

INVOLVE

PUBLIC INVOLVEMENT COLLABORATION GROUP (PICG)

TERMS OF REFERENCE AND WORKING METHODS (Revised May 2010)

Purpose

The Public Involvement Collaboration Group (PICG) was established by INVOLVE in 1999 to provide a forum for those involved in promoting and supporting public involvement in research funding and commissioning in the Department of Health's national NHS R&D programmes.

The aims of the Group are:

- To facilitate a shared understanding of public involvement in research and help to develop consistency across the National Institute for Health Research's research programmes
- 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 other PICG 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 research funding and commissioning within the National Institute for Health Research (NIHR) e.g. NIHR Central Commissioning Facility (NIHR CCF), NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) and the NIHR School of Social Care Research (SSCR). In addition, membership also includes representatives from other organisations that also promote and support public involvement in research funding and commissioning e.g. the Medical Research Council (MRC), the Economic and Social Research Council (ESRC) and the NIHR Clinical Research Networks Coordinating Centre (NIHR CRN CC).

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

- At least three meetings will be held each year, organised and chaired by the INVOLVE Coordinating Centre
- 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 will be provided by the INVOLVE Coordinating Centre

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
- INVOLVE Coordinating Centre will facilitate the development of a web space for members of the Group which will include a secure password-protected area to share resources

Definition of terms

By '**involvement**' in research, we mean an active partnership between the public and researchers in the research process, rather than the use of people as 'subjects' of research. 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. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.

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.

PICG Terms of Reference and Working Methods
Revised and approved May 2010

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