

INVOLVE

Minutes of the Evidence, Knowledge and Learning Working Group Meeting

Tuesday 03 June 2008

Present: Peter Beresford, Louca-Mai Brady, Jim Elliott, Alison Faulkner Ray Fitzpatrick, Helen Hayes, Sophie Staniszewska (Chair), Michael Turner and Tracey Williamson

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

Apologies: these were received from Vanessa Pinfeld and Diana Rose.

Peter Beresford and Michael Turner declared their involvement in the User Controlled Examples project commissioned by INVOLVE.

2. Notes of meeting held on Thursday 6th March 2008

These were agreed

3. Matters arising from working group and awayday

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

The UK Clinical Research Collaboration (UKCRC) Patient and Public Involvement Strategy has now been published and is available on their website <http://www.ukcrc.org/patientsandpublic/currentppi/projects/ppistrat.aspx>

A UKCRC Board sub group for patient and public involvement has been established to oversee its implementation and Sarah Buckland, Director of INVOLVE is to Chair this group. Sophie Staniszewska is now also a member of this group.

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

Action: Support Unit to circulate an updated list of known current research or evaluation studies to members of the working group.

c) Metrics around public involvement in research

In December 2007 Evidence, Knowledge and Learning sent a suggestion for a metric on public involvement for research commissioners to Peter Sneddon at the Department of Health. It was noted that this was raised at the recent National Institute for Health Research (NIHR) Board meeting and discussed along with the need for a more qualitative approach in reporting NIHR outcomes, especially to clinicians, patients and the public in general.

d) Communication and cross working across the working groups

Following discussions at the Chairs meeting in April 2008 it was agreed:

- To start working group meetings 15 minutes earlier at 10.30 on a trial basis.
- To explore different options for cross working group discussions including where appropriate, agenda items in the morning groups to allow shared discussion across two working groups; afternoon meeting to provide opportunity for working groups to rotate leading on a discussion based on an aspect of their work programme and / or to raise issues of shared interest across working groups.

It was noted that the Support Unit are trying to develop a system so that email alerts go to working group members when new items have been placed on their section of the discussion forum, to encourage cross working on the forum.

The working group welcomed opportunities for joint working. It was suggested that focussed, specific topic teleconferences, of 20-30 minutes in length might also help facilitate some discussions.

e) Research topic suggestions for the methodology programme

The research topic "How can public involvement in health and social care research best be assessed and evaluated" was submitted to the Department of Health for consideration by the MRC-NIHR Methodology Research Programme at their meeting in April 2008. Working group members will be kept informed of any future developments by the Support Unit.

4. Development of a programme of research to generate evidence on the impact of public involvement in research – paper 4

Working group members discussed the development of a programme of research following agreement at the Chairs meeting in April 2008, that this should be developed and submitted for consideration to the Department of Health.

Working group members reviewed appendix 4 and agreed the following amendments:

- The programme of research should be extended to include evidence on the impact and the **mechanisms** of public involvement in research.
- Remove 'critical discussion and guidance to move the debate forward' from the bullet points under point 3.

Following further discussion it was agreed that the proposed research programme should:

- Focus on primary research
- Promote a pluralistic approach drawing on a wide range of methods
- Encourage a balanced approach reflecting on both the positives and negatives of public involvement in research
- Encompass a range of themes including:
 - How to involve the public in research
 - Methods and mechanisms for involvement
 - What works for different groups and throughout the different stages of the research process
 - Goals and aspirations for public involvement in research
 - Why some choose to involve the public and others choose not to
 - How to evaluate public involvement in research
 - How to capture and measure evidence
 - Economic evaluation and capacity building

It was considered that this should be an ambitious programme of work and that funding of £5 million should be requested. The funding would support collaborative and user led/controlled research and the following suggestions were made:

- Public involvement in the research to be a criteria of funding
- Programme to fund 8 -12 projects of varying sizes
- Two stage approach with submission of outline proposals with detailed feedback prior to full submission.
- Adequate timescales to allow for feedback and three months to work up full proposal

- All projects to be completed within 3 years
- Welcome international contributions
- Support for small organisations and consideration of small development grants to develop full proposal

Action: Support Unit to incorporate ideas into a draft brief for consideration by members of the working group by email and submission to the Department of Health mid July 2008.

5. Budget 2008 / 2009 (for information)

This was noted.

6. Operational Plan 2008 / 2009 – paper 8

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

l) invoNET

The draft invoNET report has been received and an audio and a transcription of the debate is now also available.

The invoNET project team will meet shortly to finalise the documents and also to discuss options for the next event.

m) Dissemination of publications

The Support Unit are to produce a 'special edition' newsletter for publication just before the 2008 conference. It will be an expanded edition containing articles from a selection of the conference presentations.

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

Working group members were updated on the progress of the INVOLVE Impact Project.

s) Mapping and monitoring of public involvement in research in commissioning and funding bodies

Several pieces of work are now ongoing in this area and they are outlined below:

i) Survey on public involvement in health research commissioning and funding processes

INVOLVE worked with the UK Clinical Research Collaboration, Association of Medical Research Charities and James Lind Alliance to send out a web based questionnaire to research funders about public involvement in research commissioning 2007.

The 36 responses have been analysed and the summary will be discussed at the main Group meeting this afternoon – paper 1.

ii) Research priority setting amongst the main UK clinical research funders

Sally Crowe and Kristina Staley will be presenting on the work the James Lind Alliance has been carrying out on research priority setting at the main Group meeting in the afternoon

iv) Public involvement in the Research for Patient Benefit Programme

Discussions are taking place with the Research for Patient Benefit Programme Director on the best way to utilise the information they have collected on public involvement in research

v) Public involvement in National Institute for Health Research (NIHR) Biomedical Research Centres

It was noted that three questions on public involvement in research were included on the Biomedical Research Centres annual review forms.

7. Working group members Information Exchange

Working group members reported on any items of interest that they had either been involved in or were aware of:

- The funding for the Young Peoples Public Health Reference Group (YPPHRG) from the Wellcome Trust has now been confirmed. A website will be developed and there will be a small amount of funding for young people to carry out their own research
- INVOLVE project identifying examples of public involvement in research has received 30 completed questionnaires
- Patient and public involvement strategies are being developed for Oxford Biomedical Research Centre and South East Research Design Service
- 4th Biennial Disabilities Studies Conference to be held in Lancaster 2nd - 4th September 2008

- Inclusion and Exclusion Conference, Race Equality Foundation, Social Services Research Group, and INVOLVE – 20th November 2008
 - Macmillan Cancer Support are about to advertise for their third round of user led research grant competition
http://www.macmillan.org.uk/About_Us/Force_for_change/Cancer_care_research/Macmillan_research_grant_competition.aspx
 - Revolving Doors are working with Rethink training a team of service users to carry out research
 - NHS Centre for Involvement undertook a survey of patient and public involvement in the NHS and the findings are now available on the website
<http://www.nhscentreforinvolvement.nhs.uk/index.cfm?Content=208>
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8. Any other business

Date of next meeting: Awayday 10/11 September 2008

Working group members congratulated Vanessa on the birth of her daughter Alice on 12th May 2008.
