

**ESRC-NIHR Dementia Research Initiative 2018  
Full proposal call (invitation only)**

**Guidance for applicants on involving patients, families and  
carers**

**This invitation-only call is open to applicants who have been invited to submit a full proposal under the ESRC-NIHR Dementia Research Initiative 2018 call. All uninvited or ineligible applications will be rejected.**

Involving members of the public with an understanding of dementia means involving people with dementia, patients and potential patients, carers, family and friends. Patients, families and carers have expertise which comes from their lived experience of dementias. The funders believe that patient and public involvement (PPI) is important in developing research ideas into study proposals, advising on or participating in undertaking the research once underway, and in assessing and reviewing research proposals.

It is expected that proposals under this call will have given due consideration as to how to appropriately involve patients, carers and relevant members of the public in their research proposal.

**Applicants will need to clearly describe their approach and budget for patient and public involvement in an attachment to their proposal. Please refer to the Je-S guidance notes for this call for more information:**

<https://esrc.ukri.org/funding/funding-opportunities/esrc-nihr-dementia-research-initiative-2018/>

Members of the public with experience or understanding of dementia will join academics and wider non-academic users of the research in the assessment process so the funders can get a 'first-hand experience' perspective on the research proposals.

INVOLVE ([www.invo.org.uk](http://www.invo.org.uk)) was established in 1996 and is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. It defines the term 'involvement' as referring to an active involvement between people who use services, carers and researchers, rather than the use of people as participants in research (or as research 'subjects'). Many people describe involvement as doing research with or by people who use services rather than to, about or for them. This could 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, advising on 'best practice' for public involvement throughout the research, and giving their views on the best ways to involve other users and carers in research.

There are a wide range of supporting materials available to draw upon when developing your approach to PPI and organisations that can advise on methods for involving patients and the public.

- **INVOLVE resources for researchers** ([www.invo.org.uk/resource-centre/resource-for-researchers](http://www.invo.org.uk/resource-centre/resource-for-researchers))

An online resource of 10 briefing notes on how to involve members of the public in research, including supplements with detailed information on public involvement in specific types of research and on specific involvement activities, case studies and templates.
- **INVOLVE putting it into practice database** (<http://www.invo.org.uk/resource-centre/putting-it-into-practice-database>)

A library of useful information on how to involve. It includes published guidance on good practice, reports of the lessons learnt from direct experiences of involvement and descriptions of involvement in research projects.
- **INVOLVE payment and recognition for public involvement** (<http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement>)

This page links to guides and practical advice on payment and non-monetary methods for recognising the time, skills and expertise provided by members of the public.
- **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.
- **INVOLVE guidance on patient and public involvement in research and the requirements of research ethics review** (<http://www.invo.org.uk/posttypepublication/public-involvement-in-research-and-research-ethics-committee-review/>)
- **NIHR Research Design Services** (<https://www.nihr.ac.uk/about-us/how-we-are-managed/our-structure/research/research-design-service/how-we-can-help/>)

NIHR's Research Design Services (RDS) provides support for health and social care researchers to develop and design patient-focused research proposals for submission to NIHR and other national, peer-reviewed competitions. This includes providing advice on the patient and public involvement elements of your proposal. The national RDS network operates from ten regional centres across England which can be contacted directly for support
- **Dementias Portfolio Development Group** (<https://www.nihr.ac.uk/research-and-impact/research-priorities/dementias-portfolio-development-group.htm>)

  - Portfolio Development Groups (PDGs) provide advice and support for researchers working together to submit grant proposals for clinical studies. The Dementias PDG offers support of Writing Groups – comprised of researchers who wish to collaborate to take a research idea into a

submitted grant proposal. The PDG includes three lay members who are able to be members of Writing Groups and give Public and Patient Involvement advice on grant proposals. If you are interested in receiving support from the Dementias PDG, please complete the following form: <https://goo.gl/forms/VTXWKf5q9WYNfg9il>

- If you have any queries, please contact the Dementia PDG at [admin.nddr@nhr.ac.uk](mailto:admin.nddr@nhr.ac.uk)

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

Alzheimer's Society has a longstanding 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.

The charity welcomes approaches from researchers or research teams to work in partnership with them. They are open to discussions as to how any individual partnership will work, but previous partnerships have included: lay co-applicants; lay advisory groups; facilitation of focus groups; lay consultations on research materials to support ethics applications; staff expertise as a co-applicant; assistance with recruitment; dissemination through printed and online media; and letters of support. They will endeavour, as capacity allows, to support the development of research themes and protocols through engagement with the Research Network volunteers or staff, where appropriate. If you are interested, contact [researchpartnerships@alzheimers.org.uk](mailto:researchpartnerships@alzheimers.org.uk) to book an initial discussion with a member of the research team or fill in and submit a partnership form available on their research partnerships page: [www.alzheimers.org.uk/researchpartnerships](http://www.alzheimers.org.uk/researchpartnerships)

### More resources

- Involving people for applicants from Wales  
<https://www.healthandcareresearch.gov.wales/researcher-request-for-public-involvement-support/>
- Involving people for applicants from Northern Ireland  
[www.research.hscni.net/personal-and-public-involvement-researchers](http://www.research.hscni.net/personal-and-public-involvement-researchers)
- Involving people for applicants from Scotland  
<https://www.edinburghcrf.ed.ac.uk/Patient-Involvement>