



igniting our potential

Activities Log

Developing an evidence base for patient & public involvement in research

There are a growing number of individuals, teams and organisations that are working towards increasing knowledge and understanding of patient and public involvement in research – developing an evidence base for patient and public involvement.

The Patient & Public Involvement Project Group of the UK Clinical Research Collaboration is particularly interested in identifying **current projects/activities that are in some way researching, evaluating or reflecting on the impact of patient and public involvement in research.** The Group wants to both capture and share information about these projects through an openly accessible resource (a database) that facilitates knowledge sharing and better coordination of current activities in this field.

The Activities Log will:

- **Provide brief information about the broad range of current activities that are in some way researching, evaluating or reflecting on the impact of patient and public involvement in research.**
- **Encourage knowledge sharing by providing contact information for each activity**
- **Be regularly updated to amend existing entries and include new activities**
- **Be available via the UK Clinical Research Collaboration web site and regularly shared with contributors**

The Activities Log aims to complement the work of:

- **invonet** (www.invo.org.uk/invonet) which holds a library of references to articles or reports where the primary focus is a research analysis or reflective analysis of public involvement in NHS, public health or social care research.
- the **NHS Centre for Involvement** (<http://www.nhscentreforinvolvement.nhs.uk/>) one of whose aims is to map and review existing evidence about patient and public involvement and identify knowledge gaps.

If you know of an on-going project to add to the Activities Log or if you would like more information about the Log, please turn to the end of this document for contact details.

Title of activity:

**Evaluating the impact of public involvement in health research:
An international perspective**

Type of activity:

(E.g. research project, regular group meeting, single event, discussion forum)

Research project

Summary:

(Brief description of the activity – approx. 250 words)

Public involvement is said to improve both the quality and relevance of health and social research, yet there is little information about the specific impact of public involvement on the process of research, on research outcomes and on researchers and members of the public. This raises questions about whether it is feasible to evaluate the impact of public involvement in health and social research. Can it be done? This study is being undertaken to see if agreement can be reached, among an international panel of experts who have knowledge and/or experience of public involvement in research, on whether the impact of public involvement can be evaluated.

A two-round Delphi process, together with follow-up telephone interviews with a sub-sample of Delphi participants, is being carried out.

Lead contact

(Please provide contact details for further information)

Name: Rosemary Barber

Job title: Consultant Clinical Psychologist/Honorary Senior Research Fellow

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Schedule:

(Where known, please provide key milestones)

Near the end of the Round 1 Delphi process

Intended Outcome:

(What effect is the activity intended to have?)

The findings from this study will provide information on aspects of public involvement that might be evaluated, and how this can be achieved.

Funding source:

(How has this project been funded?)

Sheffield Health and Social Research Consortium

Title of activity:

Evaluating the impact of consumer involvement in Primary Care Research

Type of activity:

(E.g. research project, regular group meeting, single event, discussion forum)

Developmental Evaluation

Summary:

(Brief description of the activity – approx. 250 words)

Nottingham Primary Care Research Partnership was keen to involve consumers in the research they undertake. Mindful of the limited evidence base about the impact consumer involvement has on the outcomes of research a developmental evaluation is taking place alongside the development of consumer involvement. Key aspects of the developmental evaluation approach are that it recognises different stakeholders' perspectives and has an immediate practical focus; emerging findings are fed back thus allowing for change and improvement as issues arise.

The evaluation is being undertaken by a research active service user. We are using a variety of methods to collect the information. Consumers and professionals are asked to complete feedback sheets after each meeting, e.g., what contributions were made by consumers, what changes were made in response to their suggestions, any training needs identified. The evaluator observes meetings and training sessions and notes communications styles of attendees and active participation of consumers. She is also conducting telephone interviews with consumers and professionals to identify what is working well and not so well.

Lead contact:

(Please provide contact details for further information)

Name: Jane Stewart

Job title: Research Fellow/Lead for Public Involvement in Research

Organisation: Nottingham Primary Care Research Partnership (hosted by Nottinghamshire County Teaching PCT)

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Schedule:

(Where known, please provide key milestones)

Data collection was completed in September 2007 and reports are being prepared for dissemination and publication.

Intended Outcome:

(What effect is the activity intended to have?)

Provide practical example of developing consumer involvement in research including a report of facilitators and barriers to successful consumer involvement.

Funding source:

(How has this project been funded?)

Funded by a Trent RDSU research capacity building award.

Title of activity:

Identifying the impact of service user involvement on the lives of people affected by cancer

Type of activity:

(E.g. research project, regular group meeting, single event, discussion forum)

Research project

Summary:

(Brief description of the activity – approx. 250 words)

Service user involvement has been advancing in the area of cancer and palliative care services and research, but there has been very little attention paid to the effect involvement has on those service users who become involved.

What has been researched so far has been more about the impact of involvement on services and/or research. This is important but it has told us little about the impact of being involved on service users themselves.

We aim to establish the:

- Key factors that attract service users to become involved and stay involved
- Key factors that make involvement difficult for service users

Focus groups and interviews are being held with groups and individuals in each of three settings of involvement, cancer care, palliative care and research in cancer and palliative care.

Lead contact

(Please provide contact details for further information)

Name: Phil Cotterell

Job title: Research Fellow

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Schedule:

(Where known, please provide key milestones)

2007-2008

Intended Outcome:

(What effect is the activity intended to have?)

In addition to an end of project report and based upon the research findings, indicators regarding how to maximise involvement and increase recruitment to user/research steering groups will be produced.

Funding source:

(How has this project been funded?)

Macmillan Cancer Support

Title of activity:

INVOLVE research project

Type of activity:

(E.g. research project, regular group meeting, single event, discussion forum)

Research project

Summary:

(Brief description of the activity – approx. 250 words)

This research project will develop the evidence base on the nature, extent and impact of active public involvement in research. It aims to:

- demonstrate the benefits and value of public involvement in research
- understand the best approaches to public involvement in research
- reflect and learn from the evidence

The work follows a preliminary piece of work commissioned by INVOLVE to collate existing research undertaken in this area. The work was undertaken by TwoCan associates and is available on the invoNET library area through the INVOLVE website (<http://www.invo.org.uk/Library.asp>). It includes details of 85 reports and articles.

Lead contact

(Please provide contact details for further information)

Name: Maryrose Tarpey
Job title: Public Involvement Adviser
Organisation: INVOLVE Support Unit
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Schedule:

(Where known, please provide key milestones)

Sept 2007 - February 2008 Phase One:

- Literature review, add new references and abstracts to the invoNET library database
- Reflect and analyse the current literature and new work identified
- Present at invoNET event in February 2008

March - November 2008 Phase Two and Three to be agreed following discussions with Evidence Knowledge and Learning Research Advisory Group.

Intended Outcome:

(What effect is the activity intended to have?)

To disseminate more widely research on the evidence base about public involvement in research.

Funding source:

(How has this project been funded?)

INVOLVE Evidence Knowledge and Learning Working Group

Title of activity:

James Lind Alliance (JLA) - A description of research priority setting (and the presence of Patient and Public Involvement in priority setting) amongst the main UK clinical research funders.

Type of activity:

(E.g. research project, regular group meeting, single event, discussion forum)

Mapping project

Summary:

(Brief description of the activity – approx. 250 words)

The aim of this project is to carry out a preliminary scoping exercise to find out how clinical research bodies set their priorities and whether and how patients and the public are involved in this work.

A rapid appraisal of the key publications on research priority setting (including those identified in the brief and any new papers listed on the invoNET library). We will also look for further examples of patient and public involvement (PPI) in research priority setting within the UKCRC Activities Log and liaise with the UKCRC PPI Project Group to check whether any similar work is taking place.

Initial mapping of priority setting processes, using interviews - interim report

Detailed mapping of priority setting processes, using interviews with:

- an example of an organisation where PPI in priority setting is working well
- an example of an organisation where there is currently no PPI in priority setting
- organisations which have expressed an interest in exploring how JLA priorities could feed into decision-making during the interviews in Stage 3
- organisations who are very influential in terms of research budgets and political leverage
- organisations that represent 'typical' models of decision-making processes so that the general lessons are more likely to be widely applicable - final report

Lead contact:

(Please provide contact details for further information)

Name: Sally Crowe

Job title: Chair of Monitoring and Implementation Group

Organisation: James Lind Alliance

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Schedule:

(Where known, please provide key milestones)

Start in October 2007

Stage 1: Initial preparation

Stage 2: Literature review

Stage 3: Initial mapping of priority setting processes within different research funding bodies

Stage 4: Detailed mapping of selected funding bodies

Stage 5: Final report

Complete in April 2008

Intended Outcome:

(What effect is the activity intended to have?)

The James Lind Alliance is funding this work as it will help them to:

- Make informed decisions about how best to work with research funders and know when they can add value to decision-making
- Know how best to present 'worked up' shared clinical and patient priorities in treatment uncertainties to research funders
- Strengthen their relationship with research funders and extend their networks
- Add to the evidence base of PPI in research priority setting

Funding source:

(How has this project been funded?)

From core James Lind Alliance funds (Medical Research Council / Department of Health)

Title of activity:

Modelling Sexual Healthcare for Substance Misusing Women

Type of activity:

(E.g. research project, regular group meeting, single event, discussion forum)

Research project

Summary:

(Brief description of the activity – approx. 250 words)

This is a 2 stage research project.

Stage 1 will collect questionnaire and interview data from substance misusing women about their sexual health care needs and experiences. Stage 2 will model sexual health services for women using stage 1 data, appropriate national guidance and focus groups with stakeholders.

The study will involve service user collaboration and will engage reflective methods to evaluate the contribution of that collaboration to the research methods and findings.

Lead contact:

(Please provide contact details for further information)

Name: Natalie Lambert

Job title: Senior Research Fellow

Organisation: South East Research and Development Support Unit

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Schedule:

(Where known, please provide key milestones)

Project start date: September 2008

Project completion: December 2009

Intended Outcome:

(What effect is the activity intended to have?)

To improve sexual health of substance misusing women by implementation of the model developed in this study. To contribute to the evidence base for public involvement and to identify transferable recruitment and data collection procedures for further research with this, and similar, populations.

Funding source:

(How has this project been funded?)

Research for Patient Benefit Programme

Title of activity:

Public involvement in health research commissioning and funding

Type of activity:

(E.g. research project, regular group meeting, single event, discussion forum)

Single event - follow up with partner organisations

Summary:

(Brief description of the activity – approx. 250 words)

INVOLVE (www.invo.org.uk), the UK Clinical Research Collaboration (www.ukcrc.org), the Association of Medical Research Charities (www.amrc.org.uk) and the James Lind Alliance (www.lindalliance.org) are working together to find out what progress is being made on public involvement in health research commissioning / funding in the UK.

Email sent to the Programmes that are part of the National Institute for Health Research, the Policy Research Programme, the Devolved Nations Research Programmes, Members of the AMRC and Research Councils asking them to complete an online questionnaire in order to find out what their current activities are re. public involvement in research commissioning/funding.

The purpose of requesting information is :

- To provide a snapshot of public involvement across the health research commissioning / funding bodies
- To establish the scope and provide the basis for future development and support to research commissioners and funders
- To share the knowledge and understanding of progress in the UK by producing a report which will provide separate information on what each organisation is doing as well as summarising the nature and extent of public involvement across the different commissioning / funding bodies.

Responses received will be the starting point for further supporting the development of public involvement in research commissioning / funding.

Lead contact

(Please provide contact details for further information)

Name: Maryrose Tarpey

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Schedule:

(Where known, please provide key milestones)

Draft report December 2007

Intended Outcome:

(What effect is the activity intended to have?)

Information for commissioners/funders on public involvement in research

Funding source:

(How has this project been funded?)

INVOLVE

Title of activity:

Systematic review of research reports about patients', clinicians' and researchers' priorities for research: Phase 1 of extending the James Lind Alliance (JLA) Bibliography into a systematic review

Type of activity:

(E.g. research project, regular group meeting, single event, discussion forum)

Research project

Summary:

(Brief description of the activity – approx. 250 words)

This project will consolidate and extend past work building the James Lind Alliance Bibliography.

The JLA has been funded by the Medical Research Council and the Department of Health to foster discussion among patients and clinicians (doctors, nurses, therapists, and others who treat patients) about variations in health care practice and the related unanswered research questions about the effects of care. The JLA assembled an initial bibliography of reports of studies addressing patients' or clinicians' research questions and outcome priorities, some of which also addressed researchers' priorities or research activities. It was not known whether there were other, similar studies that could inform discussions among patients and clinicians, by reporting either their ideas about priorities for new research, or ways in which these priorities might be identified.

This project will extend the current Bibliography with additional efforts to source relevant literature. All reports will be read and analysed by two independent researchers. Furthermore we will identify and categorise the patients' and clinicians' research priorities reported in the literature.

Lead contact

(Please provide contact details for further information)

Name: Dr Ruth Stewart

Job title: Assistant Director

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Schedule:

(Where known, please provide key milestones)

Report completed by end April 2008

Intended Outcome:

(What effect is the activity intended to have?)

This will extend the current James Lind Alliance Bibliography providing a fuller picture of patients' and clinicians' research priorities.

Funding source:

(How has this project been funded?)

By the James Lind Alliance

More about the Activities Log

Process of compiling the Activities Log

Information included in this second version of the Activities Log was collected in late 2007 and early 2008. A copy of the previous version of the Log (March 2007) and an application form were emailed to individuals who have an interest in building evidence, knowledge and learning about the impact of patient and public involvement in research. This included members of invoNET (<http://www.invo.org.uk/invoNET.asp>) and used INVOLVE's email alert system and other formal and informal networks.

Thirteen completed forms were received and eight projects are included in the current version of the Log as they satisfy the criteria of being an on-going project where:

- public involvement in research is itself the subject of study OR
- public involvement in research is taking place and an element of the activity has been to consider the impact of that public involvement

The remaining five projects were all examples of public involvement in research but did not satisfy the above criteria.

Earlier versions of the Activities Log

You can still download the earlier version of the Activities Log from the UK Clinical Research Collaboration's website (<http://www.ukcrc.org/patientsandpublic/currentppiprojects/activitieslog.aspx>). Projects that were previously, but are no longer recorded in the Log, are presumed to have been completed. Hopefully as reports from these completed projects become available they will then become part of the invoNET Library (<http://www.invo.org.uk/Library.asp>).

To submit a project to the Activities Log

If you are involved in, or know of, a project that could be part of the Activities Log please contact Philippa Yeeles at the UK Clinical Research Collaboration:
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For more information

If you would like any more information about the Log please contact Philippa Yeeles at the UK Clinical Research Collaboration.