A PATIENT AND PUBLIC INVOLVEMENT STRATEGY

RESEARCH DESIGN SERVICE NORTH WEST

November 2011 – Version 2.0
Our aim
The overall aim of the NIHR Research Design Service North West (NIHR RDS NW) in the 5-year funding period 2010-2015 is to support the production of high quality proposals for health research funding. A key aspect of this overall aim is to promote and contribute to improved patient and public involvement (PPI) in health research.

Background
The Department of Health, the NHS Executive, research funding bodies and the medical charities all emphasise the importance of PPI in clinical research\(^1\)\(^2\)\(^3\). PPI is a central aspect of the research programmes of the National Institute for Health Research [NIHR]\(^4\) and one of the criteria on which research proposals received into the NIHR are assessed. PPI in health research is seen as people being active partners in the research process by, for example, advising on a research project, assisting in the design of a project, or in carrying out the research, rather than simply being the ‘subjects’ of research. NIHR states that:

*We want patients and the public to be involved in all stages of research. This covers:*
  - Setting research priorities
  - Helping to decide what the research is setting out to achieve
  - Choosing the methods used to carry out the research
  - Recruiting people into research studies
  - Understanding what the research findings mean for patients and how it can be applied in the health service
  - Publicising the results.

NIHR RDS NW has a strong history of and commitment to patient and public involvement in health research and has positioned itself as a significant repository of expertise in this important area of activity. Under the current funding stream, PPI activity will be led by a Strategic Lead for Public and Patient Involvement and three specialist public and patient involvement advisers,\(^5\) supported by a lay Reference Group.

Our objectives
In order to achieve our overall aim, we will:
  - develop and maintain skills and knowledge in PPI amongst NIHR RDS NW advisers so that high quality PPI advice is routinely part of the RDS
  - work with national and regional partners to optimise opportunities for and quality of PPI input to research proposals in the NW;
  - contribute to an evidence base on PPI in research

Objective 1: Develop and maintain skills and knowledge in PPI amongst NIHR RDS NW advisers
To meet this objective, the PPI lead and specialist advisers will:
  - Establish appropriate means for gaining lay perspectives and inputs to support our PPI work
  - Undertake regular needs assessments among NIHR RDS NW frontline advisers to inform an educational programme addressing specific PPI topics of interest
  - Provide additional *ad hoc* expert support to frontline advisers as and when necessary

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2 Department of Health [1999] Patient and Public Involvement in the New NHS. London: DH.
4 Best Research for Best Health: A new national health research strategy, DH, 2006.
5 PPI Lead is currently Prof Ann Jacoby; specialist PPI advisers are Dr Sara Morris, Lancaster; Dr Paula Byrne, Liverpool; Dr Tracey Williamson, Manchester
Building on existing links, seek to recruit research-active members of the public to assist in delivering training and other learning opportunities to NIHR RDS NW advisers.

Direct frontline advisers to appropriate sources/resources for linking academic researchers to interested patients and members of the public.

**Objective 2: Work with national and regional partners to deliver a co-ordinated approach to building capacity in PPI amongst NW researchers, patients and the public**

To meet this objective, the PPI lead and specialist advisers will:

- Contribute financial support, alongside other key stakeholders, to a new regional PPI resource, the North West People in Research Forum (NWPIRF); and represent the views of NIHR RDS NW on the Forum Executive Group to ensure it contributes actively to delivery of the NIHR RDS NW agenda.
- Work with the Forum to develop a rewards policy for lay contributors to NIHR RDS NW activity, to include both financial and non-financial reward and recognition which is flexible, consistent across the region and in line with national policy.
- Sit on the NIHR RDS NW Steering and Executive Groups, to ensure communication flow between NIHR RDS NW, the NWPIRF and other external organisations.
- Represent NIHR RDS NW on external bodies including the INVOLVE-hosted RDS Involvement Forum.
- Ensure appropriate and properly supported lay representation on the NIHR RDS NW Steering Group.
- Work with the NWPIRF to optimise collaborative relationships relevant to the development of research proposals (see Appendix 1).
- Develop and manage a system for disbursement of PPI bursaries to NW researchers with no other access to funds to support development of high-quality PPI in funding bids and formally evaluate the impact of these.
- Develop and maintain a multi-level PPI toolkit, for use by/with different stakeholder groups, including providing links to key self-help resources.
- Target all publicity materials and activities at both professional and lay audiences, ensuring such materials are written in plain language.

**Objective 3: Contribute to an evidence base on PPI in research**

To meet this objective, the PPI lead and specialist advisers will:

- Seek agreement from researchers provided with PPI bursaries to a) their plans for PPI being retained in an NIHR RDS NW database and b) resources being included in project budgets to evaluate the PPI elements of their research.
- Encourage evaluation of PPI in research in the North West, which will be a formal requirement for those in receipt of PPI bursaries.
- Summarise and publicise findings from these evaluations, so adding to the evidence base.
- Seek research funding and collaborate with others in projects to evaluate PPI in health research, as appropriate.
- Through these activities, add to the existing evidence base on PPI in research and contribute to further development of theory and models of PPI involvement in research.

**Indicators of our success**

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6 The NW People in Research Forum (NWPIRF) replaces the now disbanded North West Users in Research Advisory Group (NWURAG; see Appendix 1). Two reports on the rationale and process of development of this new body are available on request from RDS.

7 Scott J [2008] Payment for involvement in research: helpful benefit rules and systems for avoiding benefit problems, INVOLVE
• Increased expertise in PPI in research amongst NIHR RDS NW advisers (as demonstrated through repeated needs assessment exercise)
• Uptake of the NW PPI bursary scheme; and positive outcomes of funding bids for research applicants receiving bursaries;
• Comprehensive regional resources to support PPI in research
• Evidence of active involvement of service users and members of the public in health research in the NW (drawing on information in CATS the NIHR RDS NW client, advice and proposal tracking system)
• Provision and uptake of support and training for service users and members of the public who wish to be involved in health research
Appendix 1: Identified NW PPI groups

NIHR RDS NW has connections with many groups in the North West, and has previously worked with many of them. These include:

Lancaster University Public Involvement Network (LUPIN)
LUPIN aims to provide and increase public involvement in the Lancaster Doctoral Programme in Clinical Psychology. Group members include users of clinical psychology services, carers, course staff and trainee clinical psychologists. LUPIN consists of a main steering group and a number of subgroups, one of which relates to research.

Older People Researching Social Issues (OPRSI)
OPRSI is a co-operative consortium created by a group of older people. The founder members studied for the Certificate in Research Methods on a course sponsored jointly by the University of Lancaster and the charity Counsel and Care, which included participation in a research project regarding older people, published in 2003. Collectively, members have a considerable amount of experience which is growing all the time, following work in collaboration with other professional and academic researchers.

Spectrum Centre for Mental Health Research User Researchers
The Spectrum Centre was set up at Lancaster University to conduct research to develop, test, disseminate and implement psychosocial interventions for mental health problems that are clinically effective. The Centre has a major focus on translational research to improve clinical outcomes for people with bipolar disorder. The centre employs several Service User Researchers.

University of Manchester Primary Care Patient and Public Involvement Forum (PRIMER)
PRIMER acts as a resource for academic researchers by: inputting into research at an early stage; suggesting areas of work for future research; networking with other groups and using existing networks to talk about research and test out ideas; working with researchers to advise on best practice in PPI; and contributing to policy within the National Primary Care Research and Development Centre and the NIHR-funded School for Primary Care Research.

Age Concern Northwest Cumbria
Age Concern Northwest Cumbria uses volunteer community researchers to collect the views of older people and undertake evaluation of services for older people. Projects are generally short-term, typically lasting a month and around three or four projects per year are undertaken. The service is also available to outside agencies which provide services for older people.

Service User Research Endeavour (SURE)
SURE is made up of former patients and carers at the Liverpool Heart and Chest Hospital. The group meets monthly to discuss proposed new research projects; ensures that research projects are relevant to both the Hospital Trust and to patients; ensures that all information provided to patients on research is accurate and employs 'patient friendly' language; ensures the results of research are shared with participants and the general public. SURE is fully supported by the Trust, with free training provided to its members on a variety of research topics.

Appendix 2: Other Key Regional Partners

The Comprehensive Local Research Networks
The North West of England has three Comprehensive Local Research Networks [CLRNs] which form part of the NIHR Comprehensive Clinical Research Network [CCRN] and provide
support for clinical trials and other studies. The key aspect of the CLRNs’ remit is to provide advice on and facilitate effective recruitment to the NIHR portfolio studies.

Primary Care Research Network for the North West of England (PCRN)
The PCRN-NW has developed a PPI strategy and is committed to: involving patients, carers and the public in the development and provision of research within primary care through all activities; ensuring systems are in place to enable effective two-way communication; providing training, mentoring and support to all patients, carers and the public involved in network activities; equipping researchers and professionals with the necessary skills to involve patients, carers and the public in the research process.

Topic-specific research networks
North West Mental Health Research Network (MHRN)
Service user involvement in the NW MHRN Hub takes place in local hub committees, research project teams and at a national level. A Service User Development Officer is employed to develop user involvement and a group of involved service users.

North West Stroke Local Research Network
The NW SLRN has set up groups in different areas of the North West to comment on research and the network activities. Four stroke survivors and carers members sit on the Steering Group.

Medicines for Children Research Network (MCRN)
The MCRN is very committed to PPI. The National Coordinating centre for MCRN is located in Liverpool, and there are also two Local Research Networks (LRNs) in the North West: the Greater Manchester, Lancashire and South Cumbria LRN and the Cheshire, Merseyside and North Wales LRN.
The Coordinating centre hosts a Consumer Involvement Steering Group (CISG) which advises on the strategic direction of consumer involvement within the Network and provides an impetus for action. The Network is very active and both children and parents are involved in many ways in the North West.

National Cancer Research Network (NCRN)
There are two Local Research Networks (LRNs) for Cancer in the North West: Greater Manchester and Cheshire Cancer Research Network and the Lancashire & South Cumbria Cancer Research Network.

Dementias and Neurodegenerative Diseases Research Network (DeNDRoN)
North West DeNDRoN aims to involve patients and the public at all stages of their work. Coordination of patient and public involvement presents a particular challenge: there are a number of issues, some cross-cutting, some condition-specific, which need to be addressed to enable people affected by these diseases to become more actively involved in research. Nonetheless, DeNDRoN aims to pursue its strategy for coordinating PPI across the network through community contacts and Forum events.

Diabetes Research Network (DNR)
North West DNR is tasked with increasing PPI in diabetes research, as well as supporting workforce development and open and transparent communication.

Other Specialist Research Groups
NOWGEN
Nowgen is a leading centre for genetics in healthcare and sets out to inform and improve the practice of genetic medicine. Nowgen is part of the National Institute for Health Research (NIHR) Manchester Biomedical Research Centre, specialising in genetic and developmental medicine. Its work includes a firm commitment to public engagement (PE) through educational activities involving the public and patients in dialogue about genetic medicine.

Biomedical Research organisations
Several biomedical research organisations across the North-West have shown an interest in PPI. These are:
- Biomedical Research Centre in Manchester
- Biomedical Research Centre in Microbial Disease in Liverpool.
- Cancer Research Centre Biobank in Manchester
- Biomedical Research Unit for Pancreatic Disease Liverpool,
- Clinical Trials Unit in Manchester

Local Involvement Networks [LINks]
LINKs do not have a specific remit for involvement in research but aim to give citizens a stronger voice in how their health and social care services are delivered. Independently supported by local authorities, the role of LINks is to find out what people want, monitor local services and to use their powers to hold them to account.

INVOLVE \(^8\)
INVOLVE is the national advisory group, funded through the NIHR to support and promote active public involvement in NHS, public health and social care research. In 2008, INVOLVE established the ‘RDS Public Involvement Forum’ to assist the process of embedding and supporting PPI in research design in the newly established RDSs. The aims of the ‘RDS Public Involvement Forum’ are to:
- Exchange ideas and share examples of good practice
- Facilitate shared understanding about public involvement across Research Design Services
- To discuss and address issues of common concern in relation to PPI in research design
- To avoid duplication
- To facilitate access to support and resources that are available from INVOLVE and other organisations

INVOLVE circulates resources for making contact with local and national patient groups.

‘People in Research’ \(^9\)
The People in Research Website (http://www.peopleinresearch.org/) holds a database of organisations that have opportunities for members of the public to get involved in research. Individual RDSs may submit details of the opportunities for public involvement within their structures and will be added to the database.

\(^8\) http://www.invo.org.uk/
\(^9\) http://www.peopleinresearch.org/
Appendix 3: Definitions of terms (taken from the INVOLVE literature)

By ‘involvement’ in research, we refer to an active partnership between the public and researchers in the research process, rather than the use of people as ‘subjects’ of research. Active involvement may take the form of consultation, collaboration or user control. Public involvement in research is often defined as doing research ‘with’ or ‘by’ the public, rather than ‘to’, ‘about’ or ‘for’ the public. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.

By ‘public’ we mean:
• patients and potential patients
• people who provide care or support on an informal (i.e. unpaid) basis
• parents/guardians of child patients
• people who use health and social care services
• disabled people
• members of the public and communities who might be targeted by health promotion, public health and social care
• groups asking for research because they believe they have been exposed to potentially harmful substances or products
• organisations that represent people who use health and social care services.

The term ‘the public’ is understood to include a rich diversity of people, whether defined by age, colour, race, ethnicity or nationality, disability, gender or sexuality, who may have different needs and concerns.