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# INVOLVE

## Minutes of the Empowerment Sub-Group Meeting

Thursday 08 June 2006

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**Present:** Sarah Carr, Karen Collins, Susie Parr, Rachel Purtell, Kate Sainsbury (chair), Roger Steel (minutes)

**Apologies:** Mary Nettle, Deborah Tallis

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

- 1.1 Kate welcomed Rachel Purtell as a new co-opted member to the sub-group.
  - 1.2 Susie Parr declared a potential conflict of interest as she was doing a small amount of paid work in relation to the accessibility of the INVOLVE conference. Kate said the group would be aware of this when the item came up. No other conflicts of interest were declared in relation to the agenda.
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### 2. Minutes of 15<sup>th</sup> March 2006

These were agreed as accurate. However the sentence 'The group asked Roger to write a short piece bringing together the main issues if the time could be found' should be separated from paragraph 6.3 as an action point.

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### 3. Matters arising

#### 3.1 Public leaflet

There have been enquiries from 4 organisations interested in helping us pilot the leaflet. Samples have been sent and they will decide whether they want to go

ahead. If they do go ahead, they will be sent a number of leaflets, instructions, and a questionnaire.

### **3.2 Black and Ethnic Minority (BEM) work**

Roger reported on his meeting with Jabeer Butt:

- Jabeer felt that INVOLVE needed better representation from BEM groups. Roger had asked Jabeer to think about whether he could recommend anyone for temporary membership.
- Jabeer was able to suggest agencies to approach for race awareness training, but was sceptical about it really being that effective if it wasn't linked to a specific piece of work. He said people tend just to forget otherwise, and it was no substitute for having representatives who would consistently raise the issues as part of discussion. (This issue was discussed in the Chair's meeting and there it was thought that INVOLVE should be prepared to fund members to attend training individually if they wanted it.)
- We had a long discussion about the strategic needs for addressing the issues raised about minority research, and minorities being properly taken into account in mainstream research. There were a whole range of different actions which different agencies might take (and some had already made significant progress) but what was needed was a more coordinated approach. We considered who the current key players were and also looked at which other influencers need to be brought into the discussion eventually. We then short listed some people to invite for an initial meeting just to gauge the support for developing a strategy group for BEM research. If after the first meeting there is a will to go ahead with a strategy group, then it would be useful to have some financial support from INVOLVE in the long term for booking venues etc, but also specific projects that may arise from discussion e.g. developing a critical appraisal tool for peer review that addresses BEM factors in research.
- Jabeer also asked for INVOLVE support for the 'Inclusion and Exclusion 2006' conference.

**Action: Roger will progress this development work with Jabeer**

**Action: The Empowerment sub group will keep a watching brief as this work develops with a view to identifying specific projects for funding in the next financial year.**

### **3.3 Terms of reference**

Roger presented some notes which drew together some of the issues around empowerment, as background for possible terms of reference for the sub-group if members want to go ahead. There was some discussion about this and it was agreed that terms of reference would be helpful.

**Action:** Kate, Susie and Karen agreed to develop some draft terms of reference to send to the whole group for comment.

**Action:** Roger to send the terms of reference so far developed by the other sub-groups to Kate, Susie and Karen.

### **3.4 Contributing to the research agenda**

Roger presented some notes drawing together some of the issues which influence the opportunity for people who use services to contribute to the broad national research agenda. There was some discussion about this which highlighted the difficulties in producing a coherent piece of work. It was thought that this needed to be a research project in the long term. There may be ways to encourage external researchers to address this issue independently of INVOLVE, perhaps through invoNET. It was also suggested that the work might be linked with the work that Maryrose Tarpey has done for the EKL sub-group on public motivation for involvement in research. There was also a suggestion that this could be linked with the development of terms of reference for the Empowerment sub-group (see 3.3).

**Action:** Roger to look into how researchers might be encouraged to consider this issue independently and seek wider strategic links across sub-groups.

**Action:** To be proposed as an agenda item for the main Group meeting in October or December for discussion.

**Action:** Roger to speak to Maryrose Tarpey about potential links with her work on public motivation to get involved in research.

### **3.5 Colliding Worlds video**

Roger reported that the Support Unit now have a master DVD of the video, and the equipment to copy it. The Support Unit will copy as many as there are written 'Colliding Worlds' reports and insert them into transparent envelopes attached to the inside of the back page of each. The cost of converting the video to DVD was covered by Empowerment underspend from the last financial year.

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## **4. Operational Plans for 2006/2007**

### **4.1 Accessibility**

The Central Office of Information (COI) has now been contracted to audit INVOLVE written communications. The audit will commence on 5<sup>th</sup> June, and a report will be available in the first part of August. There was a query about the definition of accessibility being used for the audit. A specific definition had not been agreed but the framework for the audit is accessibility to INVOLVE

communications in respect of the very wide range of stakeholders we wish to reach. We will need to define accessibility when an Accessibility Strategy is developed following the audit. It was agreed that the Accessibility working group should reconvene by email in August to review the COI report and begin considering the Accessibility Strategy for INVOLVE. A face to face meeting should be arranged as part of the INVOLVE Group meeting in October. Rachel Purtell agreed to be part of the accessibility working group and will contribute as her time allowed.

COI are in a position to audit the conference should this be required. This would be an additional contract to the current communications audit. The group asked for a conference audit to be arranged.

**Action: Roger to arrange for the accessibility working group to reconvene in August and to meet as part of the INVOLVE meeting in October.**

**Action: Roger to arrange for a contract with COI to undertake an accessibility audit of the INVOLVE conference.**

#### **4.2 Information Pack**

Good progress is being made with the Public Information pack. The draft content has been written and is now being looked at by a reader's panel. There have been some delays with commissioning design work due to issues with Leeds University procedures. Originally we had hoped to have the pack published by the September conference, but in view of a shortage of staff due to Philippa leaving the Support Unit this deadline is no longer realistic. We anticipate publication in January.

#### **4.3 Good practice leaflet**

Work for this has not yet been started and is likely to be put back towards the end of the financial year. Roger sought clarity from the group regarding a) the final form of the leaflet, and b) the extent of scoping for identifying the good practice issues. It was agreed that whereas the content should be drawn and condensed from existing INVOLVE literature, it would be important to check this against other work done externally (i.e. Folk.us guidelines, SCIE guidelines). The form of the leaflet would depend on the amount of essential content.

**Action: The form of the leaflet to be discussed by Empowerment sub-group after core guidelines have been gathered.**

## **5. Budget**

### **5.1 Previous meeting's budget**

Due to an administrative error the estimated final spends were not adjusted for VAT, hence on two lines the estimated spends appeared as less than the actual spends. Roger apologised for this error on behalf of the Support Unit.

### **5.2 Final budget for 2005/2006**

Roger explained the final budget figures for the last financial year. Although underspends were anticipated, these were partly taken up by some unplanned additional costs associated with the Information Pack. Overall, most of the Empowerment budget was usefully spent. There were comments that this was a good thing even if some of the spending was not as originally planned.

### **5.3 Current budget**

There are no data available yet for the current budget year.

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## **6. Conference**

Kate spoke to the sub-group about the arrangements for the conference. In terms of accessibility the venue has a large main auditorium with good physical accessibility, and the rooms being used for smaller presentations and workshops were all accessible and easily reached. There was a query about signing and whether colour coding would be used.

A letter had been sent to all presenters with guidance on making presentations accessible. Rosemary of Professional Briefings is the appointed accessibility lead for the conference agents.

Susie has been doing a small amount of work on making the conference guide more accessible. This is paid work through Connect, hence a potential conflict of interest was declared by Susie.

Work is being done to identify suitable chairs for the themed sessions. The themed sessions are for more in depth debate on issues INVOLVE know to be topical and important to people. There will be an opportunity to feedback the key points from these sessions at the plenary session at the end of the conference and a discussion to tie them together. The themed sessions are:

- User Led & User Controlled research
- Tensions of Involvement

- Clinical Research
- Communication and Aphasia
- Engaging Communities
- Developing Strategies for Involvement
- Evaluating the Impact of Involvement
- Children and Young People
- Commercial research

There was a query about whether a quiet space had been planned.

Roger asked that group members attending should all fill in registration forms, although members would attend free of charge.

**Action: Roger/Kate to check about arrangements for conference signing.**

**Action: Roger to make sure everyone has a booking form.**

**Action: Roger to check about arrangements for a quiet space at the conference.**

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## **7. Any other business**

There were no items of other business.

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