



*National Institute for
Health Research*



**Research Design Services
and
Public Involvement**

A national map

INVOLVE

Promoting public involvement
in NHS, public health and
social care research

About this report

This report was written and compiled by Lucy Simons, from the INVOLVE Coordinating Centre, drawing on information provided by the Research Design Services.

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Introduction

INVOLVE

INVOLVE is a national advisory group which promotes and supports greater public involvement in NHS, public health and social care research. INVOLVE is funded through the National Institute for Health Research.

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
- 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.

Research Design Services

In 2008-9 the National Institute for Health Research (NIHR) funded 10 Research Design Services (RDS); one service for each strategic health authority area (see map on the following page). The purpose of the Research Design Services is to help NHS researchers and those working with NHS partners to prepare proposals for submission to national funding competitions for applied health or social care research. They will do this by providing expert advice and support on research design and methodology.

Figure 1: Strategic Health Authority Areas in England¹



Public involvement in Research Design Services

The commissioning brief for the RDS required that all applications included a description of the plans for public and patient involvement in research, had a named individual within the team to address public and patient involvement and explained how they intended to work with INVOLVE to promote public involvement in research. The criteria for selection of the applications included an assessment of the strength of the plans for ensuring public and patient involvement in all stages of the research process.

To support and promote public involvement in the RDS, INVOLVE facilitates the RDS Involvement Forum. Membership of the forum is open to all those who have a lead role in promoting and supporting public involvement in the RDS. The forum meets at least three times a year, will have dedicated private web space and adopts a shared learning approach to support the public involvement leads in RDS. The forum aims to:

¹ Map based on one downloaded from the NIHR Central Commissioning Facility Research Design Service website (accessed 26th October 2009).

- facilitate a shared understanding about public involvement across the RDS
- discuss and address issues of common concern in relation to public involvement in RDS
- facilitate access to support and resources that are available from INVOLVE and other organisations
- exchange ideas, strengthen skills and share examples of good practice to develop public involvement in research.

Individual support is also available to the RDS as required. For further information about the RDS Involvement Forum and how INVOLVE is supporting the RDS, please contact Lucy Simons, Public Involvement Advisor at the INVOLVE Coordinating Centre (lsimons@invo.org.uk or 023 8065 1088).

By compiling this 'map', we hope to provide a comprehensive description of how the 10 RDS plan to promote and support public involvement in research. It is helpful to see the full range of approaches to public involvement in research across the regional services. We hope this document will be of interest to the RDS and other organisations concerned with public involvement in research. It will also raise the profile of the new Research Design Services.

How this report is organised

This 'map' was compiled by INVOLVE using documents and materials provided by the RDS and from publicly available information, for example, on the RDS websites. While at INVOLVE we use the term 'public involvement' to describe active involvement in research, in this document the preferred term of each RDS, for example, consumer involvement or public and patient involvement, has been retained. Each RDS has approved the relevant section for inclusion in the map.

It should be noted that the Research Design Services are new services and subject to development as they discover the support needs of the local research community. It is likely, therefore, that the information contained in this document will change as the services develop and mature. This version of the 'map' will be reviewed and updated at the end of 2010. We also have plans to develop this document into an interactive resource on the INVOLVE website.

The main ways in which the RDS aim to promote and support public involvement in research has been organised into nine main categories. These are:

1. Dedicated staff with a public involvement in research remit.
2. The development of a public involvement panel, forum or group.
3. 'Matchmaking' between research teams and research-interested members of the public.
4. Training programmes for public involvement in research.
5. The provision of information and resources for public involvement in research.
6. Provision of advice procedures for public involvement in research.

7. Joint or collaborative working with other organisations on public involvement in research.
8. Public involvement in the management or evaluation of the Research Design Service.
9. How public involvement in research design will be financed or resourced.

The next section of the map provides a summary of the activities across all 10 RDS. Following this the public involvement work in each regional RDS is described in more detail.

Summary of Public Involvement in Research Design Services

For further information on the particular activities referred to in this section, please see the full description in the relevant regional section. To aid cross-referencing each RDS is identified by the initials of the regional area in this summary section:

North East	(NE)
North West	(NW)
Yorkshire and Humber	(YH)
East Midlands	(EM)
West Midlands	(WM)
East of England	(EE)
London	(L)
South East	(SE)
South Central	(SC)
South West	(SW)

All of the services are delivered by a partnership or consortium of organisations across each region, mostly led by Universities, with one being based primarily in NHS Trusts (SW). Each service was designed by the partner organisations in the region in response to how they viewed the support needs of the research community.

1. Dedicated public involvement posts

Most of the RDS have a core member of the senior academic team designated as the lead for public involvement.

In addition to this all but one of the RDS (SW) have additional staff who have been specifically appointed to work on public involvement:

- the configuration of dedicated public involvement staff is different in each RDS, with some having one dedicated post and others having a number of posts (often part-time or with other responsibilities) to cover particular parts of the region
- some of the posts are jointly funded by other local health or research organisations
- the roles are essentially development worker-type posts with responsibility to deliver on the plans for public involvement in the RDS as described in this map
- some of the roles also include research or other academic responsibilities.

2. Development of a panel/forum/group

All but one (SW) of the RDS plan to develop a panel, group or forum comprised of members of the public and patient-led groups who will contribute to the work of the RDS in some way:

- four RDS (NE, NW, EM, SE) plan to offer a lay review of grant applications prior to submission to the funding body
- three RDS (EM, WM, SE) will offer opportunities for members of the panel to become involved in suitable research projects

- two RDS (YH, L) view the function of the panel to have an advisory or strategic role in the RDS itself (see section 8)
- two RDS (EE, SC) will achieve the development of the group by close working with existing groups in the region.

3. 'Matchmaking'

All RDS will aim to match up research teams who wish to involve people in their research with groups and people who are interested in getting involved:

- as described above three RDS (NE, EM, WM) will aim to do this from people and groups who join their panel
- six RDS (NW, YH, EE, L, SE, SC) will develop a dedicated database to achieve the matching process
- one RDS (SW) will do this on a project by project basis using existing contacts and links in RDS and research teams.

4. Training for public involvement

All RDS will develop and deliver training programmes for public involvement in research. These training programmes are aimed at:

- members of the public/service users who become involved with the RDS or research (NE, YH, WM, EE, L, SE, SC, SW)
- researchers who want to develop their skills in public involvement (NE, NW, YH, EM, EE, L, SE, SC)
- RDS advisors and other staff (NW, WM, EE, SE, SC).

One RDS (NW) plans a support scheme for members of the public who become involved with research.

5. Information and resources

The RDS all plan to make available information and resources to support public involvement in research:

- four RDS (NE, EM, WM, L) will collate and disseminate existing resources, for example, those produced by INVOLVE
- six RDS (NW, YH, EM, EE, L, SE) plan to have resources and information available via the RDS website
- two RDS (EE, SE) will develop leaflets about public involvement in research to raise awareness and advertise the services of the RDS

6. Advising on public involvement

The key function of the RDS is to offer advice to research teams when developing grant applications. In the main the RDS are taking two approaches to provide this advice:

- advice will be provided by the public involvement leads and other dedicated staff (YH, WM, L, SE), however, as expertise develops within the RDS staff team, other advisors may take on this role
- initial advice is provided by general RDS advisors, with referral onto the public involvement lead and other dedicated staff as required (NE, NW, EM, EE, SC, SW), for example if the project is complex or challenging.

7. Joint or collaborative working

All the RDS have described how they intend to develop links with other organisations within the region in relation to public involvement. This includes other NIHR infrastructure organisations, for example, research networks, and other locally based public involvement groups:

- for three RDS (NE, EE, SC), the development of the panel (see section 2) is in collaboration with other local organisations
- four RDS (NW, YH, EM, L) also plan to develop a collaborative strategy with other organisations in relation to public involvement in the region.

8. Involvement in the management or evaluation of the RDS

All of the RDS plan to involve the public in the strategic management of the RDS, usually through one or more patient representatives becoming members of a management-type committee or group.

Five of the RDS plan evaluation of at least some of the methods of public involvement:

- four RDS (EE, L, SE, SC) have plans to evaluate the public involvement input into grant applications
- one RDS (NE) plans to evaluate public experiences of contributing to the RDS.

9. Resourcing/financing involvement in research

Seven of the RDS (NE, NW, WM, EE, SE, SC, SW) have a budget to fund the public involvement work in the RDS. This includes covering all out of pocket expenses and payment for people's time, skills and expertise. One of these (NW) plans to consult and develop a 'recognition and reward policy', which will consider other possible rewards, in addition to payment, that involved members of the public would value.

Most of the RDS have provision for funding public involvement in the development of grant applications (i.e. before project-specific funds are available to research teams). This is often referred to as pre-protocol work:

- three (NE, EE, SW) will approach this on an *ad hoc* or informal basis as required
- five (NW, YH, EM, WM, SE) have set up a bursary scheme which research teams can apply for.

10. Other public involvement activities

While most of the public involvement work planned by the RDS falls into one of the categories listed above, there was a selection of other activities:

- one RDS (NE) has a work programme to develop links and materials for engagement of minority and disadvantaged groups in research
- three RDS (NW, YH, EM) have plans to evaluate the pre-protocol bursary scheme (see section 9)
- two RDS (NW, EE) have specifically identified that they will promote and support user-led research
- one RDS (SW) runs a residential school for research teams who are developing bids which will be open to any public member of the research team

- one RDS (NW) plans to contribute to a review of the evidence for public involvement in research.

The next 10 sections of this report provide a description of each of the Research Design Services, contact details of the public involvement lead/dedicated post, and a fuller description of the plans for public involvement in each service.

Research Design Service North East

Newcastle and Durham Universities together with NHS partners provide the Research Design Service for the North East region. The RDS (NE) is managed from two centres which broadly relate to, but not exclusively for, the two Comprehensive Local Research Networks in the region:

- Newcastle University (Northumberland, Tyne and Wear) with Professor Elaine McColl as Director
- Durham University Queen's Campus (County Durham and Tees Valley) with Professor James Mason as Co-Director.

Aim of public involvement in RDS (NE)

Public and patient involvement will be a key element in the RDS (NE) with the aim to promote the idea that patients, carers and other consumers should be fully engaged in the research process from the design stage onwards.

The Public and Patient Involvement lead is Professor Elaine McColl

Institute of Health and Society
University of Newcastle upon Tyne
21 Claremont Place
Newcastle upon Tyne
NE2 4AA

Phone: +44 (0)191 222 7260
Email: e.mccoll@newcastle.ac.uk

1. Dedicated public involvement posts

The Patient and Public Involvement Officer, Andrew Robinson, is based at the Durham centre satellite hub, James Cook Hospital, Middlesbrough.

2. Development of a panel/forum/group

The RDS (NE) aims to develop a panel of consumers, interested in and trained for a role as consumer members of grant application teams, as advisors to researchers and peer reviewers.

Patients, carers and advocates interested in becoming involved in applied health and social care research will be approached and recruited through existing links, using job descriptions derived from those produced by INVOLVE. Drawing on successful models developed by INVOLVE and others, the PPI officer will deliver basic training to those selected for the range of consumer roles outlined above. These individuals will be retained on the RDS consumer panel, to be approached and engaged for specific research studies, as the need arises.

3. 'Matchmaking'

See Consumer Panel in section 2 above. The panel approach is intended to allow rapid deployment of consumers in response to the requirements of specific bids and research teams as the need arises.

4. Training for public involvement

The training for members of the consumer panel will include an introduction to research methods and an overview of the principles of public involvement.

The PPI officer will also deliver training to researchers in the importance and value of PPI, and on methods for achieving effective consumer engagement in research. The aim of this training will be to equip researchers with the skills to develop appropriate public involvement in research projects over the longer term without close support from the RDS.

5. Information and resources

The PPI officer will collate and disseminate materials on best practice in and methods of consumer involvement, produced by INVOLVE and other groups, and will develop locally relevant materials as appropriate.

6. Advising on public involvement

In the first instance researchers will have contact with a 'first contact advisor'. Once the advisor has established the proposed project is within scope for the RDS (NE), the advisor will identify the appropriate sources of support within the service, including support for public involvement. The PPI officer will brief and train the first contact advisors in public involvement. However, if the need for support in relation to public involvement is outside the expertise of the advisor, a referral onto the PPI Officer or PPI lead will be made.

7. Joint or collaborative working

The consumer panel is planned as a joint endeavour with the UKCRC North East Centre for Translational Research in Public Health.

The RDS (NE) has connections with:

- the topic-specific Research Networks in the region, for example, DeNDRoN
- the Newcastle-based Stroke Research Network and their Patient, Carer and Public Involvement Manager
- Liver North, a regional liver patient support group
- VOICE North, a regional engagement panel for older people
- the two Comprehensive Local Research Networks.

The Public and Patient Involvement Officer takes part in the RDS involvement forum facilitated by INVOLVE.

8. Involvement in the management or evaluation of the RDS

Consumers will contribute to formative evaluation of the RDS (NE) and to its management. Members of the consumer panel, consumer advisors and peer reviewers will provide feedback on experiences of and satisfaction with their engagement with the RDS. These will be taken into account in developing and refining the service.

Consumer representatives will be members of the Partner Advisory Panel (PAP). The PAP will be a virtual panel, comprising the RDS Executive members (i.e. the RDS Director (at Newcastle University) and Co-Director (at Durham University), the two NHS-based Associate Directors and the RDS Manager), a representative of the NE Strategic Health Authority, the Comprehensive Local Research Network Clinical

Directors (or nominated deputies), representatives from the regional Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) organisations, a senior member of staff (Dean of Research, Pro-Vice Chancellor or nominated deputy) from the two host universities, representatives of the Research and Development Directors or Managers from the NHS Trusts across the region, representatives of the consumer panel and the Chair (or nominated deputy) of the NE Research for Patient Benefit programme board. This group will correspond primarily by email, to ensure that the focus of the RDS (NE) is congruent with the needs of its users.

9. Resourcing/financing involvement in research

The RDS (NE) will follow INVOLVE and NIHR guidelines for the recruitment, engagement and reimbursement of consumers involved in research activities. Resources to enable research teams to involve consumers in the development of funding applications will be provided by the RDS.

10. Other activities

The PPI Officer will lead the development of links and materials for engagement of minority and disadvantaged groups: This will include collating resources on cross-cultural working, including details of services providing translations of research materials. The PPI Officer will also develop and disseminate resources for the engagement of children and of adults lacking capacity and/or with communication difficulties. These will include guidance on the relevant legislation (e.g. Mental Capacity Act) and resources for ensuring access and participation for those with incapacity, communication, sight, hearing, literacy and other special needs.

Research Design Service for the North West

The Research Design Service for the North West (RDS NW) is a partnership between the Universities of Lancaster, Liverpool and Manchester, working with the Universities of Bangor, Cumbria, Central Lancashire and Salford. The RDS NW Coordinating Centre is based at Lancaster University, with three local services matched to the Comprehensive Local Research Network areas: Cumbria and Lancashire, Merseyside and Cheshire and Greater Manchester.

Aim of public involvement in the RDS NW

A working group comprising the Strategic Lead for Public and Patient Involvement, the three specialist public and patient involvement advisors (see section 1 below) and lay members will produce and oversee implementation plans to:

1. Develop and maintain skills and knowledge in public and patient involvement (PPI) amongst RDS NW staff so that high quality PPI advice is embedded in the service offered.
2. Collaborate with regional partners to deliver a co-ordinated approach to building capacity in PPI amongst NW researchers and members of the public.
3. Contribute to the evidence base on PPI in research.

The anticipated outcome of these three aims is to increase the expertise in PPI in research amongst RDS staff, increase the number of research proposals involving patients/the public in their development and higher quality plans for PPI in research, and become an effective resource to support PPI in health research in the North West.

The Strategic Lead for patient and public involvement in the RDS NW is

Professor Ann Jacoby
School of Population, Community and Behavioural Sciences
University of Liverpool
Whelan Building
Quadrangle
Brownlow Hill
L69 3GB

Telephone 0151 794 5602
Email: ajacoby@liverpool.ac.uk

1. Dedicated public involvement posts

Each of the three local centres will have a nominated specialist PPI adviser, drawn from either the RDS team or an RDS partner organisation. These are currently:

- Dr Sara Morris (Cumbria and Lancashire)
- Dr Tracey Williamson (Greater Manchester)
- Dr Paula Byrne (Merseyside and Cheshire)

Their primary role will be to develop the capacity in the RDS NW to support authentic and effective PPI in health research and develop 'self-help' resources on PPI.

2. Development of panel/forum/group

Building on existing intelligence and regional networks, a database will be developed of lay people and groups with experience of, or willing to collaborate in, research. Contacts for the database will be drawn from patient /care support groups, groups and individuals working with networks and universities, local Local Involvement Networks (LINKs).

The database will enable the RDS NW to (i) establish a system for lay review of research proposals before submission to funding bodies and (ii) facilitate links between research teams and members of the public (see section 3 below).

3. 'Matchmaking'

Using the database described in section 2 above the RDS NW will facilitate links between research teams and members of the public who are interested in getting involved in research.

4. Training

The RDS NW will seek to recruit research-involved members of the public to deliver training and other learning opportunities to the RDS advisers and other researchers.

In addition, a 'buddying' scheme is planned to support lay people involved in research, for example, as members of project teams, Comprehensive Local Research Network speciality group, or network executives.

5. Information and resources

It is anticipated that many enquires will be received for initial information on PPI. Therefore the RDS NW will continue to offer, and build upon, existing self-help resources which have been developed by the previous Research and Development Support Unit. These will be hosted on the RDS NW website.

All publicity materials and activities will be targeted at both professional and lay audiences.

6. Advising on public involvement

One role of the specialist PPI advisers will be to extend the knowledge and capacity of all the RDS NW staff and senior methodologists to ensure advice on PPI becomes embedded into the routine service.

The first point of contact for people accessing the RDS will be trained administrators who will provide information, signpost to self-help resources and/or other services or refer to an RDS advisor.

Case management-type support will be offered to studies that are judged to be scope for RDS support. A named RDS advisor will provide initial support for PPI with referral to a specialist advisor if required.

7. Joint or collaborative working with other organisations

A regional partnership is planned to establish a resource to support PPI in health research across the NW region. Partners in this initiative with the RDS NW include the Strategic Health Authority, the Comprehensive Local Research Networks, and other NIHR Networks and funded research centres and units. The regional resource will build on and modernise existing regional structures including the North West Users in Research Advisory Group, and will include lay members and representatives from funding partners. The new regional organisation will oversee the development and management of PPI training, the 'buddying' scheme, the database of lay people and groups, and self-help PPI resources.

The Strategic Lead for PPI and specialist PPI advisors will take part in the RDS involvement forum facilitated by INVOLVE.

8. Involvement in the management or evaluation of the RDS

Patients and the public will be involved in the management and governance of the RDS NW at two levels:

- the lay chair of the NW Users in Research Advisory Group will be part of the Regional Steering Group
- local management groups at each of the three local centres will establish formal mechanisms for obtaining input from lay people with experience of research. The precise form will depend upon local arrangements, for example, in Lancaster, the School of Health and Medicine's lay advisory panel will advise the Lancaster local centre.

9. Resources/financing involvement in research

The RDS NW will provide PPI bursaries to enable researchers with no other access to funds to involve lay people in the development of their research proposals. In return researchers will be asked to agree to their PPI plans being retained in a database and to include modest resources in their project budget to evaluate the PPI elements of their research. The results of these evaluations will be collated into a database.

The PPI working group will develop and consult on a rewards policy for lay contributors to the RDS. It is anticipated that members of the public who get involved will be offered payments for their contributions and expenses will be reimbursed. However, it is recognised that some may prefer other means of reward and recognition, for example, computer courses or other training. The possibility of offering involved members of the public honorary status at the regional universities will be explored. This will allow use of the facilities such as the library.

10. Other activities

Encouraging lay clients: The RDS NW plans to support patients and members of the public to develop their ideas into high quality research proposals. Steps will be taken to engage with patients and the public in ways to ensure the RDS NW is accessible and they help to identify potential clients for the service. The regional PPI working group will recommend activities in this area but they are likely to include world café events, listening events or other activities. The aim is to share PPI research successes, generate ideas for future research and promote a sense of community amongst lay researchers.

Contribute to the evidence base on PPI in research: In addition to the evaluation of PPI in studies which receive bursaries to enable PPI in proposal development, the RDS NW will also consider undertaking a systematic synthesis of the existing evidence for public involvement in research. This will be done in consultation with INVOLVE and in collaboration with the Medical Research Council Hub for Trials Methodology Research at the University of Liverpool.

Research Design Service for Yorkshire and the Humber

The Research Design Service for Yorkshire and the Humber (RDS YH) is a White Rose academic partnership across the universities of Leeds, Sheffield and York, adopting a 'hub and spoke' model. The hub is based at the University of Sheffield with spokes located at the Universities of Leeds and York. The geographical area of the RDS YH spans three Comprehensive Local Research Networks: South Yorkshire, West Yorkshire and North and East Yorkshire and Northern Lincolnshire.

Aim of public involvement in RDS YH

The RDS YH aims to be a centre of excellence for offering advice and support for involving patients and the public in health services research.

Dr Jonathan Boote, Research Fellow, at the Sheffield hub, has lead responsibility for patient and public involvement (PPI).

Research Design Service for Yorkshire and the Humber
School of Health and Related Research
University of Sheffield
Regent Court
30 Regent Street
Sheffield
S1 4DA

Tel: 0114 222 0892

Email: j.boote@sheffield.ac.uk

1. Dedicated public involvement posts

Along with Dr Jonathan Boote at the Sheffield hub, Dr Maureen Twiddy, Research Fellow, based at the University of Leeds, is the Leeds spoke PPI lead. The Sheffield office covers the areas of the South Yorkshire and the North and East Yorkshire and Northern Lincolnshire Comprehensive Local Research Networks. The Leeds office covers the area of the West Yorkshire Comprehensive Local Research Network.

The PPI leads are involved in delivering the public involvement strategy for the RDS YH, providing advice to researchers and clinicians about PPI in research design and the development of research funding applications, and delivering learning events to researchers and clinicians on PPI in research design.

A PPI Management Group comprising the RDS YH Director, the Sheffield-hub PPI lead and the Leeds-spoke PPI lead meets quarterly to oversee the implementation of the PPI strategy and to co-ordinate PPI activity across the RDS YH region.

2. Development of a panel/forum/group

The strategic approach to PPI in the RDS YH is overseen by a PPI Forum. This Forum comprises RDS PPI representatives, one academic each from Sheffield, Leeds and York University with an interest in PPI, six patients/service users/advocates drawn from the Sheffield, Leeds and York areas of the RDS YH

region, and PPI managers and research-active clinicians from NHS trusts within the region.

The terms of reference for the PPI Forum are to:

- provide a PPI input into decisions made at RDS YH Executive Group and Board
- contribute to the development of a PPI strategy for the RDS YH, and to review progress
- provide advice on potential PPI strategic collaborations between the RDS YH and local external organisations
- provide input into the PPI learning events delivered by the RDS YH
- provide input into the PPI pages of the RDS YH website
- provide input into the PPI section of the RDS YH annual report
- contribute to the review of applications for the RDS YH Public Involvement in Grant Applications Funding Award (see section 9 for further details).

3. 'Matchmaking'

An incremental approach to the development of matchmaking databases across the RDS YH region will be taken, as part of co-operative strategic activity on PPI with other NIHR-funded organisations within the region such as the Comprehensive Local Research Networks and the Collaborations for Leadership in Applied Health Research and Care (see section 7 for further details of collaborative working).

4. Training for public involvement

The RDS YH offers learning events on PPI in research design as well as bespoke advice and training to clinicians/practitioners and health service researchers wishing to engage with patients and members of the public in research design. Training activities include:

- a half-day learning event entitled 'PPI in research design and the development of grant applications'. In 2009, this learning event will be delivered at the universities of Leeds, Sheffield and York to researchers and NHS clinicians from within the RDS YH region
- an hour-long seminar on 'PPI in the development of grant applications' has been prepared and plans are being made to deliver this seminar in NHS Trusts within the RDS YH region.

5. Information and resources

Web-based information and resources for clinicians, researchers, patients and members of the public on PPI in research is provided on the RDS YH website at: <http://www.rds-yh.nihr.ac.uk/patient-and-public-involvement.aspx>

6. Advising on public involvement

Advice to researchers and clinicians from the RDS YH is delivered in 'advice clinics'. Researchers seeking advice on PPI in their research funding application will first complete an advice clinic form. This will be reviewed by the PPI leads to decide who is best placed to provide advice (usually determined by the location of the researcher). At present all advice on public involvement is provided by the PPI leads. In future, other advisors within the RDS YH may take on this role as demand increases and they have developed relevant expertise.

7. Joint or collaborative working

The RDS YH aims to develop collaborative working with other research support organisations in the Yorkshire and Humber region. For example, the South Yorkshire Comprehensive Local Research Network has established a local priority group on PPI. The RDS YH Director and the Sheffield hub PPI lead are members of this group. Along with the Sheffield-based Collaboration for Leadership in Applied Health Research and Care (CLAHRC), this group is developing a South Yorkshire-wide PPI strategy. Funding has been identified to recruit a Research Associate with responsibility for taking forward the South Yorkshire PPI strategy. Two key aspects of the post will be developing training and support for patients and members of the public interested in getting involved in research activity, and the development of a database of patients, members of the public and organisations representing their interests who have an interest in health research. This database will assist the RDS YH with its matchmaking function in the South Yorkshire region.

Once this strategy has been rolled out, the intention is to encourage similar strategic approaches in the West Yorkshire and North and East Yorkshire and Northern Lincolnshire regions of the RDS YH.

The RDS YH PPI leads are members of the RDS Involvement Forum facilitated by INVOLVE and are also members of invoNET.

8. Involvement in the management or evaluation of the RDS

As described above, the RDS YH has developed a PPI Forum. The Forum will enable patients and members of the public to have the opportunity to be involved in the development and running of the RDS YH. In addition, there will be PPI representation on the RDS YH Board, Executive Group and Consultative Group.

9. Resourcing/financing involvement in research

The RDS YH recognises that PPI in grant application development requires financial support that may not be available from other sources. The RDS YH Public Involvement in Grant Applications Funding Awards are available to researchers in the RDS YH area working in health and health-related social care to support the involvement of patients and members of the public in developing grant applications for projects that will form part of the National Institute for Health Research (NIHR) Portfolio.

Grants of up to £500 are available. Applications are invited throughout the year, although only one application for this funding may be made for each grant in development. Guidance has been developed to assist researchers in making their applications. Applications will be judged against this guidance. Members of the PPI Forum are involved in reviewing these applications for funding. The application form for this award and the accompanying guidance can be found at: <http://www.rds-yh.nihr.ac.uk/patient-and-public-involvement/ppi-in-grant-applications-funding-award.aspx>

Successful applicants are asked to write a short report, within one year of the payment of the award, to state how the award was used, the extent and ways in which patients and members of the public contributed to the development of the grant application, and whether the grant application was successful. Applicants may also be asked to take part in an evaluation process of the scheme to ascertain its effectiveness.

10. Other activities

A comprehensive thematic bibliography of the literature on PPI in health research has been developed and is on the RDSYH website at <http://www.rdsyh.nihr.ac.uk/file.ashx?id=1020>. This bibliography will be regularly updated.

Research Design Service for the East Midlands

The Research Design Service for the East Midlands (RDS EM) is a partnership between the universities of Nottingham, Leicester and Northampton and De Montfort University. The two main bases are Nottingham (covering Nottinghamshire, Derbyshire and Lincolnshire) and Leicester (covering Northamptonshire, Leicestershire and Rutland).

Aim of public involvement in RDS EM

To actively facilitate patient and public involvement in health or social services research via training and forming links between researchers, academics and service users and carers.

1. Dedicated public involvement posts

The RDS EM has three posts dedicated to public involvement:

- Regional PPI Lead: Raksha Pandya* based at Centre for Social Action, De Montfort University
- Local Lead with PPI responsibility 1: Dawn Marie Walker at the University of Nottingham
- Local Lead with PPI responsibility 2: Kate Windridge at the University of Leicester.

*Centre for Social Action
Faculty of Health and Life Sciences
Room 0.15b
Hawthorn Building
De Montfort University
The Gateway
Leicester
LE1 9BH

Tel: 0116 207 8778

Email: rpandya@dmu.ac.uk

2. Development of a panel/forum/group

RDS EM Lay People's Group (March 2010): The creation of a panel of lay reviewers will help to inform research design and refine grant applications. Individuals will be invited to join this panel from existing service user groups and networks in the region. They will be introduced to the range of NIHR funding opportunities, and will receive training regarding reviewing research proposals or becoming committee members on the regional management board to assist the RDS EM in strategic and operational direction. RDS EM staff will offer continuous support to lay members who will receive appropriate reimbursement for their input.

RDS EM People Interested in Research Group (on-going as of March 2009): This is a database of interested members of the public and patients who wish to get involved in research. The database will be organised into disease specific groups. The advertising for this service will be promoted widely to ensure it reaches a diverse audience.

3. 'Matchmaking'

Stemming from the groups outlined in section 2 above, a matchmaking service will be offered by RDS EM which will link together researchers with service users according to disease and geography. This will be bilateral with both researchers looking for service user team members and service users wanting to be considered for any forthcoming projects. Support will be offered to ensure that the matching is appropriate and sustainable.

4. Training for public involvement

The RDS EM will offer PPI training with the following learning objectives:

Participants will:

- understand the ethos and value of public involvement in health and social care research
- understand different styles of lay involvement, and levels of engagement in the research process
- consider the challenge of lay involvement, and explore some possible responses to these (including the needs of all research stakeholders)
- know where to find further information and support.

This training is delivered on demand to Research and Development managers and heads of departments at academic institutions who are willing to host the training. This training can be tailored on request to a specific audience. As from September 2009, PPI training sessions will be scheduled as part of the RDS EM short course timetable to enable individuals to attend.

5. Information and resources

The RDS EM website will have up-to-date information and resources for researchers, clinicians, lay people and RDS staff to use and download. It will also contain links to other useful websites such as INVOLVE or Macmillan Cancer Support. The PPI Lead also manages a library of resources with electronic and paper versions of resources. At the weekly RDS team meetings, PPI will be a standing item on the agenda and RDS EM will work collaboratively with lay people on the Partners' Council (see section 8 below).

6. Advising on public involvement

All RDS EM staff are aware of and trained to discuss the benefits and challenges of PPI when advising research teams. Research Advisors have an understanding of the systems and processes to enable meaningful involvement. RDS EM will maintain a range of PPI resources including relevant policy documents and practice guidelines (such as those produced by INVOLVE) and a directory of local service-user groups and networks (which both RDS staff and external researchers may utilise). The regional and local PPI leads will guide other staff members in advice-giving in this area and will manage more complex or challenging cases, for example, when the principal investigator is a service user, or when working with vulnerable groups.

7. Joint or collaborative working

Regular contact with bodies such as INVOLVE, the Centre for Social Action, NIHR Clinical Research Network, LINKs, NHS Trust Patient Panels and so on, will ensure that the RDS EM is able to support a co-ordinated approach to PPI and to share ideas, expertise and best practice in supporting patient and public involvement in research.

To further develop local strategic working and the sharing of best practice, RDS EM will explore, and support, the establishment of PPI Good Practice in Research Alliance across Leicester, Northampton and Rutland with representation from all relevant stakeholder groups and organisations. A similar initiative will be supported across Nottinghamshire, Derbyshire and Lincolnshire should the model be useful and efficient.

The regional and local leads for PPI take part in the RDS Involvement Forum facilitated by INVOLVE.

8. Involvement in the management or evaluation of the RDS

Support for Patient and Public Involvement will be a standing item on the agendas of all strategic and operation groups within the RDS. The RDS stakeholder group, called the Partners' Council, will have two public/patient/lay representatives who will provide advice and oversight of the service offered. The PPI representatives on the Partners' Council will work closely with the RDS EM public involvement Lead, who will be a member of the Regional Management Board. Local Leads for PPI in Nottingham and Leicester will raise relevant issues at Local Operational Groups. Where appropriate, members of the lay review panel (see section 2 above) will be invited to attend Local Operational Groups.

9. Resourcing/financing involvement in research

Currently the RDS offers a grant of up to £500 for pre-protocol work. These awards allow researchers from health and social care to engage with service users to develop their research idea and to write funding applications. The money can cover items such as organising a PPI consultation event, or enabling service user attendance at research meetings.

10. Other activities

As the public involvement work in the RDS EM evolves, it will be necessary to evaluate the processes and adapt them accordingly. This will be an ongoing process. Other anticipated developments to be considered are:

- regional PPI in Research Strategy and Action Plan
- lay person's role description
- report on the effectiveness of the pre-protocol awards.

West Midlands Research Design Service

The West Midlands Research Design Service (WM RDS) has three hubs:

- School of Health and Population Sciences at the University of Birmingham
- Research Institute for Primary Care and Health Sciences at Keele University
- Warwick Medical School at the University of Warwick.

The WM RDS will help researchers in the region develop and design high quality research proposals for submission to the Research for Patient Benefit (RfPB) Programme.

Aim of public involvement in WM RDS

The Keele hub will host the User Involvement Unit, led by Professor Pauline Ong and Dr Clare Jinks, who is also the methodological lead for user involvement within the WM RDS. The Unit will provide pan-regional support for public involvement in research.

Dr Clare Jinks
Senior Lecturer in Health Services Research
Arthritis Research Campaign National Primary Care Centre
Primary Care Sciences
Keele University
Staffordshire
ST5 5BG

Tel: 01782 734831

Email: c.jinks@cphc.keele.ac.uk

1. Dedicated public involvement posts

The Unit has appointed a Research Fellow in Patient and Public Involvement, Dr Pam Carter. The main roles of this post will be to develop and support the User and Carer Advisory Forum (see sections 2 and 3 below), provide public involvement advice to researchers whose projects are adopted by the WM RDS (see section 6 below), and work on projects to evaluate the impact of PPI on research.

2. Development of a panel/forum/group

The WM RDS will establish a Users and Carers Advisory Forum drawn from existing user groups within the Academic Units and local Trusts. The Forum will provide a network of users who will be involved in specific proposals developed with the support of the WM RDS. A pool of patients and users will be recruited to the Forum from existing patient groups on the basis of their interest in specific disease areas and a concern to ensure that research has an impact on aspects of healthcare that are a priority for patient groups.

3. 'Matchmaking'

The User Involvement Unit will facilitate access for researchers to members of the User and Carer Advisory Forum. Forum members may be asked to comment and advise on:

- the relevance of specific research questions
- aspects of the research design, documentation, recruitment and consent processes
- how research results may be disseminated and applied to practice.

4. Training for public involvement

User and Carer Advisory Forum members (see sections 2 and 3) will participate in training activities on research methods and patient involvement strategies.

The User Involvement Unit is planning to develop materials and processes to inform other WM RDS research advisors and staff about public involvement in research. Models and approaches adopted by other RDS will be reviewed to support this.

5. Information and resources

The Research Fellow in User Involvement will gather together up-to-date guidance in relation to public involvement in research and information about the range of research projects which involve service users (regionally and nationally). This will ensure research teams being supported by the WM RDS have access to current best practice guidance and information.

6. Advising researchers on public involvement

Researchers will apply to the Director of each hub with WM RDS for support with a research funding application. Projects eligible for specialist WM RDS support will be those that meet the eligibility criteria of the National Institute for Health Research, Research for Patient Benefit Programme and are capable of being investigated within its funding and project time-scale limitations.

Once researchers are adopted on the WM RDS, they will be directed to the User Involvement Unit, when required, for support and advice about public involvement in research.

7. Joint or collaborative working

The WM RDS User Involvement Unit is located within the Arthritis Research Campaign National Primary Care Centre (the Centre). User involvement is central to all the research in the Centre, supported by a User Support Worker. This post has been developed to provide support to the service users and carers involved in specific projects taking place within the Centre. As the Centre and the User Involvement Unit of the WM RDS are co-located, close collaboration between the two organisations is anticipated. It is anticipated that West Midlands RDS will also liaise with the Local Involvement Networks (LINKs), Comprehensive Local Research Networks (CLRNs) and the topic-specific research networks.

The User Involvement Lead and Research Fellow will take part in the RDS public involvement forum hosted by INVOLVE.

8. Involvement in the management or evaluation of the RDS

The Users and Carers Advisory Forum (see section 2 above) will nominate two representatives to the WM RDS Steering Group. The Forum will advise the Steering Group on involvement strategies; for example on ways to ensure health professionals

are encouraged to develop proposals that are relevant to patients, on ways of improving patient involvement in research.

9. Resourcing/financing involvement in research

Members of the Service User and Carer Advisory Forum will be paid for their involvement according to the rates set out in the National Institute for Health Research Programmes payment and reimbursement rates for public involvement (INVOLVE, July 2008).

Adopting and adapting this model of payment will also be encouraged in the research applications which the WM RDS User Involvement Unit are supporting.

West Midlands Research Design Service offers a small bursary scheme to support the involvement of patients and the public in the design of a research project and the related grant application. A maximum of £500 is available per application. The application can be submitted at any time throughout the year.

Research Design Service for the East of England

The Research Design Service for the East of England (RDS EoE) is led from the University of Essex in partnership with four other Universities (Bedfordshire, Cambridge, East Anglia and Hertfordshire) and four NHS Trusts (Cambridge NHS, Addenbrookes, Norfolk & Norwich and Essex & North Hertfordshire) to offer research advice and support across the six counties (Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk) of the region.

Aim of public involvement in RDS EoE

The overall aim is to develop a systematic approach to public and patient involvement (PPI) across the region and to share existing PPI expertise within the RDS EoE, working towards a well-developed network of PPI at the national, regional and local level.

A PPI working group has been set up led by the PPI lead.

Professor Gill Green
School of Health & Human Sciences
Room 2S2.5.20
University of Essex
Colchester Campus
CO4 3SQ

Telephone: +44 (0)1206 874144
E-mail: gillgr@essex.ac.uk

The PPI working group includes:

- Jennie Todd, RDS Advisor, University of Essex
- David Matthews, RDS Advisor in PPI, University of Essex
- Emma Wilkinson, RDS Advisor, University of Bedfordshire
- Matthew Norton, RDS Advisor, Cambridge NHS
- Lee Berney RDS Advisor, University of East Anglia
- Jacqueline Romero, Coordinator for Patient and Public Involvement in Research (PPIRes), East Norfolk & Waveney Research Consortium.

It is anticipated that lay representatives will also be asked to join the group. The working group will develop and oversee the PPI strategy for the RDS EoE.

1. Dedicated public involvement posts

Two part-time posts have been created in collaboration with the Comprehensive Local Research Networks, one based in Cambridge (0.5 wte) and the other at the University of Essex (0.2 wte). The main purpose of these posts is to develop links with individuals and groups who are interested in getting involved in health research.

2. Development of a panel/forum/group

In the region covered by RDS EoE there are two resources which exist to facilitate public involvement in research: the Patient and Public Involvement in Research Group (PPIRes Group), covering Norfolk and Suffolk funded by the East Norfolk and

Waveney Research Consortium and the Public Involvement in Research Group (PIR Group), based within the Centre for Research in Primary and Community Care at the University of Hertfordshire.

Close working with these groups has been established and a further panel based at the University of Essex is being developed.

3. 'Matchmaking'

The PPI input to RDS-supported research applications has built on the links that the applicants already had in place with user groups or members of the public. However, it is recognised that not all researchers applying for research funding will have existing links upon which to draw. Therefore, the RDS EoE needs to ensure that a suitable pool of service users who can be called upon to provide input to RDS-supported research applications on these occasions is available. The existing PPI in research groups already provide assistance. The PPI post based at Essex is identifying groups which are already operating and developing new links with other people and groups interested in getting involved in health research. Consideration will be given to the need to develop further panels of members of the public to link with the RDS EoE if required.

4. Training for public involvement

In order to ensure that service users who have input to RDS-supported research have the requisite skills, some training may be required. A number of Universities in the region already offer this type of training, for example, Essex, Hertfordshire and Anglia Ruskin Universities currently run courses targeted at service users. The RDS will use some of the training budget to sponsor service users who provide input to the RDS.

It is intended that all RDS staff engage with PPI in their research support work. Therefore, a bespoke training course for RDS staff about the role of PPI in research and how to promote it will be devised and delivered.

5. Information and resources

Information and resources in relation to PPI in research will be added to the RDS website. Leaflets about PPI in research are being produced targeted at both researchers and the public interested in getting involved in research. In addition, we are liaising with other groups about the possibility of having a dedicated regional website about PPI in research possibly hosted by the Local Involvement Network (LINKs).

6. Advising on public involvement

The PPI input to RDS EoE-supported research applications that has evolved thus far is organised on a case by case basis according to the needs of the project and building on the PPI links that the applicants already had in place. This is co-ordinated by the RDS advisors.

7. Joint or collaborative working

A key aim of the PPI strategy is to develop joined-up, productive working with key partners who also have a PPI remit in the East of England region:

- the RDS EoE will establish links with the regional 'service user in research' groups, for example, PPIRes and PIR (see section 2 above) and other local service user groups
- collaborative working has been developed between the RDS EoE and the Comprehensive Local Research Networks in the region with joint PPI posts established (see section 1 above)
- Essex-Hertfordshire Comprehensive Local Research Network worked closely with the RDS EoE to organise a 'getting involved with research conference' targeted at service users in Essex and Hertfordshire which attracted over 50 people.

The Public and Patient Involvement Lead takes part in the RDS Involvement Forum facilitated by INVOLVE.

8. Involvement in the management or evaluation of the RDS

The RDS EoE is exploring the idea of an External Reference Group. Such a group might include a range of stakeholders (clinicians, R&D trust managers, academics and service users) who could be called upon as and when required to discuss specific issues. This would provide a forum in which service users would be consulted on RDS matters that were relevant to the development of PPI in research in the region.

Evaluation of PPI input in research applications, especially for the Research for Patient Benefit Programme, is planned. This will help develop knowledge in relation to whether the RDS EoE networking, support and training is effective, what works well and where the gaps are in terms of PPI knowledge and development. No specific methods for this evaluation are available at present.

9. Resourcing/financing involvement in research

A small PPI ring-fenced budget was included in the original RDS bid. This budget supports the costs of implementing the PPI strategy and is managed by the PPI working group. Further funding from within the RDS EoE will be sought with the possibility of financing the costs of public involvement in the development of research funding applications.

A consistent approach to the payment of members of the public for their time and expertise when contributing to research will be sought across the region/organisations. The guidelines developed by INVOLVE for paying for involvement in research will be drawn upon. However, the difficulties in paying service users who receive benefits without affecting their benefit claim is acknowledged. Travel and subsistence expenses as well as any training costs should always be covered.

10. Other activities

User-led research will be supported by the RDS and RDS staff will develop links with existing user groups to promote user-led research.

Research Design Service London

The Research Design Service London (RDS London) is a partnership between King's College London, Imperial College London, Queen Mary, University of London and University College London. It is focused on supporting applications for funding from NHS researchers and those working in partnership with the NHS. Priority will be given to those applying for NIHR Research for Patient Benefit (RfPB) funding.

Each partner organisation will cover the NHS organisations within specific geographical areas of Greater London. Detailed information on this is available on the RDS London website (<http://www.rdslondon.co.uk/contact.html>).

Aim of public involvement in RDS London

A user involvement strategy will be developed, drawing on the existing expertise in the RDS host institutions. The implementation of the strategy will provide advice on when and how to involve users in research design and will build up a database of contacts for different diseases, services and communities in London.

The RDS London will draw on existing expertise within the organisation and that of other organisations such as INVOLVE to ensure the development of researchers' abilities to involve patients and the public at all stages of the research process i.e. from development of the research idea through to the dissemination of findings.

The User Involvement Officer is Carol Porteous.

Research Design Service London
King's College London
5th Floor
Capital House
42 Weston Street
London
SE1 3QD

Tel: 020 7848 6763

Email: carol.porteous@kcl.ac.uk

1. Dedicated public involvement posts

Carol Porteous, User Involvement Officer is based at King's College London. Her role is to develop the user involvement strategy for the RDS London and act as a point of contact for enquiries about user/public involvement.

2. Development of a panel/forum/group

A User Involvement Advisory Group comprised of service users, members of the public and researchers will be established to support and develop the public involvement work of the RDS London.

3. 'Matchmaking'

To facilitate links between research teams and members of the public, a database of contacts of patients and members of the public interested in research will be developed and maintained. This will commence by drawing on existing public involvement in research groups currently supported within the region, for example,

mental health and stroke, but will be expanded to a full range of different disease groups, services and communities in London.

4. Training for public involvement

Development of skills to enhance the involvement of health and social care service users and public in research is central to public involvement strategy of the RDS London. Training needs across the institutions within RDS London, both University and NHS, in relation to public involvement will be assessed.

Information on training and resources offered by other organisations will be compiled. It is also anticipated that training will be provided by the RDS London for (i) researchers in methods to involve service users/members of the public and (ii) service users/members of the public in the skills needed to engage with researchers.

The User Involvement Officer will organise workshops, conferences, institutional seminars and other events targeted at key stakeholding communities as appropriate.

5. Information and resources

The User Involvement Officer will gather up-to-date information about the user involvement expertise across the RDS London partner organisations. Their role will also be to develop guidance for researchers accessing RDS about the methods for and appropriate levels of involvement. This will include directing researchers to existing resources. The RDS London will develop online guidance for many topics, including user involvement. This is linked to a national RDS initiative, to ensure consistency of message and no duplication of effort.

6. Advising on public involvement

In the initial stages of the RDS London the User Involvement Officer and the strategic user involvement lead will be the first points of contact for researchers seeking advice in relation to public involvement in their research applications. As expertise develops across the partner organisations, other RDS staff may get involved with this.

7. Joint or collaborative working

The RDS London will work in partnership with other national and local agencies to raise the profile of service user involvement in research, these include:

- Clinical Research Network Coordinating Centre
- National Patient Safety Agency
- National Institute for Clinical Excellence.

The User Involvement Officer and user involvement strategic lead take part in the RDS involvement forum facilitated by INVOLVE.

The London Comprehensive Local Research Networks, North West London Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and Comprehensive Biomedical Research Centre are very keen to work with RDS London on PPI so that the organisations have a consistent message, adopt best practice and do not duplicate effort. The organisations plan to align budgets so that resources are used wisely.

8. Involvement in the management or evaluation of the RDS

The User Involvement Advisory Group will support and develop the public involvement work of the RDS London.

A further role of the User Involvement Officer will be to develop strategies to monitor the public involvement activities in the RDS London and to develop and implement methods to assess the effectiveness of public involvement. This strand of work will be supported by the collaboration with other organisations across the London region.

9. Resourcing/financing involvement in research

There are no specific plans about the resourcing or financing public involvement in research applications at present.

Research Design Service South East

The Research Design Service South East (RDS SE) is a partnership between the Universities of Brighton, Kent and Surrey. The RDS SE has centres in Canterbury, Brighton and Guildford covering the counties of Kent, Sussex and Surrey.

Aim of public involvement in RDS SE

The overall aim is to ensure that public involvement is fully integrated into all the activities and services provided by the RDS SE. Public involvement will be built into NIHR applications and RDS SE staff, researchers and lay contributors will have the skills to achieve this. All aspects of RDS SE work, including the advice service, management and communications will be informed by public stakeholder perspectives.

The intended outcomes of the Public Involvement strategy are:

- effective public involvement in research protocols supported by the RDS SE
- increased knowledge and confidence of researchers in the region in working with the public on research
- increased knowledge and confidence of lay members involved in RDS SE activities
- regular updating of the public involvement knowledge for RDS SE research advisors
- RDS SE contribution to national public involvement awareness
- public involvement in RDS SE processes and strategy
- greater public awareness of opportunities for involvement in NHS research
- maintenance and expansion of RDS SE links with community groups.

The Public Involvement Lead is Natalie Lambert based at the University of Brighton. During Natalie's maternity leave in 2009, Dr Kay Aranda is acting public involvement lead.

Dr Kay Aranda
Research Design Service South East
Centre for Nursing & Midwifery Research
Mayfield House (room 262)
University of Brighton
Falmer
BN1 9PH

Telephone: 01273 644109
Email: k.f.aranda@brighton.ac.uk

1. Dedicated public involvement posts

There is a Public Involvement Coordinator or Officer at each RDS SE site:

- Joanna Wunsch (Coordinator) based at the University of Brighton
- Amanda Bates (Officer) based at the University of Kent
- Kay Stephenson (Coordinator) based at the University of Surrey.

The Public Involvement Lead will oversee the activities of the public involvement Coordinators/Officer who will be putting into operation the public involvement strategy

as described in the sections below. The Lead will also provide specialist public involvement support, referral to advisors and NHS researchers and disseminate new initiatives from INVOLVE.

2. Development of a panel/forum/group

A panel of 8-12 members of the public will be established. The role of the panel will be to:

- review research funding applications being supported by the RDS SE as required, including an assessment of applications in partnership with one academic member of staff
- review RDS SE communication materials including RDS SE website
- be offered membership of RDS SE advisory and work plan groups.

The members of this panel will be supported to review research funding applications by undergoing practice with an application for the Research for Patient Benefit programme. Individual support from the Public Involvement Lead will be arranged according to their preferences, for example, face to face locally or email at designated date and time.

3. 'Matchmaking'

A liaison database will be kept by the Public Involvement Coordinator/Officer at each site. This will comprise contact details and interests of lay people and groups interested in being contacted about discrete research projects. The Coordinator/Officer at each site will be responsible for recruiting to and updating this database. The Public Involvement Lead will work with individual research advisors/NHS researchers to broker contact and communication with relevant lay people.

A number of steps will be taken to recruit lay people to the liaison databases:

- a leaflet will be drafted with lay involvement, which details the public involvement activities of the RDS SE
- attendance at group meetings to disseminate leaflets detailing the public involvement strategy
- attendance at relevant public involvement conferences (eg. Local Involvement Networks (LINKs)) to disseminate leaflets detailing the public involvement strategy
- information placed in relevant newsletters, for example, the University community partnerships and LINKs
- information provided through well-maintained and clear public involvement pages on the RDS SE website.

To maintain communication and contact with lay people, a 6-monthly newsletter will be sent to all RDS-linked lay people, containing an update on lay activities in the RDS and examples of how lay involvement is being incorporated in study design. This will be sent by email where possible, but by post where preference is indicated.

4. Training for public involvement

The RDS SE will develop training programmes on public involvement for:

- researchers (via timetabled courses)
- RDS SE Public Involvement Panel members (via bespoke training)

- lay people involved in research projects (via bespoke training)
- RDS SE advisors and other staff (annual training and regular updates on policies and initiatives).

Options for user involvement in training provision will also be explored.

5. Information and resources

Information on public involvement will be provided through well-maintained and clear public involvement pages on the RDS SE website. This will include three leaflets:

1. One for researchers setting out the basics of public involvement in research design, key elements of good practice and key terminology and the main ways in which to conduct public involvement. This document will be designed to be handed out and referred to by RDS SE research advisors also.
2. One setting out the public involvement bursary scheme, including the eligibility and assessment criteria, how to apply, and a pricing guide for public involvement activities (see section 9 below).
3. One for members of the public setting out what getting involved in research means and how people might get involved with the RDS.

The public involvement web pages will be linked to relevant national public involvement websites such as INVOLVE and People in Research.

A quarterly email update will go out to all RDS SE staff regarding the public involvement strategy. This will detail:

- the different populations/conditions represented on the liaison database (see section 3 above)
- update on the bursary award scheme (see section 9 below)
- deadlines for lay review of funding bids
- dissemination of any relevant national or regional news
- information on public involvement training
- documentation relevant to both RDS advisors and NHS researchers
- tips on best practice for public involvement.

6. Advising researchers on public involvement

In order to provide a clear and consistent service to researchers, the RDS SE will adopt a model for supporting public involvement in applications to the National Institute for Health Research Programmes. This will be modelled on three broad research stages:

Research Stage 1: Proposal development

- advice on how to build public involvement into proposals and referral to INVOLVE guidance.
- RDS SE support to find lay people (via RDS liaison database and/or community group lists).

Research Stage 2: Funding application

- an offer for the RDS SE public involvement panel to review the bid
- research advisor bid review
- advice on costing public involvement into the bid.

Research Stage 3: Implementation

- RDS SE training in public involvement for researchers and lay contributors for involvement in research design
- RDS SE support to find lay people (via RDS database and/or community group lists).

In the initial period of the RDS SE the Public Involvement Lead and Officer will provide advice to researchers on public involvement. As expertise develops within the team of RDS advisors others will also be encouraged to take on this role.

7. Joint or collaborative working

The Public Involvement Lead and Officer take part in the RDS involvement forum facilitated by INVOLVE. All relevant information will be disseminated by the Lead to the public involvement Coordinator/Officer at each site, for them to disseminate to research advisors, via the quarterly internal email, or to relevant lay members as appropriate. All issues arising concerning public involvement can also be fed 'upwards' to INVOLVE and other national groups on behalf of the RDS SE.

8. Involvement in the management or evaluation of the RDS

Members of the user panel (see section 2 above) will be invited to review RDS SE communication literature including the RDS SE website and be offered membership of the RDS SE stakeholder group and advisory group.

The RDS SE is developing a method, using metrics, for monitoring and evaluating all aspects of public involvement activity. Specific fields are being developed in the RDS SE database where all RDS SE activity is recorded.

9. Resourcing/financing involvement in research

Members of the public who become involved in the panel (see section 2) will be paid for their involvement under the Brighton University policy for paying outside contractors.

The RDS SE has opened a small grant scheme to finance the involvement of lay people in the design of discrete healthcare research studies. For researchers who wish to involve members of the public in the development of a research funding application up to £350 can be requested. Only one application can be made per study, which should be already receiving support from the RDS SE and where the researchers intend to submit an application to the Research for Patient Benefit or other National Institute for Health Research Programmes. Applications will be assessed by the RDS SE lay review panel and an academic member of staff. Successful applications will demonstrate value for money and plans for lay involvement which are appropriate to the study. Successful applicants will be required to provide evidence of how the award was used and to complete a brief report within one year of receiving the award.

Research Design Service South Central

The Research Design Service South Central (RDS South Central) is a partnership between the Universities of Southampton, Oxford and Portsmouth, with the main coordinating office at the Southampton General Hospital. Each site will work closely with the local Research and Development offices in the NHS Trusts.

Aim of public involvement in RDS South Central

The aim of public and patient involvement in the RDS South Central is to facilitate the involvement of patients and the public in designing research and involve lay members in the processes of the RDS.

The strategic public and patient involvement lead is Claire Ballinger, Senior Qualitative Methodologist based at Southampton. She will coordinate public involvement activities with local public and patient involvement leads in Oxford, Professor Ray Fitzpatrick, and Portsmouth, Derek Ward.

Research Design Service South Central
Level C (805) South Academic Block
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD

Tel: 023 8079 4778

Email: C.Ballinger@soton.ac.uk

1. Dedicated public involvement posts

A Public and Patient Involvement (PPI) Officer, Hayley Haines, has been recruited and is based at the Southampton office, funded initially for one year through the Strategic Health Authority. The main purpose of this post is to establish a network of patient groups and public forums interested in being involved in research. This will facilitate the 'matchmaking' role between research teams and members of the public (see section 3) and the development of the Public Involvement Core Team (see section 8).

2. Development of panel/forum/group

A Public Involvement Core Team comprising patients and the public will be developed to contribute to the work of the RDS South Central (see section 8 below) and to provide assistance on particular projects.

3. 'Matchmaking'

To enable links between researchers and members of the public interested in getting involved with research a PPI Network will be established. The network will draw on existing patient groups and public forums, such as LINKs and Engage (a Portsmouth-based patient involvement group) and information will be held on the RDS South Central database. The database will contain information about national organisations, for example, Diabetes UK as well as local groups and individuals.

4. Training

Training programmes will be planned by the PPI officer for RDS South Central research advisors, principal investigators/researchers across the region and members of the public interested in getting involved with research.

The training needs of the RDS research advisors will be assessed at the team away day and a training programme devised to meet these needs.

A workshop will be devised for principal investigators and researchers. The training will be planned to coordinate with National Institute for Health Research (NIHR) Research for Patient Benefit Research Programme deadlines. This programme will be complemented by public and patient involvement advice surgeries. This will involve the PPI officer visiting sites across the region to meet with and support researchers to develop their plans for public involvement in their proposed research as needed.

The RDS South Central will organise master classes on research methods and terminology for members of the public. They are also exploring current training available for the public.

5. Information and resources

A series of information packs about public and patient involvement will be developed for RDS research advisors, principal investigators/researchers and members of the public.

The information pack for RDS advisors, principal investigators and researchers will include:

- information about the levels of involvement (consultation – collaboration – user-led) and tips on how to implement these levels
- an example person specification for a public member of project steering committees
- personal details capture form for members of the public
- information on the role members of public may have in a study and the importance of all members of the team understanding this
- advice on payment and access to other sources of advice, for example, the Involvement Helpline (Milton Keynes Citizens Advice Bureau)
- contact details of other public and patient involvement organisations.

In addition, the information pack for RDS advisors will also include:

- information on how to search RDS South Central public and patient involvement database (see section 3 above) and a contact sheet
- how public and patient involvement is addressed in NIHR funding streams
- tips on overcoming researcher opposition to public and patient involvement.

The information pack for members of the public will include:

- information on the funding process for the NIHR research programmes
- a glossary of research terms
- details of points of contact within the RDS South Central

- case studies on how other people have been involved in research
- questions to ask the principal investigator/researcher about the proposed involvement.

6. Advising on public involvement

Research advisors across the partner organisations will be advising principal investigators and researchers about involving the public in their research. This will be supported by the public and patient involvement officer and leads and by the information packs (see section 5 above) and training (see section 4 above) and the Public Involvement Core Team.

7. Joint or collaborative working with other organisations

The RDS South Central has joined with a number of other Southampton and Hampshire based research organisations to resource a collaborative recruitment drive to attract members of the public to get involved in research. This group includes the Hampshire and Isle of Wight Comprehensive Local Research Network, local branches of the Topic-specific Clinical Research Networks (DeNDRoN, Primary Care), the NIHR Evaluation, Trials and Studies Coordinating Centre, local NHS Trust R&D Offices and the Clinical Trials Unit at the Southampton General Hospital.

This joint working may lead to other collaborative initiatives, for example, joint financing of the Public and Patient Involvement Officer post after the initial one year funding provided by the Strategic Health Authority. The RDS South Central will also aim to develop this type of collaborative working in other parts of the South Central region.

The Public and Patient Involvement Lead and Officer take part in the RDS involvement forum facilitated by INVOLVE.

8. Involvement in the management or evaluation of the RDS

The Public Involvement Core Team (see section 2) will contribute to the management of the RDS. Person specifications and descriptions of the role have been developed to help people to decide whether they are interested in this role. Resources are available to support this team throughout the five year contract of the RDS. Ways in which the team can be self-sustaining after the end of the one year Public and Patient Involvement Officer post will be explored.

The RDS South Central plan to follow-up and track the plans for public involvement in the research proposals which they support. The aim of this is to assess the impact involvement has on the research process and develop a series of case studies to promote the idea of public involvement with researchers within the region.

9. Resources/financing involvement in research

The RDS South Central will pay for expenses as well as time, skills and expertise of members of the public getting involved with the development of any projects currently being supported. Funding for continuing involvement in research projects will be costed into research grant applications. The RDS South Central intends to offer spaces on training courses and support in terms of advice on involvement issues.

Research Design Service – South West

The Research Design Service South West (RDS-SW) covers the geographically largest Strategic Health Authority area in England. There are nine RDS offices across the region, primarily hosted by NHS Trusts with links to local Universities: Bath, Bristol, Exeter, Gloucester, Plymouth, Poole, Salisbury, Taunton and Truro.

Aim of public involvement in RDS-SW

The RDS-SW is committed to ensuring that patient and public involvement is at the centre of the work of the service and the advice it provides.

The public and patient involvement will fall into two key areas: the provision of a strategic overview of public and patient involvement for the RDS-SW and the inclusion of service user involvement into projects.

The Public Involvement Lead is Julie Hapeshi, Deputy Director of the RDS-SW, based at the Gloucester office (0.5 wte).

Leadon House
Gloucestershire Royal Hospital
Great Western Road
Gloucester
GL1 3NN

Tel: 08454 225465

Email: julie.hapeshi@glos.nhs.uk

1. Dedicated public involvement posts

At present there are no planned staff posts dedicated to public involvement in addition to the public involvement lead, although there is an acknowledgement that developing public involvement expertise in each of the offices across the region will be required to ensure researchers can access good quality, timely advice.

2. Development of a panel/forum/group

At present there are no plans to develop an RDS-SW dedicated panel of members of the public.

3. 'Matchmaking'

Individual project-related public and patient involvement will be achieved on a project-by-project basis by accessing potential service users and carers via local or national service user and carer involvement organisations, charities, by engagement with existing public and patient involvement systems within local stakeholder Trusts and through local Research Networks. This will provide local user involvement wherever possible and the potential for the recruitment of users and carers from the whole region, if necessary.

The link with the Patients' Scrutiny Committee linked to Folk.Us (see section 5 below) will provide the RDS-SW with a quality assurance mechanism to ensure appropriate and adequate project level public and patient involvement.

4. Training for public involvement

The RDS-SW will provide training for service users and carers interested in getting involved in research. This will primarily be focused on empowering individuals to contribute to project meetings.

5. Information and resources

The public involvement lead/other research advisers will work with project leaders to develop appropriate role descriptions so that there is a clear description of the public and patient involvement role required for individual projects.

6. Advising on public involvement

The first contact research advisers, with support from the public and patient involvement lead, will be providing support and advice to researchers and research teams in relation to public involvement in research.

7. Joint or collaborative working

The RDS-SW have established formal links with Folk.Us, a Department of Health funded organisation based in Exeter which works to support and help develop service user, patient and carer involvement in research. Researchers in Devon will be able to seek advice from Folk.Us in partnership with RDS-SW. The Folk.Us Director, Rachel Purtell, will be a member of the RDS-SW management team.

The Public and Patient Involvement Lead and Folk.Us Director take part in the RDS involvement forum facilitated by INVOLVE.

Staff within the RDS have links with other NIHR infrastructure organisations within the region, for example, the Comprehensive Local Research Networks.

8. Involvement in the management or evaluation of the RDS

The strategic overview of public and patient involvement in the RDS-SW will be supported by the expertise of the Director of Folk.Us through membership of the Management Team. This will improve the capability to promote user involvement and to engage with the public appropriately.

9. Resourcing/financing involvement in research

The RDS-SW has developed a policy on the reimbursement and payment of service users and carers involved in the development of research proposals for submission to NIHR funding streams. The policy is underpinned by the desire to demonstrate the value of the contributions made to research by service users and carers. The expense of involving service users and carers in pre-protocol activity will be funded by the RDS with ongoing project involvement funded directly from research grants.

10. Other activities

The RDS-SW runs a residential research school each year. The school provides coaching and support to develop a research proposal to the standard required to be competitive in seeking high quality research funding. Places at the school are available to small research teams through open competition. Members of the public, service users or carers can be included as members of the research teams applying to this scheme.

INVOLVE is a national advisory body that is funded by the National Institute for Health Research 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

**Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD**

Email: admin@invo.org.uk

Telephone: 02380 651088

Textphone: 02380 626239

Web: www.invo.org.uk

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