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# INVOLVE

## Minutes of the Empowerment Working Group Meeting

Tuesday 03 June 2008

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**Present:** Ann-Louise Caress, Karen Collins, David Evans (Chair), Mary Nettle, Patsy Staddon, Rosemary Barber, Susie Parr, Sarah Buckland, Barbara Dawkins (meeting notes).

**Apologies:** Ade Adebajo, Hugh McLaughlin, Sarah Carr

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

David welcomed everyone to the meeting

There were no conflicts of interest declared.

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### 2. Notes of meeting held on 06 March 2008

The notes of the previous meeting were agreed

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### 3. Matters arising

- **Feedback on accessibility of paperwork for Group meetings**

Working group members welcomed the changes made to assist members identify the different papers for group meetings. For further clarity a suggestion was made to use symbols eg. moon, sun and stars to identify each working group. Sarah also offered in advance of group meetings to go through the papers with any members who would find this helpful.

**Action: Support Unit to explore using symbols to identify which working groups papers referred to.**

**Action: Working group members to contact Support Unit prior to Group meetings if they would like support in going through the papers.**

- **Levels for influencing the research agenda – paper 5**

Sarah presented a reworked version of the paper that Roger Steel had produced for the March meeting, adding two further levels. Group members felt the table had considerable potential use in a variety of ways. David Evans suggested that the table should be shared with other working groups to see if it was useful to them. For example, for Evidence Knowledge and Learning in their analysis of the literature on public involvement in research, and Strategic Alliances in relation to the grid that they are developing to review activity in different areas.

There was some discussion about some of the detail under the levels and whether some of the information and personal questions should be omitted. It was noted that the original document was designed to reflect how the public might be able to influence the research agenda and not service delivery.

It was also suggested that in place of 'levels' that alternative headings should be used. It was agreed that this document should be an internal working document for INVOLVE and not for wider circulation. Ann-Louise offered to redraft the document.

**Action: Ann-Louise to redraft the paper on levels for influencing the research agenda**

**Action: Support Unit to circulate document to Empowerment and Strategic Alliances working groups to consider piloting and feed back to main Group meeting.**

**Action: Levels to be changed to - international influence, national influence, influencing commissioners, influencing organisations, influencing researchers and research projects.**

- **Presentation packs for INVOLVE members**

Sarah reported that whilst the communication consultants had produced a powerpoint template for future presentations for Group members, they had not as had been originally hoped, produced the draft content for presentations.

**Action: Support Unit to send Ann-Louise copies of current slides used by the Support Unit to assist her with a talk she was giving in late June.**

- **Statement about INVOLVE**

Members were asked to comment on the draft leaflet produced by the communication consultants for the Strategic Alliances working group. The leaflet was designed to replace our INVOLVE generic leaflet. The following suggestions were proposed:

- It is important to make clear who INVOLVE is, to avoid confusion with other organisations. A statement highlighting how long INVOLVE has been established, coupled with the NIHR logo might help in this. It might also be useful to continue to include that formerly known as Consumers in NHS Research, as some people still think of INVOLVE as such.
- The examples need to be punchier and maybe have less of them. The language was too academic and dry and might also be improved by including illustrations of how INVOLVE has helped individuals. An alternative suggestion was to highlight key words instead of using quotes.
- Information about INVOLVE needs to be at the front of the leaflet. The website address of INVOLVE should be at the bottom of each page.
- The content of the first page was fine. The leaflet needs to be clear about who it is for and what it is about.

**Action: Support Unit to revise leaflet prior to piloting**

**Discussion Forum**

It was agreed that Empowerment working group members should try and use the discussion forum to debate issues between group meetings. A couple of requests were made to assist people in using the forum:

- A method for alerting members that someone had added something to the forum.
- Further training on using the discussion forum

**Action: Support Unit to look into the feasibility of alerting Group members of new entries on the Discussion Forum. In the short term, Support Unit staff will email working group members when new comments are added.**

**Action: Support Unit to give telephone support to working group members on using the discussion forum and / or support at the awayday. Rosemary, Susie and Patsy all asked for some training.**

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#### **4. Budget**

No monies had been spent, although £7,397 is committed for the user controlled examples work.

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## **5. Operational Plan 2008 / 2009**

### **a) Improving accessibility of INVOLVE materials, processes and events**

Work to take forward the accessibility strategy is progressing, although we still have things to do.

**Action: Support Unit to report progress at the next working group meeting in September**

### **b) Examples of user controlled research**

The examples project is progressing well. They have identified 20 projects to date. Members suggested that Phase 2 should highlight champions or exemplars of user controlled research.

**Action: Support Unit to feedback progress to the working group in September as well as options for taking forward Phase 2.**

### **q) 'Social Inclusion/Exclusion'**

Sarah reported that the Race Equality Foundation (REF) Conference was scheduled for November 20<sup>th</sup>. Three places have been agreed for INVOLVE Group members.

There was a discussion of how best to address the priorities of different groups of people. Patsy raised the issue of the need to consider alongside people from black and minority ethnic communities the involvement of lesbians, gays, bisexuals and transgendered people in research. There was also discussion around terminology and the need to be consistent across INVOLVE. Members felt the phrase 'groups whose views are often ignored or overlooked in mainstream society' should be used. It was agreed that the first step was to develop a policy document to record our vision of social inclusion and to identify the issues. One suggestion as a starting point was to scrutinise the abstracts submitted to the conference to identify which groups submitted abstracts.

**Action: Ann-Louise Caress to analyse the diversity of conference abstracts submitted.**

**Action: Support Unit to recirculate the paper written by Roger Steel on involving marginalised and vulnerable groups.**

**Action: David Evans to initiate a discussion via the discussion forum**

### **c) Identifying 'empowerment' support needs for researchers**

Working group members discussed Paper 6, which summarises the responses of researchers interested in training and advice on public involvement. It was agreed that there was an overwhelming need for training amongst many researchers. A workshop was originally planned for early summer to bring together key support and funding organisations to discuss these issues. It was agreed at the Chairs meeting in April that this workshop should be postponed due to pressure of work within the Support Unit.

There was some discussion around whether we should consider commissioning the development of toolkits or training resources for researchers. This could be done in discussion with the new Research Design Services but also needed further discussion with Strategic Alliances. One suggestion was to start small by working with one region to find out what researchers wanted. It was agreed that it would be helpful to bring together the patient and public involvement leads from the Research Design Services to discuss support for public involvement.

**Action: Support Unit to plan a small workshop later in the year to discuss findings from email responses and to discuss options to support researchers.**

**Action: Support Unit to send paper to researchers inviting feedback and comments.**

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## **6. Future development of INVOLVE**

Whilst it was important to progress plans for developing and supporting champions, it was agreed that this should be done incrementally. The working group needed to pull ideas together to develop a strategy. Ann-Louise suggested that we should recognise the range of potential activities and options but focus on doing one thing well.

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## **7. Any other business**

There were no other items of business

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