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# INVOLVE

## Minutes of the Empowerment Working Group Meeting

Thursday 14 June 2007

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**Present:** Karen Collins, Mary Nettle, Susie Parr, Kate Sainsbury (Chair), Roger Steel (minutes), Deborah Tallis

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

Kate welcomed the group and reminded everyone that this would be her last meeting as chair of the Empowerment Working Group.

Apologies were received from Sarah Carr and Jane Royle (Observer)

There were no conflicts of interest declared.

#### **Change of name:**

Members were advised that it had been agreed by the Chairs to change the name of the sub-groups to working groups. It was felt that this title more accurately reflected the purpose and work of the groups. All paper work will in future refer to working groups, rather than sub-groups.

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### 2. Notes of meeting held on 21<sup>st</sup> March 2007

These were thought to be correct.

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### 3. Matters arising

#### 3.1 Public leaflet – pilot feedback

We have had some feedback from 2 of the 3 pilot sites, after 6 months of being given a supply of the leaflets we produced for researchers to give to members of

the public. There have been difficulties in obtaining any response from the 3<sup>rd</sup> pilot site, possibly the contact has moved on. Feedback from one RDSU which distributed a large number of the leaflets to patient forum groups in their area, was that they only got four responses none of which led to further involvement. They suggested that the title of the leaflet may be misleading (as it may seem to be recruiting research participants) and a bit bland, and this may be the reason. They suggested that something like 'Do you want a say in health and social care research?' may work better. The other site used the wording and content in the INVOLVE leaflet to develop their own which they are pleased with. The UK Clinical Research Network (UKCRN) also adapted the content of the leaflet to create their own. (Both organisations have acknowledged INVOLVE in their leaflet).

It was decided that the leaflet remains a useful resource, but the following changes were agreed:

- The title should be changed to 'Do you want a say in health and social care research?'
- It should be updated to mention the Public Information Pack (PIP)
- There should be a small note on the leaflet for researchers about the option of using it as a template
- It should be re-printed with these changes
- The electronic copy should be revamped similarly but be promoted as a template.

**Action: Roger to make the adaptations to the leaflet.**

### **3.2 Contributing to the research agenda**

A paper was presented to the full INVOLVE Group at the last meeting. Two suggestions that came out of the discussion were 1) the potential of creating an article for a journal based on the paper and 2) the description of the three levels of influencing in the paper was found to be useful and has the potential for application elsewhere. It could also be used as the basis of a mapping exercise.

The discussion looked at a number of related issues as well as the points raised in the last full INVOLVE meeting. It was thought that the three levels described in the paper could be developed as a more comprehensive model that would aid a mapping exercise. This could potentially be linked to the examples work already planned by Empowerment and Strategic Alliances, and could also be useful to the work on seldom heard groups currently being discussed. The development of the model could both inform and be informed by the experience of the examples work.

There was also an offer from the working group to write an article for a journal on the subject.

**Action: Roger to develop the three levels model further so that it takes in a wide and diverse range of situations.**

**Action: Debbie Tallis to start an article on contribution to the research agenda.**

**Action: Roger to send Debbie the original think piece and copy to the group.**

### **3.3 Good practice leaflet – dissemination**

There has been a promising response to the initial dissemination round of the good practice leaflet. The National Research Ethics Service (formerly COREC) have taken 500, for example, and orders have been received from some RDSUs. The Support Unit plan to arrange for a copy to be inserted into each INVOLVE newsletter for the Summer newsletter mailing.

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## **4. Budget**

Roger explained the two budget reports attached to the Group papers, one being the final budget for 2006/07 and the other being spending so far in 2007/08. Whereas in 2006/07 Empowerment overspent as a group because of unexpected costs for publishing PIP, the overall INVOLVE budget was under spent. It was explained that towards the end of a financial year, it is difficult to get accurate figures to ascertain the extent of potential over or underspend, in time enough for the Support Unit to suggest where else the funds could be put to good use before the end of the year.

Roger reported that the PIP dissemination budget for the current financial year was likely to be used up quite quickly.

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## **5. Operational plans 2007/08**

### **5.1 Accessibility**

The Support Unit team have now commented on the accessibility strategy and it seems to be viable. The strategy identifies an annual review as part of an annual cycle of accessibility development. It is suggested that this takes place in the autumn. The strategy describes the process for improving accessibility, and the part of the strategy which is the review process will then set the 'operational plan' for accessibility for the following year.

The group agreed the strategy, but asked for the operational targets for accessibility for 2006/07 to be presented with the strategy. This would mean the review group would have to undertake the first annual accessibility review in the autumn to develop the targets.

It was agreed that Susie and Roger would set a date in the Autumn to undertake the first formal annual accessibility review as described in the strategy and invite all who were interested to be involved.

**Action: Roger to put final touches to the draft Accessibility Strategy and create a summary of work agreed for 2006/07 as the effective operational plan for the previous year, for the purposes of the first review in the autumn of this year.**

**Action: Susie and Roger to present the Accessibility Strategy to the next INVOLVE main Group meeting for sign off.**

**Action: Susie and Roger to set a date for the first annual INVOLVE accessibility review and invite all who are interested to attend.**

## **5.2 Public Information Pack (PIP) – dissemination**

The new Public Information Pack was launched at the end of March 2007 and the first wave of the dissemination process has begun.

A feedback form has been included in each pack to try and review the response as to how useful the information in the pack has been.

## **5.3 Development work on BME research (examples)**

The group briefly discussed a short paper outlining the general proposition for the development work as agreed with the Social Services Research Group (SSRG), the Race Equality Foundation and INVOLVE. Roger has spoken to Sarah Carr at the Social Care Institute for Excellence (SCIE) regarding their help, and there is a good possibility of using some of the SCIE systematic reviews to identify examples. Roger has also approached the Joseph Rowntree Foundation (JRF) for potential funding for undertaking this work. It is understood that although the JRF fully support the work they have only a small amount of money available this year. The collaboration has yet to discuss this position, but it is likely they will want to start a brief example gathering process as soon as possible. It was pointed out that the issue of how we describe 'identity' (e.g. racial, religious, community) in this kind of work seemed to be of great importance, and it was agreed that attention to this was needed when gathering examples.

#### **5.4 Statement about INVOLVE**

It was identified that there needs to be easy to use and brief information about what INVOLVE is, what it does and what resources it has. Work has not yet been started on this project.

#### **5.5 Empowerment issues for researchers**

Jane Royle is developing this piece of work. The project is to find out what would support researchers to undertake more public involvement in their work. A proposal for how this work will be undertaken has yet to be fully developed, but it is anticipated that a seminar for researchers followed by a survey is likely to be the way forward. Karen expressed an interest in this area, and volunteered to work with Jane Royle on this project. Susie has been involved with some useful work through Connect exploring barriers with researchers which may be useful for the Empowerment work.

**Action: Jane Royle to finalise plans and involve Karen and speak to Susie.**

#### **5.6 Development work on User Controlled Research**

The group discussed what the user controlled research examples work would aim to achieve. Principally it is to develop a body of knowledge to:

- a) enthuse service users and user researchers
- b) inform research commissioners and funders about user controlled research.

The group discussed some of the continuing confusions over definitions between user-led and user-controlled research. The group decided that the examples work should focus on user-controlled research as defined in the research led by Peter Beresford and Michael Turner.

The examples could be used to demonstrate a number of issues, such as how little of this kind of work there is, and what can be achieved with it.

At the end of the working group meetings Strategic Alliances met with Empowerment to discuss mutual working on the examples work that they wish to do in Social Care. See below.

**Action: Roger to work up a brief for the user controlled examples work.**

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## **6. Pathways for seldom heard groups**

The working group discussed the think piece Roger had written following discussion at the last meeting on options for taking forward this work. It was agreed that the work should build upon the work this year on examples. It would be useful to be able to identify the mechanics of involvement for both service users and researchers. Using the examples work this year would enable the group to identify key principles that make a difference to seldom heard groups when they are actively involved in research. This information will help shape the more in depth tracking of the involvement and the outcome. It was thought that the development of a model as discussed in 3.2 would be helpful for this next step to look at seldom heard groups' involvement in research from the background of history of settings.

**Action: Roger to develop a draft brief for this work to circulate to the working group for comment.**

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## **7. Any other business**

The working group thanked Kate for her excellent chairing over the last few years, and were pleased to hear that she would continue as deputy chair of INVOLVE for a short while longer.

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## **8. Joint meeting with Strategic Alliances about examples work**

**8.1** The Strategic Alliances (SA) and Empowerment working groups met to discuss potential crossover working with two projects that would collect examples of research projects. These were:

- the Social Care research examples work that SA want to commission, and
- the user-controlled examples work that Empowerment want to commission.

### **8.2 Strategic Alliances is interested in gathering Social Care examples because:**

- there is a need to have examples of good practice in user involvement in research in this area to influence others
- it would be useful to have an idea of the extent of user involvement activity in social care research because of contradictory perceptions
- social care research is different to health research in respect of the way it links with services, as they are traditionally very different cultures of

provision. Examples will help to demonstrate some of the different pathways.

- the audience for the social care examples will be social care researchers and funders.

### **8.3 Empowerment is interested in gathering user-controlled research examples because:**

- they could be used to help familiarise commissioners with what happens in user controlled research
- they could be used to encourage service users to do more of their own research
- INVOLVE currently has a lack of example of this kind of research to draw on.
- it would also be useful to find out something about the research process, the findings, and the impacts.

There was a discussion about the definitions of user controlled research, and it was agreed that it would be useful to keep to the definitions in the user controlled research report written by Peter Beresford and Michael Turner. However, finding out through the examples **who** was controlling **what** could be helpful.

### **8.4 Common ground between the two projects was:**

- examples need to be kept short, otherwise using them in a publication which needs to be of a limited size becomes difficult.
- key themes could be extracted from the examples
- examples could be analysed for later work such as the Empowerment working group's ideas to track pathways and effects for seldom heard groups in getting involved in research.

### **8.5 Agreements:**

- The two projects were thought to be distinct in what they would aim to achieve, and it was agreed that they should be treated as two discreet pieces of work.
- It was thought that it would be beneficial if both projects had the same single advisory group.
- The same or different people could be commissioned to do the scoping work for the two projects.

**Action: Support Unit to produce project briefs**

**Action: Support unit to arrange for the commissioning of the work**

**Action: Support unit to recruit the advisory group from all three main working groups. Mary Nettle volunteered to be part of the Advisory Group.**