What evidence is there to show that PPI is effective?

The following page contains stories, examples and evidence that are specific to the NIHR Clinical Research Network (NIHR CRN) that show the involvement of patients, carers and the public is making the difference in research. Please go to: **www.crncc.nihr.ac.uk/ppi** and see the 'case studies' box at the top right-hand side.

INVOLVE also has information about the developing evidence base on the impact of public involvement in research. Please go to: **www.invo.org.uk/resource-centre/examples**.

I am running a workshop on Public Involvement. Can I have copies of your publications to give out?

All of our publications are available to download from this website.

We can send out small numbers in the post free of charge with at least 2 weeks notice.

To request hard copies please email **involve@nihr.ac.uk** or

telephone 02380 595628

I am looking for resources on public involvement in mental health research

Here are a selection of some of the resources that might be helpful :

The voluntary sector shared learning group has a website:

Voluntary sector shared learning group: facilitator is Bec Hanley: bec@twocanassociates.co.uk http://www.user-involvement.org.uk/

Guidance documents and articles :

The Ethics of survivor research – Alison Faulkner

https://www.jrf.org.uk/report/ethics-survivor-research-guidelines-ethical-conduct-research-carried-out-mental-health

A series of case studies of public involvement in mental health research:

http://www.invo.org.uk/resource-centre/library-resource/?id=648&section=invonet

MIND project:

http://www.mind.org.uk/media/418956/Peer-Support-Executive-Summary-Peerfest-2013.pdf

Peer worker Research project – St Georges hospital:

http://www.peerworker.sgul.ac.uk/the-team/wider-research-team#

Beyond our Expectations A report of the experiences of involving service users in forensic mental health research:

http://www.invo.org.uk/resource-centre/library-resource/?id=550&section=invonet

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How can I get involved as a lay member?

INVOLVE has information on being involved here:www.invo.org.uk/find-out-more/getting-involved

People in Research also has information for members of the public who would like to be involved in research including a database of current opportunities. Please see the following link: www.peopleinresearch.org.

I'm applying for a NIHR Fellowship and I think the design of my research proposal would benefit substantially from PPI. Could you advise?

As a start you should contact your local Research Design Service funded by the National Institute for Health Research:

http://www.rds.nihr.ac.uk/support-options/regional-centres/

I am working on a research proposal for which I would like patient and public involvement from the planning stage. Would it be possible to put me in contact with somebody who may be able to

advise on this?

As a start you should contact your local Research Design Service funded by the National Institute for Health Research:

http://www.rds.nihr.ac.uk/support-options/regional-centres/

How do I cost PPI in research projects?

The Mental Health Research Network and INVOLVE have developed a useful guide (**budgeting for Involvement**) that provides practical advice on how to budget for involving patients, carers and the public in research.

You can use the cost calculator to work out the costs of involvement at any stage of the research process – whether that's a planned focus group in a study underway or putting together an entire budget for a study. It may be particularly helpful when designing research studies and applying for funding.

Please see the following link: **www.involve.nihr.ac.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator**.

I am a researcher. Where can I find support for designing PPI involvement and funding for PPI at the research design stage?

The National Institute of Health Research (NIHR) Research Design Service supports researchers to develop and design high quality research proposals for submission to the NIHR and other national, peer-reviewed funding competitions for applied health or social care research. This support is provided free of charge.

You can find your local RDS here: **http://www.rds.nihr.ac.uk/**

Information about funding for PPI at the research design stage can be found here: **www.rds.nihr.ac.uk/ppi/funding-award**.

I don't understand all of the jargon — where can I find out what it all means?

The INVOLVE jargon buster, or glossary of words contains the definitions of some of the terms commonly used in public involvement in research. It is not a complete list of all the words you might come across. The definitions were developed for INVOLVE by **TwoCan Associates** working in consultation with

a panel of researchers and a panel of people who use services.

It can be found here: www.involve.nihr.ac.uk/resource-centre/useful-information/jargon-buster

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I have been asked to write a Plain English summary — how do I do this?

A plain English summary is a brief summary that has been written for members of the public and an interested audience rather than specialists. It should be written clearly and simply, without jargon and with an explanation of any technical terms that have to be included.

Guidance on writing plain English summaries can be found here: www.involve.nihr.ac.uk/resource-centre/plain-english-summaries/

Are there any resources on involving children and young people in research?

Several organisations are actively involving children and young people in research and have information and resources on

their websites:

The National Institute of Health Research (NIHR) Medicines for Children Research Network (MCRN) www.mcrn.org.uk/children/design

National Children's Bureau Research Centre (NCB). Includes information on a 2011 conference on young people's involvement in research and projects involving children and young people: www.ncb.org.uk/policy-evidence/research-centre/involving-young-people-in-research including:

- Guidelines on research with children and young people: www.participationworks.org.uk/resources/guidelines-for-research-with-children-and-young-people
- The Pear Project – a (now completed) project involving young people in public health research, including a conference and guidance for researchers: www.ncb.org.uk/pear
- Viper young researchers – a project involving young disabled people in research: www.councilfordisabledchildren.org.uk/what-we-do/work-themes/participation/viper/young-researchers

Participation Works. Information on children and young people's participation including downloadable versions of NCB and PEAR guidelines, 'how to' guides including 'creative methods' and 'reward and recognition', and a guide and toolkit for evaluating participation with children and young people: www.participationworks.org.uk

Children's Research Centre. Supports child-led research: http://childrens-research-centre.open.ac.uk

Young Researcher Network. Includes toolkit to support young people-led research www.nya.org.uk/integrated-youth-support-services/young-researcher-network

Children's Rights Alliance for England: www.crae.org.uk

INVOLVE has published: [**A guide to involving children and young people in research**](#)

Visit our [**Putting it into Practice library**](#) and search for children and young people to find out what others have written.

What is public involvement in research?

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.

When using the term **'public'** we 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.

Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important

distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

For more information go to http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/

1. **Here is some further guidance on who might be involved in research. See guidance [here](). We will publish some examples of how the different experiences of people can benefit research.**

   The NIHR Research Design Service (RDS) (www.rds.nihr.ac.uk/) supports researchers to develop and design high quality research proposals for submission to NIHR and other national, peer-reviewed funding competitions for applied health or social care research.