
INVOLVE

Minutes of the Empowerment Working group Meeting

Tuesday 09 October 2007

Present: Ade Adebajo, Rosemary Barber, Anne-Louise Caress, Karen Collins, David Evans, Hugh McLaughlin, Mary Nettle, Susie Parr, Nick Partridge (temporary member and chair) Patsy Staddon, Roger Steel (minutes)
Jane Royle (in attendance for part of the meeting)

Apologies: Sarah Carr

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

Nick welcomed the group and explained that he was in the role of temporary chair of the group, and a new chair needed to be found following Kate Sainsbury's retirement after 6 years as Empowerment chair. Nick explained that a new chair would be sought.

The group has gained a number of new members and there was a round of introductions.

There were no conflicts of interest declared.

2. Notes of meeting held on 14 June 2007

These were thought to be accurate.

3. Matters arising

3.1 Public leaflet

Roger has made the text changes requested at the last meeting. The title has been changed to 'Do you want a say in health and social care research?' and there is some rewording now that the Public Information Pack (PIP) and People

in research is available. There was a short discussion about publishing the revised leaflet, and an agreement that this should go ahead without a dedicated budget.

Action: Roger to arrange for the publication of the revised leaflet

3.2 Contributing to the research agenda

It has not been possible to progress the actions from the last meeting where, a) a member would write an article for a journal, and b) to develop the three levels model of influence based on the paper presented to the full INVOLVE meeting in March. The person who volunteered to write the article has resigned from the group and so has not been able to progress the action. Roger has not had sufficient time to develop the three levels yet. There was a request from the group to send out the paper referred to so that new members could see it. There was some discussion about how this might be developed in terms of accessibility.

Action: Roger to email the paper to the group.

Action: Further discussion needed at the December meeting.

Action: Roger to develop the three levels concept as time allows.

3.3 Good practice leaflet – dissemination

Roger reported that the Good Practice Leaflet produced by the Empowerment working group is proving to be very useful and popular. The leaflet continues to be given a high profile in articles and notices we produce. It has proved a useful resource when Support Unit staff deal with enquiries or are giving talks or workshops.

4. Budget

- 4.1 Roger explained the current and expected spends described for Empowerment work in the budget report.
- 4.2 Particular attention was given to the PIP dissemination budget which was expected to be substantially overspent. It was explained that the overall funds of INVOLVE enabled this overspend to happen, but it was thought that the actual dissemination cost should be recorded on this budget line.
- 4.3 There was also some discussion about the Accessibility budget and the option of spending £3,500 on getting a properly designed large print version of PIP published. The group thought that as the standard document seemed very accessible, and there was already an audio option, that we would not publish a large print version unless there was a known specific demand for it. However, in order to assess possible

demand we would indicate that other formats could be made available through the INVOLVE website and the leaflet.

- 4.4 There were a number of questions from new members about the processes of how INVOLVE was funded.
 - 4.4.1 It was confirmed that unspent budgets would be reabsorbed by the DH after the end of the financial year.
 - 4.4.2 There was a discussion about whether more central funding could be made available to INVOLVE. This was something that was raised in conversation with Professor Sally Davies, Director of NHS R&D when Nick and Sarah (Buckland) met with her recently. Sally had indicated more funds could be negotiated for particular purposes.
 - 4.4.3 There was a discussion about how INVOLVE budgets and commissioning pieces of work. It was explained that being able to undertake work was as much about Support Unit capacity as budgets available to do it. It was acknowledged that our ability to influence was more important than fluctuating other income. There was a suggestion that we could develop the capacity and accessibility of the INVOLVE website to meet increasing demands for materials.
 - 4.4.4 There was a suggestion that it would be worth exploring the possibility of funding being made available from the Department of Children, Schools and Families (DCSF - formerly DfES)

Action: Roger will take forward the suggestion to explore the potential of funding from the DCSF as well as other suggestions made.

5. Operational plans 2007 / 2008

5.1 Accessibility

See 4.3. There was no further discussion regarding Accessibility because the draft strategy and annual review report will be presented as part of the main away day programme for sign off.

NB. The Accessibility strategy and annual review report were signed off at the away day meeting and can now become formal documents.

5.2 Public Information Pack (PIP) – dissemination

Since the new Public Information Pack was launched at the end of March 2007 there have been 6,746 downloads of individual booklets from the website, 1,040 hard copy packs have been sent out and a further 660 packs have been distributed via conferences and events we have attended. A number have been

sent out to journals for review. Jenny Walton and Cary Ostrer the service users who helped us produce the pack have written a standard article publicising PIP which we will then email to a wide range of organisational newsletters.

5.3 Development work on BME research update (examples)

A small bid has been placed with the Joseph Rowntree Foundation by a collaboration of the Social Services Research Group, the Race Equality Foundation, and INVOLVE to fund a limited piece of work to gather all the databases on race and BME research into one web based place (provisionally with the support of SCIE) so that they can be easily accessed. This is a **first step** for this collaboration in a strategy to undertake further more in-depth work to establish outcomes of research for BME communities in relation to whether they were actively involved in the research or not, and will be linked with annual 'Inclusion & Exclusion' conferences which have and are being organised by the same group.

Roger asked the group if £2,000 could be made available from Empowerment's BME development budget to add an additional component to the proposed step one project (if the JRF bid were successful) to extract some research examples that show evidence of active BME community involvement. This would be so that researchers can be contacted to invite for possible presentation at the Inclusion & Exclusion 2008 conference, and who also might be encouraged to submit abstracts for the INVOLVE conference in the same year. The group agreed the spending of £2,000 of the budget for this purpose.

Ade offered his individual support for the work of the collaboration and mentioned that the Specialist Library for Ethnicity and Health would be a good source of information. <http://www.library.nhs.uk/ethnicity/>

Action: Roger will continue to progress the work with the collaboration and keep in close touch with Ade.

5.4 Statement about INVOLVE

Roger has been unable to start this piece of work yet, but asked for ideas about how it might be presented. There is a need to present an initial draft to work from, but there was good support for a suggestion that it could be put in the form of a 'Frequently asked questions' leaflet about INVOLVE.

Action: Roger to produce a draft FAQ leaflet for discussion at the December meeting.

5.5 Empowerment Issues for researchers (workshop and possible survey)

As a result of a request for expressions of interest in the planned workshop on 15th January 2008, to help us identify how INVOLVE and other organisations can further support researchers to involve the public in research, we have been

overwhelmed with responses with nearly 280 to date. Most of these responses arose from enquiring through the Research for Patient Benefit Programme (RfPB). Many of these however, have been from researchers seeking training or similar from the event in areas such as, how to find members of the public, how to involve them, and what the ethical considerations are. They want to come to be given solutions, not explore barriers as we had originally intended.

This gives rise to a number of issues. Should this be a series of hands on seminars? What about longer term considerations? It was pointed out that this sort of support is the responsibility of Research and Development Support Units (RDSUs) and shouldn't we be working with them? The INVOLVE Support Unit have already started work with RDSUs to equip them to advise and train on public involvement. There is also an awareness that the reorganisation of RDSUs planned to start in 2008 is also an opportunity, although the new (RAMs) will be limited to advising NHS researchers and will not have a remit for training, only advice.

Another point was that INVOLVE need to recognise there is a cycle of understanding and that different researchers are at different stages. We need to be prepared to move on from theoretical issues of involvement to the real practical issues.

There is also a strategic issue – how can we meet the need and what capacity is needed to do that? Perhaps the focus should be on the genesis of a training pack from INVOLVE that others can train with? There is a need to target sceptics and not just address the same audiences.

There is a need for both long and short term workshops, development which would be better seen as 'events' not 'training'. For long term capacity we may need to identify people experienced in public involvement in research to help deliver. If we had a funding stream this could be distributed as grants for particular areas of the country. Another suggestion was to develop an online facility with discussion board, e-learning, online conferencing, and online seminars. It is unlikely however that we will find one solution fits all needs, so we may need to think about a series of events and/or products for the future. The toolkit for others to train with may work for the needs of some researchers but not all.

For the immediate future enquiries need to be responded to positively, and we need to list the issues that have arisen for people who have expressed interest, and come back to them with what we are thinking of doing. We may be able to run an event initially that will work for some researchers.

The decision has to be taken by the Support Unit as to exactly what to do for the January event. Patsy Staddon and Mary Nettle offered assistance.

Action: Support Unit to respond to enquirers as soon as is practicable

Action: Support Unit to decide what the January event should look like

Action: Support Unit to look at longer term strategies that can be suggested

Action: Empowerment Group to follow up this item so that longer term measures become part of the Operational Plan and adequately resourced.

5.6 Development work on User Controlled Research (examples)

The purpose of this work is to increase our knowledge of what user controlled research is going on, and to use examples to demonstrate how it works and what it can do. The brief involves mapping out what is going on and gathering simple examples. This project will thus build a foundation for further more in depth work in future, and produce a body of helpful examples for promoting and explaining this type of research. This will be advertised in the autumn alongside the Social Care examples work (Strategic Alliances). The draft brief for the User Controlled research was briefly discussed. It was noted that the bullet points in stages 1 & 2 overlapped. It was also suggested that the time specification was deleted.

Action: Roger to take arrange for the brief to be adjusted accordingly.

6. Operational Plan 2008 / 2009

6.1 General

It was brought to the group's attention that now was a good time to start thinking about what projects the Empowerment working group would like to put forward for budgeting in the financial year 2008/2009. Apart from 'Accessibility' which is an ongoing responsibility of the Empowerment Group, one potential project has already been identified in 6.2 below, and if the group support a phase 2 project on the user controlled examples this will need to be funded for the next financial year too.

In item 7 (below) we discussed priorities for INVOLVE as a whole to take forward into the away day session and this would provide some foundation for individual working groups plans for the next financial year.

Action: Roger and the Support Unit to ensure that Accessibility, User Controlled examples phase 2, and anything identified as part of the awayday pertinent to Empowerment, is brought forward for discussion at the next meeting.

6.2 Pathways for seldom heard groups

The INVOLVE Empowerment Working Group has identified a need to find out what the longer term benefits were and are, if any, for seldom heard groups which have been actively involved in research, and Roger presented an outline

for a potential project to address these issues. Whereas, the outline was thought to be generally feasible this would only be the case if the term 'seldom heard groups' was much more clearly defined. This was identified as the next step, and it was agreed that there should be an email discussion within the Empowerment working group that would help achieve this before the next meeting.

Action: Roger to start up an email discussion to clarify the term 'seldom heard' groups.

A point was raised about INVOLVE's capacity to host virtual discussions as it was thought that it would be a significant advantage for Group members to be able to communicate with each other through a web based conferencing system. Nick said that the IT people at the Terrence Higgins Trust were able to set up conferences in this way and that this is something we should look into.

Action: Support Unit to look into the potential for setting up internal conferencing.

7. Priorities for INVOLVE 2008 / 2009

The group was asked to identify some specific questions that were thought to be important to the work of INVOLVE and place them under each of INVOLVE's broad strategic aims. It was pointed out that there was a dichotomy about what priorities actually belonged to INVOLVE and what other organisations should be doing. It was thought to be important to be able to identify areas where INVOLVE could influence other organisations as well as what INVOLVE should be undertaking itself.

The Empowerment working group contributed the following under each strategic category:

- i) "Influencing policy and practice."
 - Raise the profile of the Public Health and Social Care agendas
 - 'Money talks' – there is a need to influence where money goes in the research world.
- ii) "Helping to create an environment that encourages and facilitates involvement."
 - Developing infrastructure for training etc.
 - Support for service user groups and individuals

- iii) “Improving understanding of the extent, nature and effects of involvement.”
 - Improving evidence, identifying champions (external) and disseminating information well
 - Ask funders for copies of their evaluation of applications to help inform us of the current levels of understanding of researchers
- iv) “Encourage further understanding of the value of genuine involvement”
 - Engaging and supporting champions, i.e. in education
- v) “Increasing understanding of researchers, commissioners, funders, and the public, of the practicalities and opportunities for public involvement.”
 - Look at the what, where and when of involvement and unpacking the issues much more. e.g. where in the research cycle to involve who and why in different sorts of research projects.
 - Explore the ethics and morals of involvement more
 - Develop good practice and identify and support champions of good practice
- vi) “Developing our role as a conduit of expertise identifying and sharing good practice and increasing awareness of the remit of INVOLVE.”
 - Being clear about what we mean by involvement (as opposed to engagement etc.)
 - Being clear about what INVOLVE does and does not do.
 - The need for evidence again!
- vii) “Regularly reviewing our processes and infrastructure to improve the work of INVOLVE”
 - Review our infrastructures to ensure they fulfil our purpose.

8. Any other business

There were no items of other business.
