

INVOLVE

Minutes of the Empowerment Working Group Meeting

Thursday 13 December 2007

Present: Ade Adebajo, Rosemary Barber, Anne-Louise Caress, David Evans (Chair), Hugh McLaughlin, Mary Nettle, Susie Parr, Patsy Staddon, Roger Steel (minutes)

Apologies: Sarah Carr, Karen Collins

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

David Evans introduced himself as the new chair of the Empowerment working group having been appointed since the last meeting. The membership congratulated him on his new role.

There were no conflicts of interest declared.

There were some comments regarding confusing paperwork. It was suggested that:

- it would be helpful to have an integrated agenda for the whole day
- the ground rules should state that all **relevant** papers should be read rather than implying that all papers should be read.
- it would be useful to have a frontpiece with the papers to help with navigation
- more links should be made between items on the main Group agenda and that of the Empowerment working group.

Action: Roger will feed back these suggestions to the Support Unit and report back.

2. Notes of the meeting held on 09 October 2007

These were accepted as read.

3. Matters arising

3.1 Web conferencing

At the last Empowerment working group meeting the possibility of web conferencing was raised in relation to a discussion on defining seldom heard groups. A private area within the existing INVOLVE discussion forum has now been established for the purpose of working group conferencing.

3.2 Three levels for influencing the research agenda

Attention was brought to the fact that one of the action points from the last minutes had not transferred through to matters arising. The action was that Roger would develop the three levels model for influencing the research agenda as time allowed. Roger apologised for the oversight and added that there had not been enough time to progress this work since the last meeting. Anne-Louise Caress offered to help take this work forward, and will be Roger's contact on behalf of the group for this piece of work. It was thought that the new group discussion board could be utilised for this work.

Action: Anne-Louise and Roger to take this work forward.

3.3 Presentation packs for group members

It was raised that although the Support Unit had said they would produce new presentation packs for Group members, they had not done so yet. It was requested that this item be kept on the Empowerment agenda so that the action would not be lost.

Action: Roger to take this issue back to the Support Unit.

4. Budget

Roger briefly explained the budget figures.

There were concerns expressed about the potential Accessibility budget under-spend. The Support Unit has proposed that a good use of the budget might be to buy into the independent Welfare Benefits and Tax advice service currently being

used by SCIE and provided by the Citizen's Advice Bureau. This arrangement would mean that service users considering accepting payment for work with INVOLVE could then use this service. However, it was pointed out in discussion that the service may not be as good as it sounded and needed evaluating before INVOLVE invested in it.

It was also pointed out that there were still actions to be undertaken arising from the Accessibility review that may involve outlay – for example contracting with an easy read supplier. Roger stated that the recommendations from the Accessibility review had not yet been fully discussed by the Support Unit but a staff meeting was scheduled next week where the review was on the agenda.

5. Operational plan 2007 / 2008

5.1 Accessibility review

Following the awayday in October where the Accessibility Strategy and Annual Review report were signed off by INVOLVE, the Support Unit will shortly be meeting to agree how the recommendations can be put into action over the coming year.

5.2 Public Information Pack – dissemination

The pack continues to be in demand.

5.3 Development work on BME research

Roger reported that the proposal sent to the Joseph Rowntree Foundation had been unsuccessful in finding funding. This would mean that the budget allocated to the INVOLVE BME work will remain unspent. It was suggested that some of this could be used to ensure that the examples work INVOLVE is commissioning in Social Care and User Controlled research, addresses examples of BME research with BME community involvement in addition to the mainstream brief.

Action: Roger to explore possibilities of adding a specific BME examples component to the existing examples projects.

5.4 Statement about INVOLVE as FAQ leaflet

A rough draft of a potential FAQ leaflet was discussed. It was generally thought that the sample was the sort of product that was needed, and that the general approach was about right. However, there were differences of opinion over the use of a diagram to describe INVOLVE which were unresolved. Further work would need to be done on aspects of the content and its accessibility. It was

suggested that this piece of work is linked to the INVOLVE communications strategy development work that the Strategic Alliances working group is doing.

Actions: Roger to discuss the leaflet with the Support Unit and then develop a second draft.

5.5 Empowerment issues for researchers workshop

Those researchers who made enquiries have now been contacted, offered INVOLVE packs and invited to join our mailing list. Specific enquiries are gradually being attended to.

The group discussed the proposal from the Support Unit to have the enquiries properly analysed by an external contractor because of the rich range of information about researchers needs already embedded within them. Further, that the originally planned seminar to ascertain researchers needs, should be amended in favour of an event that brings together key support and funding organisations on the researchers pathway with researchers and service users to:

- a) highlight the needs of researchers in respect of public involvement
- b) discuss shared responsibility and co-ordination between research organisations, and
- c) agree shared action.

A workshop could be organised for March/April 2008.

The Empowerment working group agreed the proposals.

Action: Support Unit to proceed as proposed.

5.6 Development work on User Controlled Research examples

The brief for this has been disseminated and the closing date was 10 December. The decision about who will do the work will be made by the Examples Projects Advisory Group, which will meet on 20 December. There were 16 applications for the user controlled research examples work. Two members of the Empowerment working group have been looking through the proposals and it was proving to be a lot of work.

Action: Roger to look into the issue of workloads for reviewing the examples with the Support Unit and get back to those concerned.

6. Operational Plan 2008 / 2009

6.1 Tracking the outcomes for groups whose views are often ignored or overlooked in mainstream society, of having been actively involved in research

There was some discussion about the revised proposal for this work. However, it was thought to still need considerable development if it was to become a viable piece of work for funding. It was decided to carry this development over into the next financial year rather than attempt to define it as a project at this juncture.

Action: Item to be kept on the Empowerment agenda as ongoing work under development, but not put forward for funding for 2008 / 2009.

6.2 Further developments from the empowering researchers project and the INVOLVE awayday

The group proposed that a strategy and business plan should be developed to further the work of INVOLVE by cascading of skills, knowledge and expertise in active public involvement in research primarily to:

- meet the needs of currently increasing activity in this area, and
- promote high standards of practice.

The strategy would broadly be to enable others to enable others, across the field of health and social care research, and promote shared learning and support.

Thus the strategy would include:

- Supporting and empowering existing 'champions'
- Networking existing and new 'champions'
- Developing new champions in key institutions and groups
- Training for trainers, enablers, advisors and mentors
- A training toolkit for trainers, enablers, advisors and mentors taking into account the increasing availability of new technologies
- Utilising and supporting current networks
- Developing new national networks
- Encouraging, enabling and training to support the development of regional and local networks
- Developing tools for evaluation and feedback process at both micro and macro levels.
- Continued process of mapping, tracking and needs assessment

These activities would be interlinked in a 'package' rather than being treated as separate projects, or strategies.

The strategy would utilise other areas of activity already established in INVOLVE:

- Increasing examples of research involving people who use services
- Developing the evidence base
- Established and new publications
- Current informal and formal networks

To ensure this happens the business plan would have to take into account the need for infrastructure and capacity to undertake the strategy, and would be long term probably going beyond INVOLVE's current term of contract (2011).

Recent activities towards support for the new Research Design Services in providing expertise to researchers on active public involvement in research will be a useful way to both start the strategy, and gain experience to inform further roll out.

Action: Roger to take this proposal back to the Support Unit to discuss and report back.

6.3 Continuation of the user-controlled research examples work

The examples work is likely to carry over a little into the next financial year. This means that funds need to be made available in 2008 / 2009 to continue the work.

6.4 Phase 2 of user-controlled research examples work

To select a sub-set of the projects identified, to illustrate in greater detail the nature of the involvement in the projects.

6.5 Accessibility

This is an ongoing remit of the Empowerment working group.

7. Any other business

There were no other items of business.
