

INVOLVE

NHS

*National Institute for
Health Research*

3 Public Information Pack (PIP)

How to get actively involved in NHS,
public health and social care research

Finding out more



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Using this Public Information Pack

This booklet is one of a series of four booklets that make up the Public Information Pack. If you only have this booklet (Booklet 3) and would like the whole Pack, then please get in touch with us at **INVOLVE**.

Words written in **pink** mean there is a definition of what the word means to us, in **Booklet 4 – ‘Jargon Buster’**.



1 What is PIP?

1.1 What is this Public Information Pack?

Welcome to the **INVOLVE** Public Information Pack (PIP). This pack is for **members of the public** (for example, **service users, carers, patients**) who are interested in getting involved in **NHS, public health** or **social care research**.

The four booklets in the Information Pack are:

Booklet 1 – So what is it all about?

In this booklet, there are four chapters. This booklet gives some background information about research and **public involvement**, and why it is important to get involved in research.

Booklet 2 – Getting started

In this booklet there are four chapters. This booklet describes some of the different ways you can get involved in research, suggests questions to ask before deciding whether to get involved, as well as giving ideas about how to get started.

Booklet 3 – Finding out more

This booklet provides information about some of the different organisations that are involved in research, which may be useful to know about. This third edition of the booklet was published in **January 2016** to update details of organisations and other information sources, and to signpost members of the public to useful organisations and references on the **INVOLVE** website, such as **invoDIRECT**. This is a working document – if you spot any inaccuracies or would like to suggest any additions please contact us on **02380 595628** or at **involve@nhr.ac.uk**

Booklet 4 – Jargon Buster

Booklet 4 is a jargon buster explaining some of the words used in the other booklets. These explanations have been developed for INVOLVE by TwoCan Associates working in **consultation** with a panel of **researchers** and a panel of people who use health and/ or social care services.

Public involvement in research is still a developing area and some organisations and areas are developing more rapidly than others. It is not always easy to find exactly what you are looking for and it might take some time. You may need to make several enquiries. **But please do not be put off! We can help.**

Ring INVOLVE on **02380 595628** or email involve@nhr.ac.uk if you need help with contacting the organisations or obtaining the publications mentioned in this booklet. We can phone you back to save costs.



2 Organisations

2.1 Introduction

This is by no means a list of all organisations within England that either have public involvement in their research or who will provide relevant information. However we hope that this will be a starting point for you to find the information you need.

Please also be aware information in this document may become out of date – **for up to date information visit:**

invoDIRECT

www.invo.org.uk/communities/invodirect

INVOLVE's directory of networks, groups and organisations that support active public involvement in NHS, public health and social care research

People in Research website (**www.peopleinresearch.org**) to find out about opportunities for getting involved in research

Information about INVOLVE is provided first, followed by an overview of public involvement in other National Institute for Health Research (NIHR) funded organisations, then an alphabetical list of other relevant organisations.



2.2 INVOLVE

INVOLVE is a national **advisory group** funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research.

INVOLVE works in partnership with researchers, research funders and the public to:

- maximise the opportunities for public involvement
- learn and share knowledge and experiences of public involvement
- support equality, diversity and inclusion and the active involvement in research of groups and individuals who are often excluded from research
- make our work accessible
- strengthen and build upon existing work by INVOLVE and others.

Find out about opportunities for **involvement** in the work of INVOLVE and others :

- **Search invoDIRECT** (www.invo.org.uk/communities/invodirect), INVOLVE's online directory of local and national networks, groups and organisations that support active public involvement in NHS, public health and social care research. You can search by keyword or location, or view a list of all organisations to find and make contact with people carrying out public involvement.
- **View People in Research** (www.peopleinresearch.org) for involvement opportunities). Organisations and research projects that are looking for people to get involved put information and their contact details on this website, so that members of the public who are interested in getting involved can contact them. Members of the public can also sign up to receive email alerts from the People in Research website about relevant opportunities.

- View the news section of the INVOLVE website:
www.involve.nihr.ac.uk/news
- Sign up for email alerts from INVOLVE:
www.invo.org.uk/contact-us

To learn more about research projects that are involving or have involved members of the public:

- join INVOLVE's mailing list to receive the quarterly newsletter:
www.involve.nihr.ac.uk/news/involve-newsletters
- view the database of research projects: www.invo.org.uk/resource-centre/libraries/library-of-research-projects

To learn more about patient and public involvement in general:

- view the **abstracts** and presentations from INVOLVE conferences:
www.involve.nihr.ac.uk/involve2014
- download publications:
www.involve.nihr.ac.uk/resourcecentre/publications-by-involve

Contact INVOLVE for advice and paper copies of INVOLVE publications:

Telephone: **02380 595628**

Email: involve@nihr.ac.uk

Website: www.involve.nihr.ac.uk

2 Organisations

2.3 Other National Institute of Health Research (NIHR) organisations

The NIHR is funded through the Department of Health to improve the health and wealth of the nation through research. It is the research arm of the NHS. You can get involved in NIHR-funded research in a variety of ways, such as by:

- choosing a research topic
- helping to decide what the research question should be
- **peer reviewing research proposals** for the NIHR research programmes
- sitting on **commissioning panels and boards** to select research projects for funding
- working with researchers to plan and design their projects
- becoming a co-researcher, for example carrying out **interviews** and **data** analysis
- commenting on and developing information, such as **patient information leaflets** or **questionnaires**
- joining a research management or advisory group
- helping to **disseminate** good research

Visit the public involvement pages of the NIHR website to find out more.

Website: www.nihr.ac.uk

Public involvement page:

www.nihr.ac.uk/get-involved

Listed below are some of the NIHR organisations and initiatives that are involving members of the public in their work. Please visit the public involvement pages of the individual organisations to find out how they are involving members of the public or visit invoDIRECT (www.invo.org.uk/communities/invoirect) to find a NIHR organisation involving the public in your area.

See our jargon buster for **definitions** of the terms highlighted in **pink** www.involve.nihr.ac.uk/resource-centre/useful-information/jargon-buster

Clinical Research Network (CRN)

The CRN provides the support the NHS needs to carry out research which will benefit patients and the public. It has 15 Local Clinical Research Networks (LCRNs) across England, with each LCRN supporting research across many different types of health conditions. For further information on how you can get involved in their work contact your LCRN:

Website: www.crn.nihr.ac.uk/networks

Public involvement page: www.crn.nihr.ac.uk/can-help/patients-carers-public

Research Design Service (RDS)

The RDS provides help for researchers to prepare research proposals to apply for funding from the NIHR and other national health or social care research organisations. They provide advice on the design and plans for the research, how it will be carried out and how to have good public involvement in the research. There are ten RDS centres across England.

Each RDS has a patient and public involvement manager – contact your regional centre for further information : www.rds.nihr.ac.uk/support-options/regional-centres and view invoDIRECT for regional contacts

Website: www.rds.nihr.ac.uk

Public involvement page: www.rds.nihr.ac.uk/public-involvement/for-patients-and-the-public

Collaborations for Leadership in Applied Health Research and Care (CLAHRC)

CLAHRCs are a partnership between university, NHS, industry, relevant local organisations and public partners across a region. There are 13 CLAHRCs in England. CLAHRCs carry out research to find practical solutions for the NHS, and the results are used to improve health care for patients. Each CLAHRC has a patient and public involvement lead contact your local organisation to find out more about what they do and to get involved.

Website, including links to your local CLAHRC: www.nihr.ac.uk/about/collaborations-for-leadership-in-applied-health-research-and-care.htm and view invoDIRECT for local contact details

2 Organisations

Research Programmes

Central Commissioning Facility (CCF)

The CCF manages several of the research programmes of the NIHR. They are committed to involving members of the public in their work and have a small, central, staff team who support and develop patient and public involvement (PPI) activities across the organisation.

Telephone: **020 8843 8000**

Email: info@nihr-ccf.org.uk

Website: www.nihr.ac.uk/about/central-commissioning-facility.htm

Public involvement page: www.nihr.ac.uk/get-involved/public-involvement-at-ccf.htm

CCF manages the following NIHR funding programmes, each of which has its own public involvement web pages:

- **Invention for Innovation (i4i):** www.nihr.ac.uk/funding/i4i-patient-and-public-involvement.htm
- **Programme Grants for Applied Research (PGfAR) and Programme Development Grants (PDG):** www.nihr.ac.uk/funding/pgfar-patient-and-public-involvement.htm
- **Research for Patient Benefit (RfPB):** www.nihr.ac.uk/funding/RfPB_patient-and-public-involvement.htm

NIHR Evaluation, Trials and Studies (NETS)

The NETS programmes fund research to inform health and social care decision makers. They are managed by the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC). NETSCC is committed to public involvement in the funding of all of its research and they have a Patient and Public Involvement Manager for the organisation.

Telephone: **023 8059 5586**

Email: info@netscc.org.uk

Website: www.nets.nihr.ac.uk

Public involvement page: www.nets.nihr.ac.uk/ppi

NETSCC manages the following NIHR funding programmes:

- **Efficacy and Mechanism Evaluation (EME):** www.nets.nihr.ac.uk/programmes/eme
- **Health Services and Delivery Research (HS&DR):** www.nets.nihr.ac.uk/programmes/hsdr
- **Health Technology Assessment (HTA):** www.nets.nihr.ac.uk/programmes/hta
- **Public Health Research (PHR):** www.nets.nihr.ac.uk/programmes/phr

Research Centres and Units

Biomedical Research Centres and Units (BRC/BRU)

There are 11 Biomedical Research Centres and 20 Biomedical Research Units that are funded by the NIHR to focus on specialist research areas that benefit patients. Each Biomedical Research Unit is a partnership between an NHS Hospital Trust and a University. There are a variety of opportunities for members of the public to get involved in their work.

Websites:

Biomedical Research Centres: www.nihr.ac.uk/about/biomedical-research-centres.htm

Biomedical Research Units www.nihr.ac.uk/about/biomedical-research-units.htm

Other NIHR Programmes

Cochrane

Cochrane is a global independent network of researchers, professionals, patients, carers and people interested in health. They gather and summarise the best evidence from research to help members of the public make informed choices about treatment.

Telephone: **0207 183 7503**

Website: www.cochrane.org

Public involvement page: www.cochrane.org/get-involved

Cochrane Consumer Network (CCNet)

CCNet is part of Cochrane. Its main function is to provide **consumer** input into developing and utilising the best evidence in health care.

Email: ccnet-contact@cochrane.de

Website: <http://consumers.cochrane.org>

Dissemination Centre

The Dissemination Centre produces a range of summary reports, setting out the latest **research evidence** on specific topics, based on NIHR and other research findings. Further information on how to get involved is on their website.

Website: www.dc.nihr.ac.uk/

Public involvement page: www.dc.nihr.ac.uk/get-involved

2 Organisations

Horizon Scanning Research & Intelligence Centre (HSRIC)

The HSRIC look for important health technologies (new drugs, medical devices and diagnostics) that may become available on the NHS in the next few years. When they find these technologies they write reports on them for groups that make health policies and decisions within the NHS such as NICE, and for those that fund research. There are opportunities to get involved with the work of HSRIC, for example by telling them about a new health technology that is not yet available to patients in the UK.

Telephone: **0121 414 7831**

Email: nihrhsric@contacts.bham.ac.uk

Website: www.hsrc.nihr.ac.uk

Public involvement page: www.hsrc.nihr.ac.uk/for-the-public

School for Primary Care Research (SPCR)

The SPCR's focus is on research to improve everyday practice in **primary care**. Patients, mental health service users, carers and members of the public with an interest in research are encouraged and supported to work in partnership with researchers on projects carried out across the SPCR.

Website: www.spcr.nihr.ac.uk

Public involvement page: www.spcr.nihr.ac.uk/PPI

School for Public Health Research (NSPCR)

The SPHR aims to build the evidence base for effective public health practice. It is committed to ensuring that the public are involved in the development and conduct of all its research projects. It has public members on its national Advisory Board and members of the public also advise individual SPHR members on their research.

Website: <http://sphr.nihr.ac.uk>

Public involvement page: <http://sphr.nihr.ac.uk/engage-with-sphr/public-engagement-involvement>

School for Social Care Research (SSCR)

The SSCR aims to improve the **evidence-base** for adult social care practice in England. They have a User, Carer and Practitioner Reference Group (UCPRG), which advises on the School's research and related activities.

Telephone: **020 7955 6238**

Email: sscr@lse.ac.uk

Website: <http://sscr.nihr.ac.uk/index.php>

UCPRG page: <http://sscr.nihr.ac.uk/ucprg.php>

Trainees Coordinating Centre (TCC)

TCC makes training awards to researchers whose work focuses on improving health care for patients and members of the public. Patient and public involvement (PPI) is a central part of the decision making around offering a training award. PPI is part of the additional training provided to early career researchers who receive awards.

Telephone: **0113 346 6260**

Email: comms@nihrtcc.org.uk

Website: www.nihr.ac.uk/about/about-the-trainees-coordinating-centre.htm

2 Organisations

The following NIHR activities help people find out more about research and taking part in research:

Join Dementia Research

Join Dementia Research is a service that allows people to register their interest in participating in dementia research and be matched to suitable current studies. The service shows what dementia research is taking place, both locally and nationally, and connects researchers with people who want to participate in studies.

Website: www.joindementiaresearch.nihr.ac.uk

OK to Ask

OK to ask is a campaign to encourage more patients or carers to ask about research opportunities that could be available to them or their loved ones, if they have a medical condition they are receiving treatment for. It supports expectations about research choices found in the NHS Constitution.

Email: oktoask@nihr.ac.uk

Website: www.nihr.ac.uk/get-involved/ok-to-ask.htm

Patient Research Ambassador Initiative

The Patient Research Ambassador Initiative aims to promote the role of Patient Research Ambassadors (people who promote health research from a patient point of view) in local NHS services.

Telephone: **0151 252 5435**

Email: jennifer.preston@nihr.ac.uk

Website: <https://sites.google.com/a/nihr.ac.uk/involvement4access>

UK Clinical Trials Gateway

The UK Clinical Trials Gateway provides easy to understand information about **clinical research trials** running in the UK, and gives you and others access to a large range of information about these trials. It is designed to enable you and your **clinician** to locate and contact trials of interest to you.

Website: www.ukctg.nihr.ac.uk

2.4 Other organisations

This section provides an alphabetical list of a selection of other organisations that might be useful if you are thinking about getting involved in health and social care research.

If you are looking for an organisation that covers a specific health condition, search invoDIRECT (www.invo.org.uk/communities/invodirect).

Many disease-specific charities have their own patient groups. Look at their websites for further information and contact details.

Ring INVOLVE on **02380 595628** if you can't find what you are looking for or if you need help with contacting the organisations mentioned in this booklet. We can phone you back to save costs.

Academic Health Science Network (AHSN)

The two key aims of the AHSN are to improve health and create economic growth. They achieve this through 15 regional networks, which bring together academics, NHS, researchers and industry to improve the health of local communities.

Website: www.ahsnnetwork.com

Association of Medical Research Charities (AMRC)

AMRC is the national membership organisation of leading medical and health research charities in the UK. The website includes a list of all member charities.

Telephone: **020 7685 2620**

Website: www.amrc.org.uk

Critical Appraisal Skills Programme (CASP)

The Critical Appraisal Skills Programme (CASP) offers training, workshops and tools to help you read and check health research for trustworthiness, results and relevance. They run courses for organisations and have a series of e-learning modules suitable for individuals.

Website: www.casp-uk.net

E-learning modules: www.casp-uk.net/#!e-learning/cd70

Department of Health (DH)

The DH provides health and social care policy, guidance and publications. Many of their publications can be downloaded from the gov.uk website.

Telephone: **020 7210 4850**

Website: www.gov.uk/government/organisations/department-of-health

2 Organisations

European Patients Academy on Therapeutic Innovation (EUPATI)

EUPATI is a pan-European project of 33 organisations led by the European Patients' Forum. Their aim is to help patients be more educated and involved in the research and development process of new medicines by offering easy to read information and training.

Website: www.patientsacademy.eu/index.php/en/

Public involvement page: www.patientsacademy.eu/index.php/en/patients-involved

Health Research Authority Research Ethics Service (RES)

RES protects the rights, safety, dignity and wellbeing of research **participants**. It includes **Research Ethics Committees (RECs)** in England. All RECs have members of the public on them. You can find out if there are any vacancies on your local REC by following the links on the Vacancies page of the HRA website.

Telephone: **020 797 22545**

Email: contact.hra@nhs.net

Website: www.hra.nhs.uk/about-the-hra/our-committees/res

Public involvement page: www.hra.nhs.uk/patients-and-the-public-2

Vacancies page: www.hra.nhs.uk/working-with-us

healthtalk.org

healthtalk.org (formally Healthtalkonline) shares other people's experiences of health and illness, including their experiences of being involved in research. You can watch or listen to videos of interviews, read about people's experiences and find reliable information about conditions, treatment choices and support.

Email: info@healthtalk.org

Website: www.healthtalk.org

Public involvement page: www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics

James Lind Alliance

The James Lind Alliance (JLA) brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or 'unanswered questions', about the effects of treatments that they agree are most important. This will help future research be focussed on the questions that will be of most benefit to patients, carers, and health and social care professionals.

Telephone: **023 8059 5489**

Email: jla@southampton.ac.uk

Website: www.jla.nihr.ac.uk

Joseph Rowntree Foundation

The Joseph Rowntree Foundation is an independent organisation working to inspire social change through research, policy and practice. They work in partnership with private, public and voluntary sectors, as well as with individuals and communities.

Telephone: **01904 629241**

Email: info@jrf.org.uk

Website: www.jrf.org.uk

Medical Research Council (MRC)

The MRC is a publicly funded organisation, which supports research across health and the medical sciences. To help inform their work, the MRC has a group of volunteers, known as the Public Panel, who provide advice and guidance on projects that need a public or patient **perspective**.

Telephone: **01793 416200**

Email: publicpanel@headoffice.mrc.ac.uk

Website: www.mrc.ac.uk

Public involvement page: www.mrc.ac.uk/about/how-the-public-can-get-involved/public-involvement/

National Institute for Health and Care Excellence (NICE)

NICE provides national guidance and advice to improve outcomes for people using the NHS and other public health and social care services. They are committed to involving professionals, patients, carers, service users and the public in the development of their guidance and other products.

Telephone: **0300 323 0140**

E-mail: nice@nice.org.uk

Website: www.nice.org.uk

Public involvement page: www.nice.org.uk/get-involved

National Voices

National Voices is a coalition of health and social care charities in England. They campaign for people to have a stronger voice in the design and delivery of NHS and social care services. They involve a number of service users on their Service User Panel.

Telephone: **020 3176 0738**

Email: info@nationalvoices.org.uk

Website: www.nationalvoices.org.uk

Service User Panel page: www.nationalvoices.org.uk/national-voices-service-user-panel

2 Organisations

NHS England

NHS England leads the National Health Service (NHS) in England by setting the priorities and direction of the NHS and encouraging and informing the national debate to improve health and care. They **commission** the contracts for GPs, pharmacists, and dentists and support local health services that are led by groups of GPs called Clinical Commissioning Groups (CCGs).

Website: www.england.nhs.uk

Involvement opportunities: https://www.engage.england.nhs.uk/application/get-involved/consult_view

Shaping Our Lives

Shaping Our Lives is a national organisation and network of **user-led** groups, service users and disabled people. They are a user-led organisation committed to inclusive involvement and specialise in the research and practice of involving diverse communities in policy, planning and delivery of services.

Telephone: **0845 241 0383**

Email: information@shapingourlives.org.uk

Website: www.shapingourlives.org.uk

Social Care Institute for Excellence (SCIE)

The Social Care Institute for Excellence (SCIE) improves the lives of people who use care services by sharing knowledge about what works. They co-produce their products and services with people who use services and carers.

Telephone: **020 7766 7400**

Email: info@scie.org.uk

Website: www.scie.org.uk

Social Care Online

An online database of resources on all aspects of social care, including **journal** articles, websites, research reviews, legislation and government documents, and service user knowledge.

Website: www.scie-socialcareonline.org.uk

3 References

In 2014, Professor Dame Sally C Davies, Director General Research and Development and Chief Medical Officer, commissioned a strategic review of public involvement in NIHR health, social care and public health research. The findings '**Going the extra mile**' set out a new vision for public involvement across the NIHR. www.nihr.ac.uk/documents/about-NIHR/NIHR-Publications/Extra%20Mile2.pdf

The following journals feature articles about public involvement in research:

NIHR Journals Library – an open access library providing full publication of studies funded by five of the NIHR research programmes. www.journalslibrary.nihr.ac.uk

Research Engagement and Involvement – an interdisciplinary, health and social care journal focusing on patient and wider involvement and engagement in research. The journal is co-produced by all key stakeholders, including patients, academics, policy makers and service users. www.researchinvolvement.com

At INVOLVE, we collect references of public involvement in research and share them in the following sections of our website:

Evidence library of references on the impact, nature and extent of public involvement in research: www.involve.nihr.ac.uk/resource-centre/evidence-library

Putting it into practice, which contains resources for people who are planning or developing public involvement in research www.involve.nihr.ac.uk/resource-centre/putting-it-into-practice-database

Collection of examples exploring the impact of public involvement in research www.involve.nihr.ac.uk/resource-centre/examples

References on **involving children and young people in research** www.involve.nihr.ac.uk/find-out-more/involving-children-and-young-people/references-on-involving-children-and-young-people-in-research

We also have an online library of **INVOLVE publications** www.involve.nihr.ac.uk/resource-centre/publications-by-involve. You can download our publications or we can post them to you.

Email INVOLVE involve@nihr.ac.uk or call on **02380 595628** if you need help with contacting the organisations or obtaining the publications mentioned in this booklet. We can phone you back to save costs.

INVOLVE

INVOLVE is a national advisory body that is funded by the Department of Health to promote and support public involvement in NHS, public health and social care research and development.

If you would like to know more about what we do, please contact us:

INVOLVE Coordinating Centre	Web:	www.involve.nihr.ac.uk
Alpha House	Email:	involve@nihr.ac.uk
University of Southampton Science Park	Telephone:	02380 595628
Chilworth		
Southampton		
SO16 7NS		

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