

NIHR leadership in public involvement in UK health research

- Core principle of National Institute for Health Research (NIHR)
- Leadership from the top
- A solid platform on which to build
- Clear expectation set with NIHR-funded researchers
- Models and approaches built on ‘partnership’
- Support including £M investment



“I have always taken the view that public involvement in research should be the rule not the exception.”

*Professor Dame Sally Davies
Chief Medical Officer (CMO)*

What is INVOLVE?

What we aspire to:

A dynamic partnership between the public, researchers and others, to advance NHS, public health and social care research and improve the health and well being of the population

Established in 1996 INVOLVE is a national advisory group funded by, and part of, the National Institute for Health Research. <http://www.invo.org.uk/>

How we do it?

- Leadership across NIHR
- Build and share the evidence base
- Develop capacity and capability
- Influence policy and practice

INVOLVE



A working definition of public involvement

INVOLVE defines public involvement in research as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them.

This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.

Making research relevant

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WHAT QUESTIONS SHOULD PARKINSON'S RESEARCH ANSWER?

We're asking people affected by *Parkinson's* and health and social care professionals to help us identify the top 10 unanswered questions they want Parkinson's research to address.

We need the input of people who have direct and personal experience of Parkinson's to make sure we are addressing the most urgent needs.

Complete the survey now

Your survey responses will help to guide Parkinson's research.

And we'll use the responses to make sure researchers address the things that will make a real difference to people living with Parkinson's.

“ Tell us the questions you'd like to see answered by Parkinson's research - we need your input now!”

<http://www.netscc.ac.uk/news/item/08042013.asp>

Increasing effectiveness and efficiency

‘The aim of patient and public involvement is to improve the quality, feasibility and translational value of research...[This] is the first time we can see that patient involvement is linked to higher likelihood of reaching recruitment target – and as a result, study success.’

Professor Til Wykes, Director, MHRN

‘Patient involvement in research boosts success,’
The Guardian, 16/09/13

Paper reference: Ennis, L. et al. ‘Impact of patient involvement in mental health research: longitudinal study’ *British Journal of Psychiatry* (Sept 2013) [doi: 10.1192/bjp.bp.112.119818](https://doi.org/10.1192/bjp.bp.112.119818)



Building research communities: young people in research

Young people help researchers to "get real"

Clinical research is evolving. Increasingly, there is pressure on the research community to ensure that treatments are relevant and effective in daily life. This is driving more researchers to seek the input of service users in the development of their work, which is leading to a transformation of the cultural and regulatory environment for children's research.



▲The Young Persons' Advisory Group is growing in size and influence

The NIHR Medicines for Children Research Network (MCRN) has been at the forefront of patient and public involvement in research for some time. In 2006, the Network started its first Young Persons' Advisory Group in Liverpool. Since then, four more groups have been established in London, Nottingham, Birmingham and Bristol.

The initial remit of these groups was straight forward: to engage young people with research and to work in partnership with, and offer support to, researchers. Jenny Newman, NIHR Medicines for Children Research Network Consumer Liaison Manager, explains how this role has evolved:

"We set up the group to provide a forum for young people to learn about, and comment on, various aspects of the research cycle from the identification of research questions to the dissemination of research findings. We are now working with national governing bodies and helping to remodel the guidance they provide to researchers to

help them design and deliver ethically robust research for children, as well as support researchers in the design and deliverability of their studies."

"Young people... want to know what the study will mean to them."

Parents are able to consent for children to take part in clinical research if they are under 16 years of age. But researchers have to gain the assent of children too, which is why they receive guidance on how to produce materials to help young people understand a study.

The National Research Ethics Service (NRES) is responsible for producing this guidance. When they decided to review their materials, NRES approached the Medicines for Children Research Network about working with the Young Persons' Advisory Group:

"We conduct training for researchers in the area of ethics guidance and over the last five years the MCRN's Young Persons' Advisory Group has become an important part of our meetings", explains Dr Hugh Davies, consultant paediatrician and Research Ethics Advisor at NRES. "As a result, we wanted their input in our guidance review, which has led to a major statement of how we should approach children."

Group members felt that NRES guidance was producing study materials that failed to meet their needs. Holly Landon is 18 years old, and a member of the Liverpool Young Persons' Advisory group:

"A lot of the materials we see are highly formulaic. They are clearly designed to tick legal and governmental boxes, but they



workshop with the Young Persons' Advisory Group to determine whether the research question she was proposing was valid. She feels that, in an increasingly competitive environment, this input can prove vital:

"It's powerful that the people experiencing a diagnostic device have helped to shape it. Their involvement makes a study more competitive because it provides us with perspectives that we can't find anywhere else. It makes the product more likely to succeed and helps us avoid the development of expensive products that children do not want to use."

Dr Davies agrees that involving children at the beginning of the research process is crucial:

"The research community is concentrating on studies that are relevant and shaping the right question is key to this. The opportunity for genuine influence is limited, which is why it needs to be embedded in the early stages of research development."

With the paediatric research community increasingly focusing on the real-world relevance of research, the influence and impact of the Young Persons' Advisory Group is set to grow. In September this year it is holding its first national event for the life-sciences industry in which a wider range of organisations will gain an insight into how young people and families can have a positive impact on the development of clinical research.

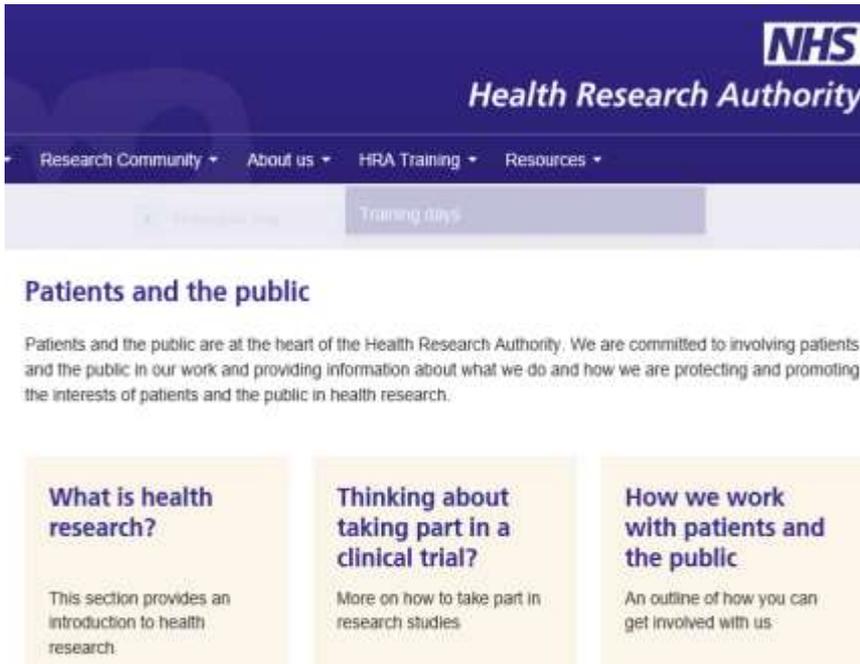
www.mcrn.org.uk



Watch a Young Persons' Advisory Group member's video diary by visiting www.mcrn.nhs.ac.uk/researchpeople

researchers need to make a distinction between child and adult studies. Paediatric studies need to stand alone."

Regulatory environment



The screenshot shows the NHS Health Research Authority website. The header includes the NHS logo and the text 'Health Research Authority'. Below the header is a navigation menu with links for 'Research Community', 'About us', 'HRA Training', and 'Resources'. A search bar is visible with the text 'Training days' entered. The main content area is titled 'Patients and the public' and contains a paragraph stating: 'Patients and the public are at the heart of the Health Research Authority. We are committed to involving patients and the public in our work and providing information about what we do and how we are protecting and promoting the interests of patients and the public in health research.' Below this paragraph are three columns of content:

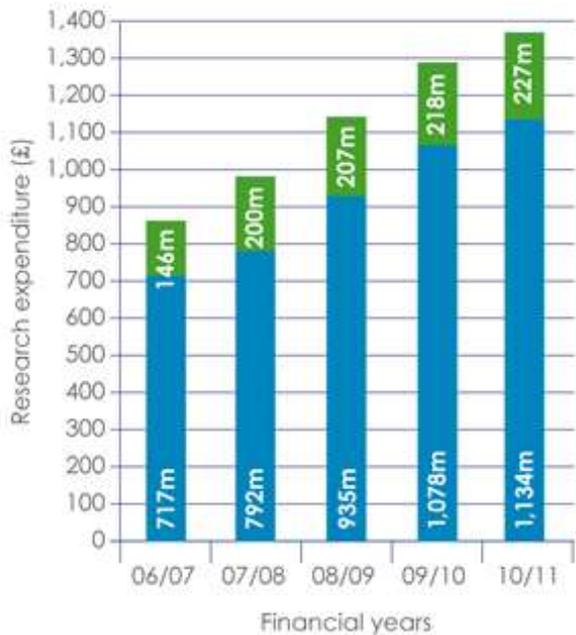
- What is health research?**
This section provides an introduction to health research.
- Thinking about taking part in a clinical trial?**
More on how to take part in research studies.
- How we work with patients and the public**
An outline of how you can get involved with us.

- 77% of people said that knowing a Research Ethics Committee had reviewed a study would increase their confidence in it.
- 44% of respondents thought that involving patients....would increase their confidence in the study.

Ipsos MORI study for HRA: 2013

<http://www.hra.nhs.uk/news/2013/11/22/patient-involvement-increases-public-confidence-health-research/#sthash.x3fCMNWj.dpuf>

amrc

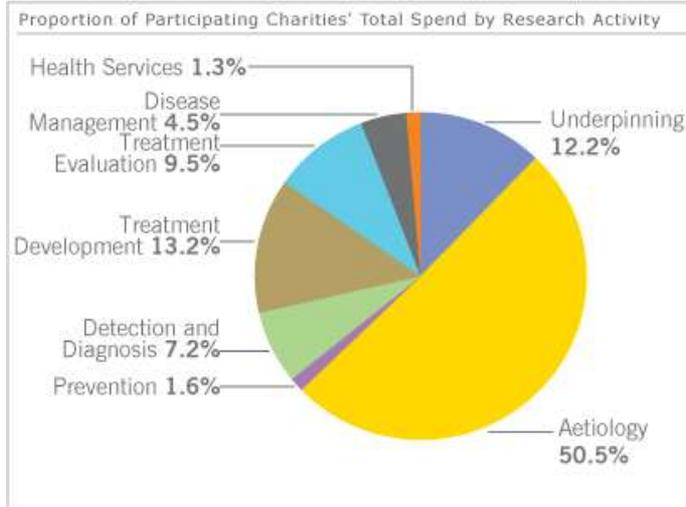


- amount spent by AMRC member charities on research in UK, not including capital expenditure
- amount via CRSF in England and equivalents in Scotland, Wales and Northern Ireland

Spend by area

Type of research	Spend by AMRC members
General research	39.3%
Cancer	33.1%
Cardiovascular	14.3%
Neurology	3.8%
Rheumatic disease	3.4%
Infectious disease	1.9%
Metabolic disease	1.1%
Respiratory	0.9%
GI, liver, kidney, uro-genital	0.6%
Sensory	0.5%
Obs/gynaecological	0.4%
Mental health	0.4%
Skin disease	0.3%

Data from AMRC grants database 2007/08



Future strategy development: evolution and revolution



NIHR Strategic Review of Public Involvement: Emerging themes

1. Value of public involvement
2. Quality and standards
3. Consistency and co-ordination
4. Evidence into practice: how to spread embed effective, purposeful practice?
5. Support, relationships, incentives that empower individuals and communities

What should public involvement look like in 10 years?

Some clear messages from the community:

- Public involvement is **normal** and accepted practice
- **Enhanced evidence** base with better consensus on value of public involvement
- **Definitions** of quality in public involvement
- **Agreed methods** and indicators of impact
- Greater **public awareness** of research and NIHR
- **Global leadership** in scholarship and the study of public involvement in research

A more user-driven health research system

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How you can get involved

Young people and research

Charities

Shape research

There are a range of opportunities for getting involved in the research that we fund. Involving members of the public in research is important to us to help ensure that the research we fund is:

- relevant
- reliable
- usable for people.



What is public involvement in research?

Public involvement in research is where our research is carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them.

When we use the term 'public' we use the INVOLVE definition which include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. You might find that others use different terms to describe people getting involved such as 'patient and public involvement (PPI)', 'service users', 'lay members' and 'consumers'.

Related content

Internal Links

- 🔗 [How you can get involved](#)

Downloads

- 📄 [PIP1 what is it all about](#)
- 📄 [PIP 4 jargon buster](#)

External Links

- 🔗 [People in Research](#)

What will it mean to be a patient or member of public in research in 2025?

‘By invitation only or co-producing the knowledge of tomorrow?’

Cometh the hour, cometh the patient

'We stand on the cusp of a revolution in the role that patients – and also communities – will play in their own health and care. Harnessing what I've called this renewable energy is potentially the make-it or break-it difference between the NHS being sustainable – or not.'

Simon Stevens, NHS CEO, NHS Confederation Annual Conference, June 2014

INVOLVE

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Questions

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