

Resources for public involvement in the research process

Research Design Service North West

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General resources

INVOLVE

www.invo.org.uk

- INVOLVE is the agency of the Department of Health responsible for promoting service user involvement in health and social care research.
- Provides information, advice and support to service users involved in research, and researchers.
- Many guidelines and reports for researchers and members of the public.
- Database of projects involving service users <http://www.invo.org.uk/Projects.asp>.
- Short guide for researchers: http://www.invo.org.uk/pdfs/R1research_grant_applications.pdf.
- Comprehensive guide for researchers <http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf>.

People in Research

www.peopleinresearch.org

- Developed by the UK Clinical Research Collaboration – a collaboration of organisations involved in promoting and co-ordinating NHS research (<http://www.ukcrc.org>).
- Aims to help members of the public make contact with organisations that want to actively involve them in clinical research.
- Has a database of organisations or groups that look for members of the public to get involved in their work.

The North West People in Research Forum (NWPiRF)

<http://www.northwestpeopleinresearchforum.org/>

- The North West People in Research Forum is an organisation which is devoted to supporting patient and public involvement (PPI) and public engagement (PE) in health research in the North West.

National Institute for Health (NIHR): United Kingdom Clinical Research Network (UKCRN)

<http://www.crncc.nihr.ac.uk/ppi>

- The NIHR-UKCRN is a network of topic specific, e.g. diabetes, stroke, medicines for children, research networks.
- Training courses for researchers and service users.
- Booklet explaining clinical trials for patients.

Joseph Rowntree Foundation

<http://www.jrf.org.uk/publications/user-involvement>

- A report “User involvement in research: building on experience and developing standards” which includes guidance on good practice for researchers and research funders.

NHS Evidence

<http://www2.evidence.nhs.uk/search?q=Patient%2C+Public+Involvement>

<http://www2.evidence.nhs.uk/search?q=Patient+and+Public+Engagement>

- This is an online library for the NHS. There are PPI sections on involvement and engagement.

James Lind Alliance

<http://www.lindalliance.org>

- The James Lind Alliance aims to identify the most important gaps in knowledge about the effects of treatments, and brings patients and clinicians together to identify and prioritise the unanswered questions that they agree are most important.

The Picker Institute

<http://www.pickereurope.org/patientpublicengagement>

- The Picker Institute promotes service user involvement in all aspects of the NHS. Focussed on the patient experience.

Invest in Engagement

<http://www.investinengagement.info/PublicEngagementTop>

- Makes recommendations (“best buys”), which are based on the available evidence, on how to engage people and what works.

User involvement in research by nurses

http://www.rcn.org.uk/_data/assets/pdf_file/0003/78744/003140.pdf

- Guidance for nurses on public and patient involvement in nursing research which other health service staff may also find useful.

TwoCan Associates

<http://www.twocanassociates.co.uk/index.php>

- TwoCan Associates help voluntary and statutory organisations to involve service users, patients, carers and the public in their work.
- They have some useful publications including a “route map” for user involvement in research.

Involving people in research

<http://www.involvingpeopleinresearch.org/>

- An Australian site, but with helpful resources including the Fact Sheet series, which has been developed in response to requests from researchers for short simple ‘tools’ to support the implementation of consumer and community participation in health research.

National Institute for Health Research comprehensive Biomedical Research Centre at Guy's and St Thomas' NHS Foundation Trust and King's College London.

<http://live.biomedicalresearchcentre.org/Professionals/Supportservices/Helpwithpatientandpublicinvolvement.aspx>

- Have useful introductory materials for staff new to patient and public involvement in research.

PatientPartner

<http://www.patientpartner-europe.eu/en/resources/active-involvement-in-the-process>

- The PatientPartner Project set out to promote the role of patient organisations in the clinical trials context. PatientPartner was based on the belief that involving patient organisations as equal partners at all stages of clinical trials contribute to research that is better adjusted to the real needs of patients.
- Its resource pages include an overview of active involvement of Patients and Patient organisations in (the) clinical trial (development process) and there are sections on policy and ethics.

NHS R&D Forum Service User and Carer Working Group

<http://www.rdforum.nhs.uk/docs/involvement.doc>

- The Involvement Portfolio is a tool for those using health and social care services who are involved in voluntary or involvement activities such as consultation, committee membership, research and development, to record and provide evidence of their activities. Its use is voluntary and it is up to the individual how they use the portfolio, what they record and how they choose to use it in demonstrating their skills and expertise.

Specific service user groups

Medicines for Children Research Network (MCRN)

<http://www.mcrn.org.uk/>

- The Young person's group have developed a guidance document for researchers designing Patient Information Leaflets for children and young people.

Listening to children: Research and consultation with children and young people

<http://www.crfr.ac.uk/cpd/listeningtochildren>

- A course for all professionals involved in listening to children.

Participation Works

<http://www.participationworks.org.uk/resources/how-to-involve-children-and-young-people-in-research>

- How to involve children and young people in research.

INVOLVE: checklist for researchers on how to involve vulnerable and marginalised groups

<http://www.invo.org.uk/pdfs/Brief%20Summary%20and%20Checklist%20for%20Researchersver2.pdf>

Service User Research Group England (SURGE)

www.mhrn.info/index/ppi.html

- SURGE is the service user arm of the UK-Mental Health Research Network (MHRN).
- Good practice guidance.

Royal National Institute for the Blind

http://www.rnib.org.uk/professionals/accessibleinformation/text/Pages/clear_print.aspx

- Guidelines on clear printing for people with sight problems.

The ACT NoW Study - Involving service users in research

https://www.uksrn.ac.uk/images/files/involving_service_users_in_research.pdf

- This guide has been written for the UK Stroke Research Network.

Payment

Sources of information and guidance about paying involved members of the public

<http://www.invo.org.uk/pdfs/PaymentGuideWEB240510.pdf>

<http://www.invo.org.uk/pdfs/involvepaymentdocument2011.pdf>

<http://www.invo.org.uk/pdfs/NIHRProgrammesPaymentRatesOct2009-030810.pdf>

[http://www.invo.org.uk/pdfs/Scott%20J%20\(2008\)%20Payment%20for%20involvement%20in%20research%20INVOLVE.pdf](http://www.invo.org.uk/pdfs/Scott%20J%20(2008)%20Payment%20for%20involvement%20in%20research%20INVOLVE.pdf)

<http://www.invo.org.uk/pdfs/INVOLVEinternalpaymentpolicyFeb2010.pdf>

[http://www.gov.uk/.....PublicationsPolicyAndGuidance/DH_4138523.](http://www.gov.uk/.....PublicationsPolicyAndGuidance/DH_4138523)

<http://www.scie.org.uk/publications/reports/report08.pdf>

Research ethics

National Research Ethics Service: The Integrated Research Application System (IRAS)

<http://www.nres.npsa.nhs.uk/>

<https://www.myresearchproject.org.uk/Signin.aspx>

- A single system for applying for the permissions and approvals for health and social care / community care research in the UK.
- The form asks if service users have been involved in the development of the research proposal.

Royal College of Nursing research ethics-guidance for nurses

http://www.rcn.org.uk/_data/assets/pdf_file/0007/388591/003138.pdf

- A booklet providing guidance on research ethics with a section on public involvement.

Reporting and dissemination

Social Care Institute for Excellence (SCIE)

<http://www.scie.org.uk/publications/misc/accessguidelines-publications.pdf>

- Guidance on how to produce information in an accessible way.