

Zone 1

Patients making a difference

The development of new and better treatments would not be possible without patients and the public taking part in research. The NIHR has created a research system that is more inclusive and representative of the population than any other across the world.

Over 618,000 participants have taken part in NIHR supported or funded studies in 2014/2015.

Involving patients and the public

The NIHR is committed to the active involvement of the public in NHS, public health and social care research. **INVOLVE**, the NIHR's national advisory group which makes this happen is one of the few government-funded programmes of its kind in the world.

Members of the public advise on our research, helping to identify and prioritise topics, assess funding proposals, carry out and disseminate the findings. This involvement ensures that what we do reflects patient needs and views, and adds immeasurable value to the quality of NHS, public health and social care research.

Our work with the **James Lind Alliance (JLA) Priority Setting Partnerships (PSPs)** brings patients, carers, clinicians and medical research charities together to identify and prioritise the treatment uncertainties which they agree are the most important for research.

In order to involve young people in research the **NIHR's Clinical Research Network (CRN) initiated GenerationR** so young people can provide their views on the design and delivery of paediatric research in the UK and internationally.

Making research part of good quality care in the NHS

A recent survey conducted by the CRN showed that 95% of people surveyed said it was important to them that the NHS carries out clinical research but less than 21% said they would feel very confident about asking their doctor about research opportunities.

The NIHR's **'OK to Ask'** national campaign encourages patients and carers to ask about research opportunities that could be available to them or their family. Patients receiving care in NHS facilities that support research experience better outcomes¹.

Our network of **Patient Research Ambassadors** are patients, carers or service users who are volunteering 'front-of-house' in hospitals up and down the country to promote health research to other NHS patients and health professionals.

1. Ozdemir, B et al. *Research Activity and the Association with Mortality*. PLoS One. 2015 Feb 26;10(2): e0118253. doi: 10.1371/



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Providing greater access to taking part in research

The NIHR wants as many people as possible to take part in clinical research as this is the way we find out which interventions and treatments work best and have the potential to improve care.

The **UK Clinical Trials Gateway (UKCTG)** is designed to enable patients and clinicians to find out about clinical trials that may be of interest to them and we are currently redeveloping it so that soon people will be able to put their name forward to be contacted about taking part in research. Just as we have already done in dementia.

Dementia is one of the biggest challenges we face today. The number of people with Alzheimer's disease, vascular dementia, and other types of dementia, is set to double over the next 30 years.

At **Join Dementia Research (JDR)** members of the public can register their interest in participating in dementia research.

"It's really important that as members of the public we are there to ask questions such as: 'Yes that's really exciting, but what benefit is it going to have for patients?' It's important to make sure that patients are part of the journey."

Member of the public

Answering those questions also requires our work and its results to be available to all. For instance, 98% of the research funded by our HTA programme is published openly and can be accessed by the public. More than any other funder².

2. Collins, Ellen. *Publishing priorities of biomedical research funders*, Ellen Collins, BMJ Open. 2013; 3(10): e004171.

In our research programmes alone more than

110

members of the public were involved in our funding panels and committees

Over the last five years more than

3,000,000 people

have participated in research supported by the CRN

1,000

patients and members of the public were actively involved in our work

The CRN supported delivery of

1,869 new studies

with **623** of these from the life sciences industry

More than **700**

research applications received by the NIHR were reviewed by members of the public

98% of NHS Trusts and 41% of General Medical Practices

were actively engaged in clinical research.

FURTHER INFORMATION

INVOLVE <http://www.involve.nihr.ac.uk>

NIHR Clinical Research Network <https://www.crn.nihr.ac.uk/>

James Lind Alliance <http://www.jla.nihr.ac.uk/>

The Palliative and end of life care Priority Setting Partnership <http://bit.ly/1ICctum>

Generation R <http://generationr.org.uk/>

Join Dementia Research <https://www.joindementiaresearch.nihr.ac.uk/>

UK Clinical Trials Gateway <http://www.ukctg.nihr.ac.uk/>

Research changed my life: <http://bit.ly/1TUpe38>