

INVOLVE

Minutes of the Evidence, Knowledge and Learning Working Group Meeting

Thursday 13 December 2007

Present: Peter Beresford , Louca-Mai Brady, Sarah Buckland, Jim Elliott, Alison Faulkner, Ray Fitzpatrick, Helen Hayes, Vanessa Pinfold, Diana Rose , Sophie Staniszewska (Chair) and Michael Turner.

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

Apologies: these were received from John Sitzia and Tracey Williamson

Conflict of interest: Peter Beresford and Alison Faulkner both declared a conflict of interest. They were both involved in proposals recently submitted to INVOLVE for the Empowerment working group project looking for examples of user controlled research.

2. Notes of meeting held on 09 October 2007

These were agreed.

3. Matters arising from working group and awayday

a) Suggestion for requesting contributions for additional funding for public involvement in research

It was noted that the Support Unit have raised this suggestion with Philippa Yeeles who leads on patient and public involvement at the UK Clinical Research Collaboration (UKCRC) and Simon Denegri, Chair of the UKCRC working group developing the patient and public involvement strategy.

It was felt that this should be a very positive suggestion which should be viewed as recognition of the level of commitment to public involvement in research rather than a purely financial proposal.

It was suggested that requests for funding from organisations for public involvement in research should be:

- voluntary
- regarded as a positive action to encourage public involvement in research

Options might include:

- consideration of a 'pot' of money that can be applied for in relation to good ideas for research into public involvement in research
- additional funding for researchers to evaluate, reflect and report the public involvement in their own research projects

b) List of current research or evaluation studies relevant to the evidence base for public involvement in research

Helen reported that she had circulated to working group members a list of ongoing research projects relevant to the development of an evidence base on public involvement in research. Members were asked to submit any projects that they are involved in to the UK Clinical Research Collaboration database of ongoing projects available on their website

<http://www.ukcrc.org/patientsandpublic/currentppi/projects/activitieslog.aspx>

c) Metrics around public involvement in research

Working group members were advised that the Support Unit were going to see if it was possible to influence the Department of Health metrics to include information on public involvement in research. A draft suggested metric had been circulated for comment to those members who indicated an interest at the awayday. Members discussed how to best distinguish between written intention of public involvement in a grant application and whether researchers followed through by involving the public in their work. Members also highlighted the tension between the need to develop a simple metric and it providing meaningful information and feedback (risk of a tick box exercise).

Action: Support Unit to circulate draft suggestion for metric to all members of the working group for comment by Tuesday 18 December 2007.

4. Issues around the development of an evidence base

a) Joining invoNET and initiating debate around the evaluation of public involvement in research

Working group members were asked to consider joining the invoNET network on the INVOLVE website and initiating debate around developing an evidence base for public involvement in research. This could either be carried out

through the invoNET members email facility or by starting a topic thread on the INVOLVE discussion forum.

Action: Working Group members to join invoNET and initiate discussion

b) Consideration of a sub group across the three working groups for those interested in developing an evidence base

This was discussed following the suggestion at the awayday that a sub group for those interested in developing an evidence base could be formed across the three working groups. It was agreed that it would be a good idea for there to be greater cross group working and discussion on building the evidence base, however the best way to practically facilitate this was unclear. invoNET currently exists for a wider audience and ideas such as additional meetings, email discussions and the website forum were raised.

Action: Issue to be discussed at Chairs meeting with the possibility of a future agenda item on the main Group around building the evidence base.

c) Consideration of how best to create and contribute to a coherent evidence base.

Discussion took place on how the community of researchers and others can best work together to create the evidence base and what role INVOLVE should play.

The following considerations were raised:

- What does evidence look like?
- Who wants evidence?
- What are they going to do with it?

It was recognised that there were different audiences for an evidence base such as:

- Funders and commissioners
- Research community
- Communities
- Members of the public

It would be important in taking this work forward to integrate and include the different views and activities. Consideration would also need to be given to the link between evidence and policy and the impact that either the evidence itself or the lack of it has on policy.

Putting People First - recently published on the Department of Health website was suggested as a relevant document to look at in relation to the discussions

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

Social Care Institute for Excellence (SCIE) is also going to be reviewing the evidence base around personalisation.

It was considered that the work Jon Hyslop is carrying out for Evidence, Knowledge and Learning will be very important in looking at what is and what isn't known about public involvement in research. Other organisations might then fund further work to inform their own policy.

Jim Elliott mentioned that two of the Macmillan Research Units were at the early stages of developing critical appraisal tools looking at quality of user involvement and how to appraise it in process, outcomes and outputs.

Evidence, Knowledge and Learning had developed a discussion paper around the development of an evidence base in Spring 2007. This is available on the invoNET area of the INVOLVE website. It was agreed that this should be circulated to the working group for review.

Action: Support Unit to recirculate Evidence, Knowledge and Learning discussion paper

5. Budget 2007 / 2008 (for information)

This was noted.

6. Operational Plan 2007 / 2008

a) invoNET

It was noted that the date of the next invoNET annual event is Wednesday 13 February 2008. Working group members were asked to let the Support Unit know if they would like to join the project team with responsibility for organising the annual invoNET event.

b) Dissemination of publications

The working group noted that Penny Cole from Dovetail Management Consultancy is helping to develop a communication strategy for INVOLVE and some practical outcomes to take forward. Further information would be available when Penny attends the main Group meeting in the afternoon.

c) Project to review, reflect and analyse the literature on the nature, extent and impact of public involvement in research

The Advisory Group for this project met in early November and a second meeting has been arranged for 17 December 2007. The objective of this work is to build on the work already started in the invoNET library. A protocol has been developed for the project and search strategies have been identified. It was reported that it had been agreed to concentrate on publications on the 'impact' of public involvement in research when carrying out searches or grey literature reviews for the project, although the invoNET library would continue to have the wider remit of publications looking at the nature and extent of public involvement in research and reflecting on public involvement in research.

Action: Support Unit to circulate copies of the research protocol to all members of the working group.

d) Mapping of public involvement in research in commissioning and funding bodies

- i) Work with the National Institute for Health Research (NIHR) Programmes
- ii) Working Group members thanked Jane Royle for her report on the work that she has been doing with the NIHR programmes and also developments around public involvement within the programmes.
- iii) Questionnaire to find out what progress is being made on public involvement in health research commissioning / funding in the UK.

INVOLVE has been working with the UK Clinical Research Collaboration (UKCRC), the Association of Medical Research Charities (AMRC) and the James Lind Alliance to find out what progress is being made on public involvement in health research commissioning / funding in the UK.

A questionnaire has been sent to Programmes that are part of the National Institute for Health Research (NIHR), the Policy Research Programme (PRP), the Devolved Nations Research Programmes, Voluntary Sector and Research Councils.

132 questionnaires had been sent out and 33 responses received to date. Further information would be available at the next working group meeting.

Working group members discussed the possibility of the questionnaire being sent out annually and how in the future the work could be extended to a wider audience, particularly to cover public health and social care funders.

7. Operational Plan 2008 / 2009

Evidence, Knowledge and Learning currently have three pieces of ongoing work. invoNET and a budget for the dissemination of publications require ongoing funding each year, last year £6,000 was allocated for invoNET and £5,000 for dissemination of publications. It was agreed as part of the discussions for the 2007/2008 Operational Plan that the project to review, reflect and analyse the literature on the nature, extent and impact of public involvement in research would be financed over two financial years 2007/2008 and 2008/2009 at £35,000 per annum. It was noted that these commitments will absorb the existing Evidence, Knowledge and Learning budget for 2008/2009.

8. Working group members Information Exchange

Louca-Mai updated members on the successful expansion of the work of the Young Peoples Public Health Reference Group (YPPHRG) which has received funding from the Wellcome Trust. The National Youth Agency are developing a young peoples' research network with small amounts of funding for research led by young people.

Peter highlighted a new publication available on the Shaping Our Lives website 'We are not Stupid' on research carried out by a group of people with Learning Difficulties. <http://www.shapingourlives.org.uk/>

9. Any other business

It was reported that a new private area for members has been developed on the INVOLVE website discussion forum.

The discussion forum can be accessed from the INVOLVE website www.invo.org.uk by clicking on the forum link on the left hand navigation bar.

Once registration has been approved members will be able to access both the general forum and the working group's private forum.

Further information is available from the Support Unit.

Date of next meeting: **Thursday 06 March 2008.**
