

## What patients and the public want

- To find out about the latest medical research and how it relates to their health
- Accessible, plain English, searchable summaries of research articles that clearly communicate the implications and limitations of the research findings
- Information they can trust (credible, reliable and unbiased)
- To engage with researchers and research funders
- To be involved
- To learn more about research because they are interested and they want to be better informed about the latest developments
- To help researchers be better communicators

## About us

**Patients Participate!** was a collaborative project between UKOLN, based at the University of Bath, the British Library and the Association of Medical Research Charities. We wanted to find out about involving the public and researchers in making sense of scientific literature for patients interested in medical and health research. This project was funded through the JISC eContent programme 2011 on developing community content: <http://www.jisc.ac.uk/whatwedo/programmes/digitisation/econtent11.aspx>

**The Association of Medical Research Charities (AMRC)** is a membership organisation of the leading medical and health research charities in the UK. Working with our member charities and partners, we aim to support the sector's effectiveness and advance medical research by developing best practice, providing information and guidance, improving public dialogue about research and science, and influencing government.

**The British Library** is the UK's national library. We provide access to the world's most comprehensive research collection. Our ambition is to 'enable access to everyone who wants to do research'. Through initiatives such as UK PubMed Central (UKPMC), we work in partnership to address some of the barriers to accessing biomedical information. <http://www.bl.uk>

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LIBRARY

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access

involvement

engagement

Patients  
participate

Involving **patients** and  
the **public** in talking  
about medical research

## Charities and medical research

Medical research takes place in universities and medical schools, research institutes, the NHS, and pharmaceutical and biotechnology companies. It is paid for by private investment from industry and by public money from the government and charities.

Charities play a significant part in funding medical and health research in the UK. Last year UK charities invested over £1 billion in health research – about a third of all public spending on medical research.

## How do funders decide what research to fund?

Funders use peer review to decide whether a research project proposal is scientifically valuable and deserves funding. It is also used when deciding whether a project's findings should be published in a scientific journal.

The research is read and commented on by people with similar interests and expertise to those who wrote the proposal or report. It is usually done anonymously to enable people to openly provide constructive criticism.

Peer reviewers can be researchers working in the same or a similar field, other professionals with knowledge of the area, or members of the public. Members of the public who are involved in peer review are often known as lay reviewers.

**sense about science** is a charitable trust that equips people to make sense of scientific and medical claims in public discussion. Its website has a section dedicated to peer review.

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

## Getting involved

Medical research charities want to fund research of the highest quality that will bring benefits to patients. That's why many charities involve patients and the public in deciding what research to fund.

This is what the charity Asthma UK says about the role of lay reviewers:

'People who are affected by a disease or condition can bring knowledge and experience of that condition, and provide a unique and valuable perspective when peer reviewing a project proposal.

They have a particularly important role in answering questions such as:

- Is the research question important to people affected by the condition?
- Is the research exploring potential benefits that would be helpful to people affected by the condition?
- Is any information for participants clear and easy to understand?
- Will participants be willing to take part in the project?
- Did the researchers seek the advice of people affected by the condition when they planned their research?
- Have the researchers considered that people affected come from different backgrounds?

These questions are not often addressed by researchers and clinicians. They tend to focus more on questions about the research methods, the project plan and value for money.'

**INVOLVE** is a national advisory group which supports greater public involvement in NHS, public health and social care research. INVOLVE is funded by the National Institute for Health Research (NIHR).

Involve has resources to help organisations actively involve members of the public in research, and information for members of the public who are thinking about getting involved in research.

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

## Finding out about medical research

People get a lot of information about health research from the news, and it can be difficult to know what to believe.

**Behind the Headlines** from NHS Choices summarises the science behind health news stories for a lay audience. 'How to read health news' is an excellent guide to critically reading health stories.

**Who's it for?** Patients and the public, health professionals, journalists and anyone involved in communicating health news.

[www.nhs.uk/news](http://www.nhs.uk/news)

## Learning from patients' experiences

**Healthtalkonline** is a website of people talking about their real life experiences of health and illness. You can watch video clips, listen to audio and read about people's stories. It also has reliable information about conditions, treatment choices and support.

**Who's it for?** Patients, their carers, family and friends, health professionals. There is a sister website, Youthhealthtalk, for young people.

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

## Reading research articles

Open access content is freely available to anyone with a connection to the internet.

**UK PubMed Central** (UKPMC) is an online database of peer reviewed biomedical and health research journal articles.

**Who's it for?** Researchers, funders, health professionals and the public. It's free to access – so everyone can make use of research findings.

<http://ukpmc.ac.uk>

**PLoS Medicine** is an open access journal that publishes clinical research. Every research article is published with an easy-to-read 'Editors' Summary' written by the journal's editorial team.

**Who's it for?** Clinical researchers, health care professionals, policy-makers, medical educators, and medical students, as well as patients, their families, and the wider public.

<http://www.plosmedicine.org>