

# INVOLVE

## **Patient and Public Involvement in Collaborations for Leadership in Applied Health Research & Care (PPIC)**

### **TERMS OF REFERENCE AND WORKING METHODS**

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#### **Purpose**

The PPIC group provides a structured mechanism to facilitate joint working for those involved in developing and supporting public involvement in the research and implementation activities of the nine National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRCs). The PPIC group was formally established in May 2010 by representatives of the nine NIHR CLAHRCs working in collaboration with INVOLVE's Coordinating Centre.

The aims of the Group are:

- To facilitate a shared understanding of public involvement in research and help to develop consistency across the NIHR CLAHRCs
- To identify, discuss and address issues of common concern and avoid unnecessary duplication of effort
- To facilitate access to support and resources that are available from INVOLVE and PPIC group member organisations
- To exchange ideas, strengthen skills and share examples of good practice

#### **Membership**

Membership of the group is open to those who have a lead role in promoting and supporting public involvement in the activities of the nine NIHR CLAHRCs. Each of the CLAHRCs will be represented on the group by a minimum of 1 and a maximum of 3 members. Having patient / public members in this group is essential and is actively encouraged and supported by the CLAHRCs and INVOLVE.

#### **Accountability**

Group members are individually responsible for reporting back on activities of the PPIC group to the Director of their own CLAHRC.

## **Review**

On an annual basis, the group will review the relevance and value of its work.

## **Working methods**

The Group has agreed to adopt a shared learning approach. This involves:

### **Group meetings**

- The Group has agreed to hold three meetings a year in 2011 & 2012
- The Group has agreed to share the location and chairing of meetings amongst the CLAHRCs
- Topics for the agenda will be generated by members of the Group in discussion with the INVOLVE Coordinating Centre
- Meeting papers will be circulated, by email, at least one week in advance of meetings. Paper copies of all documents can be posted out to members and alternative formats can be provided, if requested
- Meetings may include small group discussions to share experiences and learning
- Non members may be invited to join Group meetings on a one-off basis to aid discussion of a particular topic, for example, as speakers, observers or invited guests
- Secretariat for the Group and organisation of meetings will be provided by the INVOLVE Coordinating Centre working with the CLAHRCs

### **Sharing of information and resources (including confidential materials)**

- Through Group meetings and electronic communications members will be able to share information and resources
- It is each member's responsibility to make it clear where a matter shall remain confidential and not for discussion outside the Group
- When sharing documents, members should make it clear if there is a restriction as to:
  - Circulation of the documents beyond the Group
  - Copyright / use of the contents
- In future, should the Group wish to develop a shared web space for its members, the INVOLVE Coordinating Centre can facilitate this

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## Definitions

By '**involvement**' in research and implementation, we mean an active partnership between the public and researchers in the research and implementation process, rather than the use of people as 'subjects' of research and implementation. Active involvement may take the form of consultation, collaboration or user control. Public involvement in research is often defined as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public. The same is true of implementation where the focus is on promoting the uptake of research into routine health and social care practice. This would include, for example, public involvement in advising on a research or implementation project, assisting in the design of a project, or in carrying out the project.

By '**public**' we mean:

- patients and potential patients
- people who provide care or support on an informal (i.e. unpaid) basis
- parents/guardians
- people who use health and social care services
- disabled people
- members of the public and communities who might be targeted by health promotion, public health and social care
- groups asking for research because they believe they have been exposed to potentially harmful substances or products
- organisations that represent people who use health and social care services.

The term '**the public**' is understood to include a rich diversity of people, whether defined by age, colour, race, ethnicity or nationality, disability, gender or sexuality, who may have different needs and concerns.

INVOLVE uses the term 'public involvement' to describe our area of work. We recognise that others will use alternative terms, such as public and patient involvement, user involvement or consumer involvement.

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