
INVOLVE

Minutes of the Empowerment Sub-group Meeting

Thursday 12th October 2006

Present: Sarah Carr, Mary Nettle, Susie Parr, Rachel Purtell, Kate Sainsbury (chair), Roger Steel (minutes), Deborah Tallis

Apologies: Karen Collins

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

Kate welcomed the group. There were no conflicts of interest declared.

2. Minutes of meeting held on 08 June 2006

These were agreed as accurate.

3. Matters arising

3.1 Public leaflet

So far two organisations, Barnsley Hospital NHS Foundation Trust, and Sussex RDSU have agreed to pilot the leaflet. Marianne Miles PPI lead in the UK Clinical Research Network (UKCRN) has adapted the leaflet for UKCRN purposes, and INVOLVE is acknowledged in the final publication.

3.2 Black and Ethnic Minority (BEM) work

At the INVOLVE Chair's meeting in September it was agreed in principle that there was likely to be some 'spare' money from the INVOLVE budget to assist with the annual 'Inclusion and Exclusion' conference to take place in January, organised by the Race Equality Foundation and the Social Services Research

Group. Roger has spoken to Jabeer Butt, and in principle agreed that contributing to bursaries for the conference would be a useful way to support it. Roger is now on the planning group for this conference, and Jabeer is happy to discuss links between the conference and our ideas for a BEM strategy group. The Empowerment sub-group agreed that £2000 should be contributed to the 'Inclusion & Exclusion 2007' Conference from INVOLVE.

Roger has also spoken to Christine McGuire at the Policy Research Programme about work being done in the DH concerning BEM communities and research. A book commissioned by her on BEM communities and research was published in June 2006. This will be acquired by the Support Unit.

3.3 Contributing to the research agenda

During the discussion at the last Empowerment sub-group meeting it was thought that the issue of how, at a national level, service users and carers can make more of a contribution to the research agenda, should be discussed at a future full INVOLVE meeting. A short paper will need to be produced which looks at the current situation and where there is room for improvement in order to inform the discussion. Changes in the James Lind Alliance's (JLA) approach need to be incorporated into such a paper.

Action: Roger to speak to Lester Firkins about changes at JLA

4. Operational Plans for 2006/2007

4.1 Accessibility

The Central Office of Information (COI) has now completed an audit of INVOLVE's written communications. The Support Unit has found this a very helpful document so far. A report from the conference accessibility audit will also be completed shortly.

There have been difficulties in reconvening a meeting of the Accessibility Working Group either face to face or by telephone conference because of the other commitments of members, so Susie and Roger proposed that they produce a draft Accessibility Strategy which the other members of the working group then comment on by email.

4.2 Information Pack

The Public Involvement Information Pack which is to replace the old Guide for Consumers is progressing well. The designers are an organisation called 'Limehouse' who have done work for SCIE in the past. We have had to opt for

design options that are 'different' and interesting but remain within a reasonable budget when it comes to printing. The pack will be in four separate booklets. Sarah Buckland is finishing off the content which will then be 'inserted' into the design format. Publication is due in March.

4.3 Good practice leaflet

Roger presented a 'mock up' of a possible DL sized good practice leaflet. He will send this out electronically to group members for an initial round of feedback. It is proposed a draft would need to go to an external reference group made up of individuals who are targeted by the leaflet.

4.4 Budget

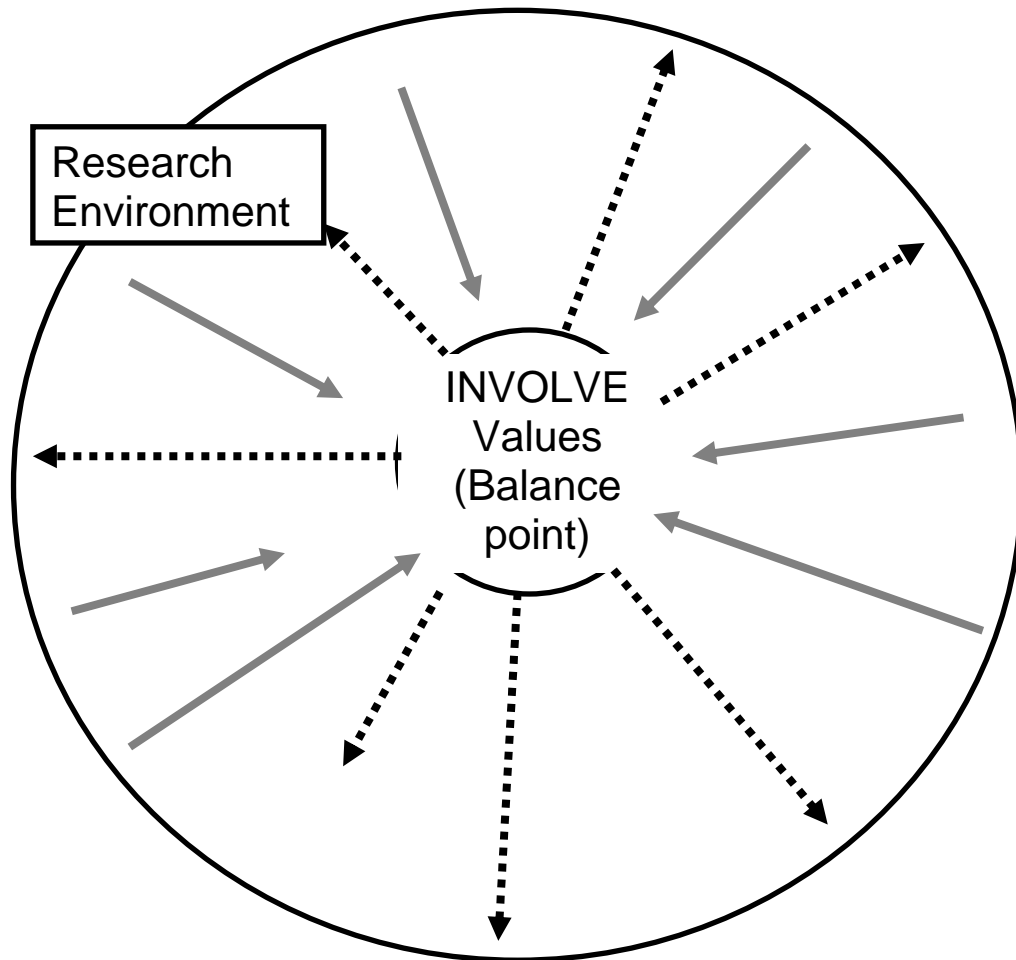
Roger explained the figures in the actual and expected spending columns in the Empowerment sub-group part of the INVOLVE budget spreadsheet. Although there were projected under-spends in the Accessibility and Good Practice leaflet projects, the Public Involvement Information pack was expected to be overspent. Overall, the spending of the Empowerment part of the INVOLVE budget is likely to be as budgeted.

5. Development of Strategic Plan

5.1 In the sub-group we reviewed the full Group morning session as it applies to the aims of the Empowerment sub-group and explored what should be the strategic direction for Empowerment that would feed into a new INVOLVE Strategic Plan. There was discussion about the need to keep alive the core values of INVOLVE and to maintain links with small independent groups and people whose voices are seldom heard. The group felt that there would be a need to keep accessibility high on the agenda as it reflected core values. There is a need to keep attention on social care research too, as there was so much effort being put into clinical research at present and it was thought this threatened to distort INVOLVE's work. A model would be to have INVOLVE's values at the centre of all the work. This would recognise that there was a constant influencing, learning and knowledge transfer interaction between these core values and the environment in which INVOLVE operated. It was important to see this environment in a holistic way, fully inclusive.

Empowerment believe that INVOLVE's values need to be maintained and resourced as central to the work of INVOLVE regardless of single environmental influences. The following diagram is an attempt to describe this visually. The group **influences** the research environment with the values of involvement in research (grey arrows), and is in turn influenced by that environment (dotted

arrows). The arrows represent a creative tension between INVOLVE's central value base and the environment.



It was thought that it would be helpful to include these issues in the Empowerment terms of reference.

5.2 Empowerment sub-group terms of reference

There was a discussion about the draft terms of reference for the Empowerment sub-group. It was thought that some changes were needed in terminology that would more accurately reflect the function of the sub-group.

Action: Roger to expedite changes and send out to the sub-group

6. Plans for 2007/2008

Following discussion of strategic priorities the sub-group started to identify themes which can be developed for further discussion and agreement at the December Group meeting. These were:

The Empowerment sub-group should ensure that INVOLVE:

- Uses its influence to enable positive change by working with other groups and organisations that are part of, or affected by, the research environment including voices that are seldom heard, individuals and small groups in the voluntary and community sector, large groups in public and not-for-profit sector, research commissioners, RECs etc.
- Includes individuals and groups often marginalised by the research community. States its support for small groups and individuals and the values they embody within the research process. Gives good practice examples specific to different groups. Works in partnership with organisations supporting these seldom heard voices – is strategic and coherent about how it works with such partners e.g. BEM work carried out by Race Equality Foundation and the Social Services Research Group
- Promote training and good practice. INVOLVE could develop a 'core curriculum' in a good practice context and could be proactive in encouraging a training network
- Develop knowledge transfer practice (ensuring core messages can be understood and put into practice by key stakeholders in different research contexts)
- Continue to promote user controlled and user led research, using stories and evidence. Collect and publish good examples of user-controlled, user-led research, establishing the credibility and rigour of research that involves the public in this way e.g. cards done by PICKER
- Work with industry to promote empowerment, informed consent, good practice, and transparency
- Promote core values so as to enable INVOLVE to position itself relative to the issue of electronic patient records
- Maintains internal cohesion given all the different external demands and influences
- Maintains its authority as a balance point at the centre of all the influencers and stakeholders in health, social care and public health

research. Acting as watchdog within the group to ensure that social care research is developed and promoted.

- Keep an eye on the issue of empowering researchers and research managers as well as the public

Action: Roger to makes some suggestions as to how these themes might be developed into specific projects.

7. Any other business

There were no further items for discussion.
