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# INVOLVE

## Minutes of the Evidence, Knowledge and Learning Working Group Meeting

Tuesday 09 October 2007

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**Present:** Louca-Mai Brady, Jim Elliott, Helen Hayes, Diana Rose, Sophie Staniszewska (Chair), Maryrose Tarpey, Michael Turner

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

**Apologies:** these were received from Peter Beresford, Alison Faulkner, Ray Fitzpatrick, Vanessa Pinfold, John Sitzia and Tracey Williamson.

**Conflict of interest:** Jim Elliott outlined work that Macmillan Cancer Support had commissioned around the impact of public involvement in cancer on the individual and a second piece of work with the NHS Centre for Involvement on the impact on organisations and the commissioning of services.

#### **Thank you and welcome:**

Sophie thanked John Sitzia for standing in as Chair during her maternity leave which was greatly appreciated. She warmly welcomed the following new members of Evidence, Knowledge and Learning to their first meeting of the working group and invited them to introduce themselves.

- Louca-Mai Brady, Senior Research Advisor, National Children's Bureau
  - Jim Elliott, Head of Research, Macmillan Cancer Support
  - Diana Rose, Co-Director Service User Research Enterprise, Institute of Psychiatry, Kings College London
  - Michael Turner, Service User Researcher
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### 2. Notes of meeting held on 14 June 2007

These were agreed.

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### **3. Matters arising**

#### **Members**

During introductions of new members the following points were raised by members around their interests, concerns and experiences of public involvement in research:

- The reluctance of some organisations to fund public involvement in research without evidence that it makes a difference.
- Suggestion that a debate could be initiated around UK Clinical Research Collaboration (UKCRC) members paying a levy to support and facilitate public involvement in research. This would be timely as the UKCRC will be seeking views on their strategy for patient and public involvement.
- Importance of influencing research databases, journals and librarians about public involvement in research. To help develop a consistency of terminology, key wording and search terms.
- Importance of influencing journal editors on public involvement in research and initiating discussions around the publication of articles with or on public involvement in research
- Explore the experience of submitting articles on or with public involvement in research to journals and write up the findings.
- The importance of the development of an evidence base and the bringing together of people who are interested in this area to ensure that the work is carried forward and not duplicated

#### **Action:**

**Support Unit to initiate and circulate a list, for members to contribute to, of work that they are aware of around developing an evidence base for public involvement in research.**

**Support Unit to raise suggestion of a levy to support and facilitate public involvement in research with Simon Denegri (Chair of the patient and public involvement strategy group) and Philippa Yeeles.**

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### **4. Budget 2007/2008 (for information) – annex E**

This was noted.

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## **5. Operational Plan 2007/2008**

### **a) invoNET**

It was noted that the date of the next invoNET annual event is Wednesday 13<sup>th</sup> 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.

The recently updated invoNET library <http://www.invo.org.uk/Library.asp> contains 85 references on articles that cover:

- the impact of public involvement on research
- the nature and extent of public involvement in research e.g. mapping public involvement
- reflections on public involvement in research

Hard copies of Volume One of the invoNET bibliography containing the 85 references and abstracts have been produced, please contact Helen Hayes at the Support Unit if you would like a copy.

### **b) Dissemination of publications**

The working group were interested to hear that Strategic Alliances are commissioning a small piece of consultancy work to assist in developing a communication strategy for INVOLVE and also practical outcomes to take forward.

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

The Terms of Reference for the Research Advisory Group were noted.

The working group welcomed Jon Hyslop who had joined the Support Unit on 17<sup>th</sup> September 2007 to take forward the Evidence, Knowledge and Learning project to review, reflect and analyse the literature on the nature, extent and impact of public involvement in research.

Peter Beresford and Alison Faulkner are joint Chairs of the Research Project Advisory Group and John Sitzia, Sophie Staniszewska, Helen Hayes and Maryrose Tarpey members of the advisory group. The first meeting is on 6<sup>th</sup> November 2007.

The working group looked forward to receiving regular updates about the work Jon is carrying out. Jon will present his work at future working group meetings.

It was noted that Empowerment and Strategic Alliances are both funding pieces of work this year to identify examples of good practice, Empowerment in user controlled research and Strategic Alliances in social care research.

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

Jane Royle will report back to the December working group meeting on recent discussions and developments on public involvement with the National Institute for Health Research (NIHR) programmes.

INVOLVE is 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.

Further information on the development of the work will be available at the December 2007 working group meeting.

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**6. 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 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 2007/08 and 2008/09 at £35,000 per annum.

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**7. Priorities for 2008 - 2009**

The working group was asked to look at the Strategic Plan as a preliminary to the Awayday and prioritise strategic questions to be addressed over the next 18 months. It was requested that these are **broad priorities** rather than specific activities or solutions and that they **relate** to the seven strategies.

Following discussion the following broad priorities were suggested:

1. Influencing policy:

- Need for development of an evidence base with clear evidence of the difference public involvement makes and what works
- Need for evaluation
- Mapping of public involvement in research
- Include other funders of research especially in social care

2. Facilitating public involvement in research through:
  - Focus on influencing editors/journals
  - resourcing development of public involvement e.g. funding for developing research protocols and for user controlled organisations to develop research bids
  - training about public involvement in research for service users and researchers
3. Improving understanding of the extent, nature and effects of public involvement in research
  - recognised as a key issue for INVOLVE
  - influence sceptics
  - developing the evidence base – document existing knowledge and find new knowledge
  - look for where there is less evidence and information on specific groups as well as generic information
4. Further understanding of public involvement in research
  - encourage people who do actively involve the public in research to become 'champions' and encourage others
  - use of stories and narratives of people involved in research
  - use and make the most of the media
  - development of 'champions' for specific audiences
5. Practicalities of involvement
  - the importance of understanding the research environment
6. Role of INVOLVE as a conduit of expertise:
  - good practice guidance and examples
  - communications – a far reaching voice needs to be developed by INVOLVE
  - influence of INVOLVE on Department of Health and other Government Departments and Research Councils
7. Regular review of processes:
  - developing links with other similar organisations at an international level
  - develop weblinks via INVOLVE website

Following discussion three priorities were agreed to put forward for the Awayday discussions the following day:

1. Developing the evidence base
  2. Applying the evidence
  3. Building relationships and communication
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## **8. Working group members Information Exchange**

Jim Elliott outlined details of the second research grant scheme that Macmillan Cancer Support had held in October at the National Cancer Research Institute (NCRI) Conference. This year two grants of £60,000 each had been offered to conference delegates for outline research proposals that had been developed collaboratively and signed off by a member of the NCRI Consumer Liaison Group. 12 proposals had been received and it was anticipated that 6 would be shortlisted and full proposals requested. These would then be sent for peer review by both scientists and patients. The projects funded last year are currently underway.

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## **9. Any other business**

Congratulations to Tracey Williamson and welcome to her daughter Elena Sophie Green who was born on Monday July 23<sup>rd</sup> 2007.

Date of next meeting: Thursday 13<sup>th</sup> December 2007.

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