
INVOLVE

Minutes of the Empowerment Working Group Meeting

Thursday 06 March 2008

Present: Ade Adebajo, Sarah Buckland, Anne-Louise Caress, Karen Collins, David Evans (Chair), Hugh McLaughlin, Mary Nettle, Roger Steel (minutes).

Apologies: Rosemary Barber, Sarah Carr, Susie Parr, Patsy Staddon

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

David welcomed everybody, and explained that Roger would be leaving INVOLVE in April and this would be his last meeting. Therefore Sarah Buckland had joined the meeting in order to help ensure continuity of secretariat.

There were no conflicts of interest declared.

Following comments and suggestions about improving the clarity and accessibility of the meeting paperwork, it was noted that some very helpful changes had been made. In particular the provision of a summary 'front sheet' for all the papers and different coloured paper for papers relating to the main Group meeting and that of the working group meeting. However it was suggested that navigation of paperwork could be further improved by linking by asterisk papers referred to in the working group notes that were actually part of the main advisory Group e.g. the ground rules were now on a separate sheet colour coded for the advisory group.

Action: Roger/Sarah will feedback these suggestions to the Support Unit and report back to the group.

2. Notes of meeting held on 13 December 2007

These were accepted as read.

3. Matters arising

3.1 Three levels for influencing the research agenda

Roger has developed the levels concept a little further and brought sample copies along to the meeting. New levels have been added, and these have been set against the three levels of involvement that INVOLVE uses – consultation/collaboration/user-control. Roger had experimented with a way of scoring levels of influence across this matrix, but this was not thought to be particularly helpful. The matrix itself however would be useful for checking against, being a useful tool for thinking with, and mapping involvement in the research environment. (The matrix was subsequently used as part of discussion in item 7 of the meeting).

Action: Anne-Louise and Roger to develop the matrix further and then send out to members of the working group for comment. A final draft would then be produced before the next meeting in June.

3.2 Presentation packs for INVOLVE members

Roger has begun to develop PowerPoint slides that can be used by Group members. Penny Cole from Dovetail Associates who is assisting in developing our communications, will work with Roger to further develop a set of slides which should be finished by the end of March.

There was a suggestion about the possibility of producing a CD Rom or similar, which showed how to give presentations for INVOLVE.

Action: Roger to send a set of presentation slides to Anne-Louise to pilot for a presentation she is doing.

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

This was a potential project deferred at the December meeting because it was not sufficiently developed to attach funding in the INVOLVE Operational Plan. The idea is something that members felt was important and that the group should keep on its agenda. It was thought that one of the problems with this potential work was that it was too big to take on in one go, and should be approached in small steps. Anne-Louise is undertaking a hard to reach groups review as part of her own work, and can feed this back to the working group at a later date. It was suggested that the issue of often ignored groups be taken up as part of the INVOLVE conference.

Action: Anne-Louise/Sarah to take this issue to the Conference Planning Group.

Action: This item to be kept on the agenda as part of a non budgeted activity of the Empowerment working group in the Operational Plan called 'Social Inclusion/Exclusion' (see item 6).

4. Budget

Roger briefly explained the budget figures. There was a query about budgets being carried over into the next financial year, and it was confirmed that this does not happen.

Sarah explained that although there was an underspend in the Empowerment budget, the whole INVOLVE Group budget would probably be slightly overspent, so this was not a problem.

It was explained that the accessibility budget could be used as part of other activities across INVOLVE, e.g. for events and conferences as well as versions of published materials, for example, used for making the dissemination packs being planned by Strategic Alliances.

5. Operational plans 2007 / 2008

5.1 Accessibility

The Support Unit have devised an action plan for how the recommendations from the review can be actioned over the coming year. If you would like to see the plan, which is a list of who is doing what in the Support Unit, then please ask Roger for a copy.

5.2 Public Information Pack – dissemination

Roger has sent an article (written by the two service users who were involved throughout PIP development) to all county Community Voluntary Services across England. There have been a number of replies indicating interest in putting the article in newsletters and on websites.

5.3 Development work on BME research

The proposal for the initial collaborative work to set up a directory of racism and ethnicity research was rejected by the Joseph Rowntree Foundation (JRF) because their priorities have changed. However, the proposal has been sent to Social Care Institute for Excellence (SCIE) to gauge interest and we wait to hear about the response. At the last Empowerment meeting it was agreed to add £2000 from the Empowerment budget to extract examples for the purpose of the Inclusion & Exclusion conference if the JRF bid was successful, which it has not been. Therefore we have £4,000 in the budget unspent. It was agreed that some

or all could be used as INVOLVE's contribution to support the Inclusion & Exclusion Conference 2008, on the understanding (as planned) there will be substantial service user input. (The theme of this conference will be research into practice from the different points of view of researchers, service providers, and service user groups).

The transfer of funds was agreed, but there should be conditions. Suggestions were to include:

- Bursaries for service user attendance
- A number of free places for INVOLVE members
- Use for locating new speakers from BME communities who have been involved in research
- The possibility of including an INVOLVE questionnaire to pick up on issues that could be used to form a short report
- A brief report of the event.

Action: Sarah and Roger to clarify the conditions and agree funding with the Race Equality Foundation.

5.4 Statement about INVOLVE as FAQ leaflet

The statement leaflet as sampled at the last meeting has gone to Penny Cole, the Communications consultant, for advice as it will concern the positioning of INVOLVE and how that is conveyed to the outside world. Advice will be fed back to the working group.

5.5 Empowerment issues for researchers workshop

Following the working group's agreement at the last meeting, we are proceeding with plans for 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.

Sarah has been discussing proposed plans for this event with key stakeholders and there is good support for it. The aim is to run the event in June. Draft aims and objectives and an outline programme will be developed shortly. It is anticipated that the workshop will provide useful information that will help develop the future of INVOLVE work (item 7).

5.6 Development work on User Controlled Research examples

The successful proposal was from a collaboration of Shaping Our Lives and the Social Perspectives Network. The lead applicants were Peter Beresford and Fran Branfield and the researchers are Michael Turner and Vicky Nicholls. This work

started on 1st February, and the first advisory group met on 20th February. The work will be completed at the beginning of October.

6. Operational Plan 2008 / 2009

The pieces of work identified at the last meeting that Empowerment wish to put forward for the 2008/2009 Operational Plan were discussed. Some items are continuations of projects started in the current year and these need to be budgeted in each individual financial year over which they run. This is because budgets cannot be carried over from the previous year. Instead unspent budgets are absorbed by the DH. The original intention of the Empowerment working group to develop a business plan for rolling out skills and resources was noted but was integrated into the 'Future of INVOLVE' paper which was looked at across the three working groups and is discussed in item 7.

It was noted that there was nothing discussed about continuing the blacke and minority ethnic (BME) work into the 2008/2009 Operational Plan at the last meeting. However, members thought this was an important piece of work, which although it might not need a budget in the coming year as there was no specific project involved yet, it should still be part of INVOLVE's plans. There was a wider ranging discussion about how this fitted in with other social inclusion/exclusion issues, including the hard to hear work discussed in 3.3. It was decided that the Empowerment working group would add 'Social Inclusion/Exclusion' to their part of the Operational Plan without a budget attached at present, and that this headline would include BME work.

Action: 'Social Inclusion/Exclusion' to be added to the 2008/2009 Operational Plan under the Empowerment working group.

Action: The seldom heard groups discussions (see 3.3) to take place under this watching brief as part of future meeting agendas.

6.1 Continuation and development of the user-controlled research examples work

Additional funds for 2008/2009 are needed to ensure the user-controlled examples mapping project can continue through to the end of September 2008. More in-depth analytical work is to begin in this financial year as a 'phase 2' project utilising the mapping work. These two budgets are included in the draft Operational Plan.

6.2 Accessibility

This is an ongoing budget which Empowerment holds, and currently the strategy is the responsibility of this working group.

6.3 Empowerment Issues for researchers workshop

The workshop is scheduled to take place in June. Whereas the venue and catering will have already been paid for in the current year, there remain other issues, such as expenses for service use participants etc. A budget has therefore been included in the draft operational plan.

7. Future Development of INVOLVE

At the INVOLVE awayday in October 2007, the working groups identified three priority areas that potentially require additional funds from the Department of Health to take them forward in a comprehensive way. Empowerment discussed this at the last meeting in terms of a proposal for a business plan as part of the Operational Plan for 2008/2009. It was decided that all three working groups needed to discuss this and that Empowerment would consider defining what is meant by 'champions', how they should be identified, and what approaches are needed to best support them as part of the morning discussion to be fed into the main advisory Group in the afternoon.

Who are champions? It was agreed that 'champions' may not be a good label to use, and that 'ambassadors' might be better. However, the kinds of people to be recruited, developed and supported typically include:

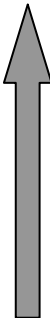
- Nationally – INVOLVE members, service users and professionals in National Institute for Health Research (NIHR) commissioning groups, senior scientists and clinicians, those involved in the UK Clinical Research Networks, National Research Ethics Service (NRES), Social Care Institute for Excellence (SCIE), Social Care inspection bodies, people in the new care quality commission, and editors of journals. Sally Davies is a key champion nationally.
- Regionally – Research Design Service public involvement leads, people in Research Ethics Committees.
- Locally – Strategic leaders in organisations, people in local research networks
- There is a sectoral dimension, i.e. that there are champions/ambassadors in the NHS, social care, Health Education Institutions (HEIs) and other places (e.g. journal editors). These sectors are very different and champions will have very different support needs.
- There are 'formal' champions with user involvement in their job specification and informal ones who do from personal commitment but without a formal organisational role.

In addition to public services, people in associated voluntary sector and private sector roles need to be considered as key influencers.

There is the possibility of re introducing an associate membership for INVOLVE provided there is an infrastructure to support and develop them as champions.

- There is a need for infrastructure to support people in these roles – so often they are left to their own devices.
- There is a need to identify those who are already champions as well as developing new champions.
- Perhaps a matrix to map out different needs and different levels would be helpful.
- There is a need to map out where intervention would make most difference so as to be able to target resources appropriately.
- There is a need for training to develop SKILLS underpinned with RESOURCES that would support champions' activities.
- Possibility that some sort of kite-marking or accreditation would be influential but it brings risks – it is resource intensive to sustain such a programme.
- The possibility of small workshops to discover what champions think we should be doing.

There was support for a three level model for champions:

Level	Status	Methods of working with	Development
Level 1	'Ambassadors' Fellows of INVOLVE	One to one. Buying out time.	 <p>Learning process. The higher you go the more individual the support and the more active the champion.</p>
Level 2	Active in PPI	Learning set, and/or national shared learning forum	
Level 3	Those getting started	'Toolkit' Email network	

It was suggested that a separate discussion group might be set up to take these ideas further.

Action: David to take these ideas to the main Group as part of the afternoon discussion

Action: Roger to add a new level to the influencing research matrix 'influencing strategic leadership in researching organisations'.

Action: Roger to start a discussion on the INVOLVE message board.

8. Any other business

There were no other items of business.