

INVOLVE

Minutes of the Evidence, Knowledge and Learning Working Group Meeting

Thursday 06 March 2008

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

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

Apologies: these were received from Alison Faulkner and John Sitzia

Sophie thanked John Sitzia for the very valuable contribution and the support he has given to INVOLVE and the Evidence, Knowledge and Learning working group during his term of office. It was hoped that John would keep in touch and still contribute through the observer role of the UK Clinical Research Network. Sophie welcomed Tracey Williamson back to the working group after maternity leave and Tony Williams from the Department of Health.

2. Notes of meeting held on 13 December 2007

These were agreed with the following amendment:

“Louca-Mai updated members on the successful expansion of the work of the Young Peoples Public Health Reference Group (YPPHRG) which has received a **provisional** offer of funding from the Wellcome Trust”

3. Matters arising from working group and awayday

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

This has not been included in the draft UK Clinical Research Collaboration (UKCRC) Patient and Public Involvement (PPI) strategy and this was raised at the UKCRC Patient and Public Involvement meeting on 27th February 2008. There was no discussion at the meeting although the suggestion has been

included in the minutes. It is hoped that there will be an opportunity to raise it again at the next meeting.

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

It was noted that an updated list of ongoing work contributing to the development of an evidence base will be circulated at the June 2008 working group meeting.

Action: Update at the June 2008 working group meeting

c) Metrics around public involvement in research

Following the last working group meeting members sent in their suggestions for a metric for public involvement for research commissioners. The Support Unit sent Peter Sneddon the final suggested metric which he then forwarded to the relevant section at the Department of Health.

The metric was not discussed at the last National Institute for Health Research Advisory Board meeting in January 2008 however it is due to be discussed at the next meeting in May 2008. Any further developments will be reported at the June working group meeting.

Action: Update at the June 2008 working group meeting

4. Issues around the development of an evidence base

Consideration of how best to work across the working groups and involve all members who have an interest in the development of an evidence base, is to be discussed at the next Chair's meeting which is to be held on Thursday 03 April 2008. Discussions around building an evidence base will be an agenda item at the main Group meeting on 03 June 2008.

Working group members noted the information on how to join the INVOLVE discussion forum and that there was now a private area for Group members.

It was suggested that it might be easier to facilitate online discussions if working group members were aware that an email had been posted on the forum. Another alternative might be emailing working group members with a time and date that a specific item was to be discussed.

Action: Support Unit to explore options for email alerts when items are posted and options for online discussions and chats.

5. Budget 2007 / 2008 (for information)

This was noted.

6. Operational Plan 2007 / 2008

a) invoNET

54 delegates attended the third invoNET event on Wednesday 13th February 2008 at the Kings Fund in London. The programme for the day included:

- a presentation from Jon Hyslop on the INVOLVE Impact Project
- a world café event discussing the following questions:

- 1. What might evidence of impact of public involvement look like?**
- 2. How do we find evidence?**
- 3. How far have we got?**

Vicky Johnson, Development Focus Trust, who facilitated the world café is producing a report of the discussions.

Sally Crowe, James Lind Alliance, facilitated the afternoon debate 'We need an evidence base for public involvement in research' with Mark Petticrew supporting the question and Alan Simpson, City University challenging. It was a lively day with excellent feedback from delegates.

Action: Working group members to receive copies of the invoNET report when available

b) Dissemination of publications

It was noted that the Public Information Pack continues to be the most popular download from our website.

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

Working group members were updated on the current situation with the project to review and reflect the literature on the impact of public involvement in research. It was agreed that Peter Beresford would contact Sarah Buckland for further information.

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

INVOLVE, UK Clinical Research Collaboration, Association of Medical Research Charities and James Lind Alliance are working together on two related projects in order to find out what progress has been made on public

involvement in health research commissioning and research priority setting in the UK.

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

The first stage of this work was carried out by INVOLVE in liaison with the UK Clinical Research Collaboration, Association of Medical Charities and James Lind Alliance. A web based questionnaire was sent out to research funders in November 2007. The 36 responses are currently being analysed and written up.

Action: Working group members to receive a copy of the summary of public involvement in health research commissioning and funding when available.

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

Related work is being undertaken by TwoCan Associates on behalf of the James Lind Alliance. This draws on the returned data from our survey of commissioners to carry out a scoping exercise to find out how clinical research bodies set their priorities and whether and how the public are involved in this work. Copies of their draft report of this work were tabled at the meeting. These were for information only and not for circulation.

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. In addition, it was agreed 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. These commitments will absorb the existing Evidence, Knowledge and Learning budget for 2008/2009.

It was agreed to request an additional £2000 for invoNET for the 2008/2009 financial year.

8. Future development of INVOLVE – paper 4

Developing the knowledge base – the development of a programme of research to generate evidence on the impact of public involvement in research

Working group members considered this to be a valuable and important research programme and were fully supportive of developing a programme and requesting that support and funding for this programme be taken forward by the Department of Health.

The following areas were considered important when developing the programme of research:

There is a need for evidence on the impact of public involvement in research and any programme of research would need to take into consideration the following areas:

- Different methods for evaluating public involvement in research
- Innovative ways of evaluating
- Exploration of the different impacts that might emerge from different methods
- Different forms of evidence
- Definitions of evidence and impact
- Different methods for different interventions
- Capturing the time it takes for impact to take place
- How do we measure evidence and can it be done robustly
- Need for qualitative and quantitative research
- Critical discussion and guidance to move the debate forward
- Development of routine measurements for public involvement in research eg with databases, publishers, authors
- Impact of public involvement in research dissemination
- User valued outcome measures generated by service users

Pluralistic evaluation was suggested as an approach that might be relevant – it starts from the assumption that different players have different goals and may not all be trying to achieve the same thing. Overt acknowledgement that there are different values and guides in public involvement in research.

It was considered that there was a need for methodological research so that appropriate methods are developed both to identify, capture and describe the impacts of Patient and Public Involvement (PPI) in Research and for routine use in a range of studies of various designs so that PPI can be routinely measured and reported.

The programme would also need to include the following:

Primary research

Implications for policy

Consideration of the audience for this work – for whom do we need evidence?
Funders, commissioners, research community, members of the public

Economic evaluation and capacity building

Evaluators of the future – how to evaluate better

Action: Helen to circulate ideas discussed at the meeting to members of the working group by email. This would allow for further comment prior to discussion at the Chairs meeting on 3rd April 2008.

9. Information exchange

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

- Public involvement will have a high profile at the 2009 Royal College of Nursing (RCN) International Research Conference (24-27th March 2009 in Cardiff)
- Patient and public involvement has been included in the new RCN Strategic Plan
- The National Prevention Research Initiative (NPRI) has just completed reviewing the second phase of funding applications. Members of the public were involved in the selection process and made an outstanding contribution.
- The Service User Research Enterprise at the Institute of Psychiatry has been awarded funding to research user valued outcomes, service users will be involved in developing the methods.
- Macmillan Cancer Support are going to be advertising a third annual funding for research with public involvement to delegates at the National Cancer Research Institute (NCRI) conference. Four full research applications were received from the last conference and are currently being peer reviewed.
- Macmillan Cancer Support are currently working on developing critical appraisal guidelines for measuring patient and public involvement (PPI).
- National Centre for Involvement is undertaking a review of public involvement in health and social care in the next year. Their research agenda will also focus on Local Involvement Networks (LINKs) and PPI

in commissioning of services. Phase One of a scoping exercise of PPI in NHS Trusts across England is available on the website <http://www.nhscentreforinvolvement.nhs.uk/index.cfm?content=80&Menu=31>

- The ESRC Research Methods Festival is to be held 30th June – 3rd July in Oxford. <http://www.ncrm.ac.uk/RMF2008/festival/index.php> There are sessions on user involvement on Tuesday 1st and Thursday 3rd July 2008.

10. Any other business

a. Another organisation called “Involve”

Concern was expressed that the other organisation called Involve was increasingly engaging in similar activities and that this was becoming confusing for people.

Action: It was agreed that Sophie would raise this in the main Group meeting in the afternoon.

b. Methodology programme

Working group members were advised that Peter Sneddon from the Department of Health had contacted the Support Unit asking for suggestions for research topics for the methodology research programme to consider. The closing date to responding to this request was Friday 14th March 2008.

Action: Support Unit to circulate information about the request to working group members so they could comment and contribute to the response by email.

c. Monitoring public involvement in research with the Research for Patient Benefit Programme

Working group members were advised that the Research for Patient Benefit Programme has asked us to work with them monitoring the information completed in their forms around public involvement in research. There is useful information on a number of different levels from monitoring over time the number of projects funded who are involving the public to more in depth information. This is an area that the Support Unit would do some initial scoping work on to look at the work involved and then decisions would need to be made about any additional funds required to take this forward.

Date of next meeting: Tuesday 3rd June 2008
