

INVOLVE

Research Design Service Involvement Forum

TERMS OF REFERENCE AND WORKING METHODS

Purpose

The Research Design Service Involvement Forum was established by INVOLVE in 2008. It has been set up to provide a forum for those involved in promoting and supporting public involvement in research (see below for a definition of these terms) in the National Institute for Health Research (NIHR) Research Design Services (RDS).

The Forum aims to:

- To facilitate a shared understanding about public involvement across the RDS
 - To discuss and address issues of common concern in relation to public involvement in RDS
 - To facilitate access to support and resources that are available from INVOLVE and other organisations
 - To exchange ideas, strengthen skills and share examples of good practice to develop public involvement in research
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Membership

Membership of the group is open to those who have a lead role in promoting and supporting public involvement in research in the RDS established in each Strategic Health Authority in 2008 and 2009.

Working methods of the Forum

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

Forum meetings

- At least three meetings will be held each year organised by INVOLVE
- The chair for each meeting will rotate between members of the forum, this will entail:

- Devising the agenda in collaboration with INVOLVE prior to the meeting
- Chairing the forum meeting
- Receiving any feedback from Forum members after each meeting and communicating this to INVOLVE (anonymised where requested)
- Meeting topics will be generated by members of the forum
- Meetings will include small group discussions to share experiences and learning
- Other people may be invited to join forum meetings on a one-off basis to aid discussion of particular topic, for example, as speakers, observers or invited guests
- Secretariat for the Forum will be provided by INVOLVE

Sharing of information and resources

- Through the Forum meetings and electronic communications members will be able to share information and resources
- Members should be able to choose what they share and when they share it
- It is each member's responsibility to make it clear where a matter shall remain entirely confidential and not for discussion outside of the forum
- When sharing documents, members should make it clear if there is a restriction as to:
 - Circulation of the documents beyond the Forum
 - Copyright/use of the contents
- INVOLVE will facilitate the development of a webspace for members of the Forum 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

Template 1 Example 4

- 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, including the RDS will use alternative terms, such as public and patient involvement or consumer involvement.

INVOLVE Coordinating Centre/RDS Involvement Forum

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