
INVOLVE

Minutes of the Strategic Alliances Working Group Meeting

Thursday 14 June 2007

Present: Sue Banton, Sarah Buckland, Chris Caswill, Stuart Eglin (Chair), Marianne Miles.

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

- Apologies were received from Carol Lupton
- There were no conflicts of interest reported

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.

2. Notes of meeting held on 21st March 2007

- There were no corrections to the minutes of the 21st of March.
-

3. Matters arising

Strategic Alliances grid

The Strategic Alliances grid, was a form produced to collect information from working group members on any activities they had undertaken, either on behalf of INVOLVE, or where they referred to the work of INVOLVE. The form was being piloted with Strategic Alliances members, but only a few forms had been returned and so it was difficult to assess their potential value.

Action: It was agreed that the forms should be circulated to all Group members to pilot the usefulness and feasibility of collecting this information.

Young Peoples Public Health Reference Group (YPPHRG) – annex I

Sarah reported that Hilary Graham, Director of the Public Health Research Consortium, had sent a longer report that was also available on the National Children's Bureau website.

Mark Petticrew reported on the Public Health Research Consortium board meeting and feedback on the work of the reference group, and the work they had been doing to identify research priorities of interest to them. Mark also reported on work he was doing around developing the evidence base re public health and education. He was considering how the priorities of the reference group could be meshed into issues around gaps in the evidence and the possibility of involvement in systematic reviews focussing on education.

Stuart raised a query around ongoing funding for the reference group. Mark reported that their future was still uncertain, but they had applied to the Wellcome Trust for funding.

Marianne asked about plans for evaluation of the reference group. The National Children's Bureau are undertaking a small scale evaluation.

Action: Sarah to circulate the report from the YPPHRG.

Action: Mark to find out further information about plans for evaluation and to share with working group members.

Social care

Chris Caswill raised concerns that contact had not been made with David Guy at the Economic and Social Research Council (ESRC) to arrange a meeting, and that this might indicate a potential lack of commitment to working with the ESRC. Stuart apologised for the delay, which had been due to pressures of work, and it was agreed that an email would be sent as soon as possible, with the intention of getting a date in the diary before the end of July.

4. Group member networks – annex F

Annex F shows the main organisations that the Support Unit currently have regular contact with, as well as others with which we could consider developing further links. The organisations in the second table have been largely (but not exclusively) drawn from those that Group members are affiliated to in some way. Organisations linked to particular health conditions or service user groups have not been included in the tables.

Discussion took place about the organisations included. It was highlighted that the Economic and Social Research Council had been inadvertently omitted from the list and it was suggested that the Medical Research Council should be moved to the front page.

It was suggested that the different organisations could be looked at in terms of the level of involvement INVOLVE has with each. For example, at the level of contact, engagement, co-operation or alliances (in the latter, the partner organisation has a clear vision of INVOLVE and would support its work). There was discussion around the wording and description of the different levels, as well as the need to consider how and whether there should be the expectation of moving up the levels with all organisations listed (for example INVOLVE might wish to work more closely with some than others).

There was some discussion around whether the work plan for Strategic Alliances was sufficiently strategic, and whether it concentrated on areas where there are important gaps. Others suggested that the work planned, such as working with the National Research Ethics Service, and with social policy researchers, as well as exploring ways of improving communication about public involvement, were areas considered by the working group to be strategically important.

Action: Support Unit to add additional organisations to list such as ESRC, Cochrane, Campbell Collaboration, Wellcome and Kings Fund.

Action: Support Unit to map out the different levels of involvement and link to the Strategic Plan, for discussion at the next working group meeting.

5. Public involvement and the National Research Ethics Service (NRES) – annex G

Sarah provided an update on the work the Support Unit has been discussing with NRES. One of the activities is developing a joint statement as well as planning training in October to help clarify when ethical approval is and isn't needed for public involvement. NRES has also agreed to establish an advisory group including service users and carers, and lay members of ethics committees, to discuss taking work forward. Roger Steel and Sarah Buckland are to be part of the advisory group. The Support Unit will also be working with NRES to undertake a survey of lay members of ethics committees.

6. Update on Operational Plan 2007/2008

Please note that the letters refer to those used in the Operational Plan.

i) INVOLVE conference 2008

An initial meeting of the Conference Planning Group was held in April.

Action: It was agreed that Marianne Miles would be a virtual member of the Conference Planning Group. Maria Palmer and Sue Banton from Strategic Alliances are members of the Group.

(j) Evaluating commissioning guidelines for public involvement in commissioning research

Jane Royle is finalising plans for taking this work forward and has developed a draft feedback form. Jane is also planning to talk to the public involvement leads of the National Institute for Health Research (NIHR) programmes to discuss awareness and use of the guidelines.

l) Communication – promoting public involvement

Possible consultants are being identified to bid for this work, and a brief will be developed by the Support Unit.

Action: The Support Unit to develop a brief to outline the work to be undertaken, which will be circulated to working group members for comment.

m) Social care

Workshop(s)

Plans for the social care workshop will be developed, in light of the discussions with David Guy at the ESRC about a possible joint workshop as well as other events.

Examples (Joint meeting with Empowerment working group)

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 wish to commission, and
- the user-controlled examples work that Empowerment wish to commission.

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.

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.

The common ground between the two projects were:

- 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.

Whilst there was considerable overlap, 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 may be helpful but not necessary for the same person or organisation to undertake both projects. However, it was agreed that both projects would be overseen by a single advisory group. Mary Nettle and Kate Sainsbury volunteered to be on the advisory group.

Action: Support Unit to recruit to the advisory group from all three main working groups.

Action: Support Unit to produce project briefs and circulate to advisory group for comment.

Action: Support Unit to arrange commissioning of work

n) James Lind Alliance (JLA)

Maryrose Tarpey has attended a JLA Operational Group meeting and will attend the next couple to further explore future working with the JLA. Two workshops are planned by the JLA. Maryrose is attending the first event in June and we have a stand booked.

7. Budget

There was no discussion of the budget.
