Research Methods (NCRM) is now being planned for 26th September 2008 in London. The aim of this seminar is to achieve a better understanding of public involvement in academic social care research and will draw on discussions that

emerge from the sessions we are involved in at the ESRC Research Methods Festival in July 2008.

**Action: Poonam Jain and Carol Lupton to be sent information on the planning and programming of the social research workshop.**

**n) James Lind Alliance (JLA)**

INVOLVE continues to be involved with the JLA and in particular to follow through on a joint project between JLA, UKCRC partners and ourselves on the extent to which research funders involve the public in commissioning and research priority setting. This report will be circulated to working group members shortly.

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**7. Operational Plan 2008 / 2009 – paper 3**

As was noted at the previous meeting Strategic Alliances' budget for 2008 – 2009 is already largely committed.

- The main activity is the INVOLVE Conference (£35,000).
- Follow up work on the social care examples (linked to item 6m above) (£10,000).
- The social research workshop scheduled for September 2008. The venue and catering costs have been allocated in the 2007/2008 budget. The 2008/2009 budget will need to allow for additional running costs and production of a conference report (£5,000).

Other activities primarily undertaken by the Support Unit but with no group budget allocated include:

- Commissioning: developing the work on public involvement and research commissioning – ongoing
- James Lind Alliance – ongoing
- Communications strategy – follow up work
- ESRC development work – ongoing
- Involving service users in research ethics review service – ongoing
- Research Design Service – INVOLVE may also need to consider applying to DH for additional resources to support this work (see below Agenda Item 8)

Additions to other activities with no budget allocated in the Operational Plan should include the on-going work planned on the Group networks grid, reviewing alliances and the work with other organisations. It would also be useful to link this grid to the communications strategy.

Members then discussed the format of the Operational Plan more generally which they felt was not fit for purpose. Concern was expressed on its nebulous quality. It doesn't say **why** we will be doing what we plan to do and where does each activity fit in relation to INVOLVE's future direction. This made it difficult to judge whether this set of proposed activities will get us where we might want to get to in three years time, for example.

As proposed for the grid (Item 4) it would be useful to have a table of each of the proposed activities listed accompanied by a description of the anticipated inputs, outputs and outcomes. The Plan should be allowed to sound more concrete and authoritative.

More generally, members said that it would be helpful to clarify the role of the main Group in relation to the Operational Plan and the linked work of the three working groups.

Concern was also expressed about the workload of the Support Unit and the feasibility of the timescales of the activities listed.

**Action: Whilst it was thought unrealistic to radically revamp the format of the Operational Plan for this financial year, over the next 12 months Strategic Alliances would welcome the opportunity to feed in ideas for reformatting the next Operational Plan and suggest it would be useful to look at Operational Plans produced by other relevant organisations.**

**Members recommend that it should:**

- **Provide greater clarity on the aims, priorities and purpose of INVOLVE as a whole, on the role of the main Group and the purpose of each of the working groups**
- **Separate out the work of the secretariat from that of the working groups and main Group**
- **Attach to each proposed activity a description of intended inputs, outputs and outcomes**

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## **8. Future development of INVOLVE – paper 4**

Strategic Alliances were asked to focus discussion about the ways in which INVOLVE will work to support public involvement within the new ten Research Design Services (RDS) due to replace the old Research and Development Support Units (RDSUs) by October 2008.

At our awayday in October 2007 RDSs were identified as potentially one of the ways INVOLVE could support the development of 'hubs' for public involvement in

research across England. One of the results of these discussions was the inclusion of a statement about the importance of a commitment to working with INVOLVE to support public involvement in research in the tender document for RDSs.

Each RDS will be expected to have a lead person responsible for public involvement in research. Whilst INVOLVE will not provide direct training on behalf of RDSs or give direct advice to researchers on behalf of RDSs, it is envisaged that INVOLVE will provide support and equip RDSs (via their public involvement leads) with the knowledge and skills to give advice and training on active public involvement through providing:

- Training workshops for trainers and advisors in RDSs
- A 'phone a friend' service where advisors need additional support and information
- INVOLVE publications for distribution to researchers and for their own reference
- An editable electronic copy of the INVOLVE 'public leaflet' for adaptation for their own equivalent corporate leaflet if requested
- Information on current and planned developments by INVOLVE and updates on the public involvement environment nationally
- A national forum for public involvement leads in RDSs to share experiences, support and information

It was suggested that this new workstream will require at least one additional post within the INVOLVE Support Unit if it is to properly develop the links and support the work of RDSs. Discussion went on to consider other models for supporting RDSs including the idea of having a more decentralised approach – i.e strategically place INVOLVE staff within regions to create INVOLVE 'hubs'; perhaps link up to the various Public Health offices of the regions.

Given this changing landscape, members felt it was important to plan now for how information / metrics on public involvement in research will be gathered to avoid a tick box approach. For example, by working with Research for Patient Benefit (RfPB) to include in their commissioning letters to researchers a reminder that they will be expected to include public involvement in their research and report back on this activity in their six monthly progress reports. Alongside this suggestion was that 10% of RfPB projects could be audited by INVOLVE to track public involvement in the research.

**Action: INVOLVE should quickly apply for resources to work up the mapping and planning for this workstream – perhaps offer a 6 to 12 month secondment to the Support Unit to get this moving.**

**9. Any other business**

There was no other business.

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