

# INVOLVE

## **Patient and public involvement in the National Institute for Health Research (NIHR) Dementia themed call for research – INVOLVE guidance for researchers**

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The National Institute for Health Research (NIHR) issued a call for research on dementia in March 2011 [www.nihr.ac.uk/research/Pages/Dementia.aspx](http://www.nihr.ac.uk/research/Pages/Dementia.aspx).

The NIHR expects the active involvement of patients and the public in the research it supports. NIHR recognise that the nature and extent of active patient and public involvement is likely to vary depending on the context of each study or award.

The term 'involvement' refers to an active partnership between patients, members of the public and researchers in the research process. This can include, for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.

This document provides information on sources of advice and information about public involvement in research that you may find useful if you are considering applying to the NIHR for funding to undertake research as part of the dementia call.

### **Definition of patient and public involvement in research**

The term 'patient and public' includes:

- patients and potential patients;
- people who use health and social care services
- informal (unpaid) carers
- parents/guardians
- disabled people
- members of the public who are potential recipients of health promotion programmes, public health programmes, and social service interventions
- groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos)
- organisations that represent people who use services

The term 'involvement' refers to an active partnership between patients and the public and researchers in the research process, rather than the use of people as 'subjects' of research. Patient and public involvement in research is often defined as doing research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them. This would include, for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.

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## Further information is provided below to signpost applicants to key sources of advice, support and available resources.

These include links to the following organisations:

1. **NIHR Research Design Service** <http://www.ccf.nihr.ac.uk/Pages/RDSMap.aspx> for advice and support on developing research proposals
2. **INVOLVE** [www.invo.org.uk](http://www.invo.org.uk) for information and resources on patient and public involvement in research
3. **DeNDRoN** [www.dendron.org.uk](http://www.dendron.org.uk)  
NIHR Dementias and Neurodegenerative Diseases Research Network facilitates the conduct of research trials in dementias and neurodegenerative diseases
4. **Alzheimer's Society** [www.alzheimers.org.uk](http://www.alzheimers.org.uk)  
The Alzheimer's Society funds research and works in partnership with researchers to develop research projects and improve governance.
5. **James Lind Alliance** [www.lindalliance.org](http://www.lindalliance.org) for information and resources specifically on involvement of patients and clinicians in the identification and prioritisation of research topics and questions

### 1. Advice and support for researchers developing research applications and planning for patient and public involvement

**NIHR Research Design Service (RDS)** [www.rdinfo.org.uk/rds/Network/Index.asp](http://www.rdinfo.org.uk/rds/Network/Index.asp)  
NIHR Research Design Services (RDS) support researchers to develop research proposals for submission to the NIHR and other national, peer-reviewed funding competitions for applied health or social care research. Your local RDS has research experts on-hand to provide advice on all aspects of preparing grant applications. This includes giving advice on patient and public involvement in the development of proposals. All of the RDS have a remit to support PPI within research proposals and advising on appropriate patient public involvement is a core component of this work.

There are ten NIHR Research Design Services:

- East of England [www.rds-eoe.nihr.ac.uk](http://www.rds-eoe.nihr.ac.uk)
- East Midlands [www.rds-eastmidlands.org.uk/](http://www.rds-eastmidlands.org.uk/)
- London [www.rdslondon.co.uk](http://www.rdslondon.co.uk)
- North East [www.dur.ac.uk/school.health/rds/](http://www.dur.ac.uk/school.health/rds/)
- North West [www.rds-nw.nihr.ac.uk](http://www.rds-nw.nihr.ac.uk)
- South Central [www.rds.soton.ac.uk](http://www.rds.soton.ac.uk)
- South East Coast [www.rds-se.nihr.ac.uk](http://www.rds-se.nihr.ac.uk)
- South West [www.rds-sw.nihr.ac.uk](http://www.rds-sw.nihr.ac.uk)

- West Midlands [www.rds-wm.nihr.ac.uk](http://www.rds-wm.nihr.ac.uk)
- Yorkshire and the Humber [www.rds-yh.nihr.ac.uk/](http://www.rds-yh.nihr.ac.uk/)

Your local RDS will be able to support you if you are preparing a research proposal for any of the funding streams that are taking part in the Dementia themed call.

Your local RDS will be able to provide you with advice on the patient and public involvement elements of your proposal to help these meet the requirements of the NIHR funding streams and to promote appropriate well developed PPI to be included in your proposal. Many RDS have databases of local patients and patient groups who may be willing to get involved in your research, and may have contact with patients who would be willing to get involved in your research proposal for the NIHR Dementia call. Your local RDS may also be able to facilitate the involvement of patients and the public in your research. Your local RDS may also be able to provide financial support for involvement in the grant development stage, either through a small bursary or grant scheme or other methods.

Please contact your local RDS to find out more about how they can support you in applying to the NIHR Dementia Call.

**DeNDRoN** [www.dendron.org.uk/cr/writing\\_and](http://www.dendron.org.uk/cr/writing_and) [www.dendron.org.uk/ppi/index.html](http://www.dendron.org.uk/ppi/index.html)

NIHR DeNDRoN and the RDS can both support PPI in the development of new proposals. DeNDRoN's Writing Groups bring together research collaborators to work on writing a multi-centre grant application; these groups can include lay representatives, such as patients or carers of people with dementia. Also, there may arise opportunities within DeNDRoN for patients and carers to attend one-off discussion groups to help develop ideas for research into NHS clinical care for people with dementia.

**Alzheimer's Society** [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Alzheimer's Society has a long standing group of carers, ex-carers and people with dementia engaged in their research programme, all volunteers in the Alzheimer's Society Research Network. The volunteers are provided with training and support to ensure their activities are effective in making all types of dementia research relevant to the people who will eventually benefit. Their website has information about the Network's activities and how to join. The website also has information for researchers who would like to work in partnership with the organisation. You may also contact [researchenquiries@alzheimers.org.uk](mailto:researchenquiries@alzheimers.org.uk).

Alzheimer's Society welcomes approaches from researchers or research teams to work in partnership with them. They may not be able to work with everybody who would like to work with them due to finite capacity but will endeavour to support development of research themes and protocols with carers, ex-carers and people with dementia or staff as appropriate. If you are interested, please fill in and submit a partnership form at: [http://alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1049](http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1049). During the Spring and Summer 2011 the Alzheimer's Society will attempt to hold special sessions to help researchers meet their objectives whilst providing the best hope for better care and treatment for people with dementia in the future.

## 2. Information and resources on patient and public involvement in research

### INVOLVE [www.invo.org.uk](http://www.invo.org.uk)

INVOLVE is a national advisory group funded by the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. INVOLVE produces a range of resources that are available from their website. These include electronic databases and publications providing information on involvement as well as research on patient and public involvement in research.

#### Electronic databases:

- **'Putting it into practice'** is a how to database of articles, reports and guidance on the planning for and development of public involvement in research  
[http://www.invo.org.uk/useful\\_Resources.asp](http://www.invo.org.uk/useful_Resources.asp)
- The **'Research project database'** provides over 200 examples of patient and public involvement in current and completed research projects  
[www.invo.org.uk/Database.asp](http://www.invo.org.uk/Database.asp)
- The **'Evidence library'** is a database of over 150 abstracts of reports and articles on research into public involvement in research. It includes references that cover the nature, extent and impact as well as reflections on public involvement in research  
<http://www.invo.org.uk/Library.asp>

#### Key Publications:

- Involving the public in NHS, public health and social care research: Briefing notes for researchers (Second edition) (Hanley B et al, 2004). [currently being updated]  
<http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf>
- Payment for involvement: A guide for making payments to members of the public actively involved in NHS, public health and social care research (2010)  
<http://www.invo.org.uk/pdfs/PaymentGuideWEB240510.pdf>
- Exploring Impact: Public involvement in NHS, public health and social care research (Staley K, 2010)  
[http://www.invo.org.uk/pdfs/Involve\\_Exploring\\_Impactfinal28.10.09.pdf](http://www.invo.org.uk/pdfs/Involve_Exploring_Impactfinal28.10.09.pdf)
- Public involvement in research grant applications: guidelines for researchers (2006)  
[http://www.invo.org.uk/pdfs/R1research\\_grant\\_applications.pdf](http://www.invo.org.uk/pdfs/R1research_grant_applications.pdf)

### People in Research [www.peopleinresearch.org](http://www.peopleinresearch.org)

People in Research is a website that is hosted by INVOLVE. It provides information for patients and the public about current opportunities for getting actively involved in research. Researchers can use the site to advertise their research and invite patients and the public to get involved.

### **3. Patient and clinician involvement in the identification of research topics and prioritisation of research questions**

#### **James Lind Alliance (JLA) ) [www.lindalliance.org](http://www.lindalliance.org)**

The James Lind Alliance (JLA) aims to bring patients and clinicians together in 'Working Partnerships' to identify and prioritise the unanswered questions that they agree are most important. This information can then be used to ensure that those who fund health research are aware of what matters to patients and clinicians. The JLA receives funding from the NIHR and the Medical Research Council (MRC).

#### **Electronic resource**

The 'JLA Guidebook' is an online resource to enable patients, clinicians or the groups that represent them to ensure that research is grounded in what matters to them jointly.

[www.JLAGuidebook.org](http://www.JLAGuidebook.org).

#### **Publications**

Other JLA publications on identification and prioritisation of research topics and questions are available on [www.lindalliance.org/Publications.asp](http://www.lindalliance.org/Publications.asp)

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