Consultation on the Patient and Public Involvement (PPI) functions within the National Institute for Social Care and Health Research Clinical Research Centre (NISCHR CRC)

Summary Report

October 2011
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1. Introduction

1.1. Background

In May 2009, the Wales Office of Research and Development (WORD) reviewed the funded research infrastructure in Wales. Subsequently, elements of the CRC Cymru research infrastructure including Thematic Research Networks, Infrastructure Support Groups and the Coordinating Centre were invited to submit funding bids as part of a re-commissioning process. All parts of the collaboration were informed that they would exist in the future as part of the National Institute for Social Care and Health Research (NISCHR) clinical research infrastructure. The clinical research infrastructure is funded and commissioned by NISCHR Welsh Government Health and Social Services Directorate.

Various elements of the NISCHR clinical research infrastructure have been funded and include:

- 17 Registered Research Groups
- Research Infrastructure and Technical Support Groups
- NISCHR Clinical Research Centre (NISCHR CRC)

NISCHR CRC was funded with a remit for increased focus on the operational management and delivery of NISCHR CRC which includes the NISCHR CRC Regional Research Networks and the Wales Cancer Research Network.

**NISCHR CRC has the following functions:**

- Develop, maintain and deploy a highly skilled workforce to deliver NISCHR portfolio research projects in health and social care.
- Develop and maintain the NISCHR research register or “portfolio” consisting of people-focussed research projects in Wales that meet clearly stated eligibility requirements.
- Support high quality research studies aimed at improving treatment and care.
- Provide an annual Wales- wide, research training programme for those involved in development and delivery of NISCHR research projects within NISCHR research portfolio.
• Recruit and train a network of patients, carers and service users and provide network members with opportunities to be involved in research development with NISCHR RRGs and subsequent funded projects.

• Communicate, engage and collaborate with CRC stakeholders, including NISCHR, NISCHR-funded clinical research infrastructure groups and the NISCHR Academic Health Science Collaboration (AHSC).

Involving People was established in 2006, as part of the CRC Cymru Coordinating Centre, with the main aim of encouraging active involvement of patients, carers and service users in health and social care research in Wales. The Wales Council for Voluntary Action (WCVA) was sub-contracted by the CRC Cymru Coordinating Centre to deliver the project and Involving People was hosted within and administered by WCVA from its inception until April 2010.

Following the restructuring (explained above), in April 2010 Involving People moved from its WCVA host to NISCHR CRC.

Patient and Public Involvement (PPI) has been identified as a core responsibility for NISCHR CRC, which will provide a single point of access to funding and resources for PPI research initiatives across the research infrastructure in Wales.

1.2. Consultation aim and objectives

The recommissioning of research infrastructure provision in Wales since April 2010 provides an opportunity to review Patient and Public Involvement (PPI) provision within that infrastructure to identify processes which will support high quality, relevant and people-centred research.

Aim

• To identify how NISCHR CRC can ensure effective PPI in high quality, relevant and people focused research within the research infrastructure of Wales.

Objectives

• To consult with a wide range of stakeholders (people who share our interest in the active involvement of service users in research) on current arrangements for the PPI functions of NISCHR CRC, and invite input to help the consultation
The task and finish group to develop recommendations for future PPI arrangements, which are:

- Effective
- Cost effective
- Encourage equality and diversity
- Allow active involvement in research by patients and the public

The primary outcome of the work will be an action plan for PPI functions within NISCHR CRC for 2010 to 2015. This document will be agreed by NISCHR CRC Directors, based on the recommendations made by the consultation task and finish group. The recommendations will be made available to NISCHR in order to inform strategy development.

### 1.3. Consultation Process

<table>
<thead>
<tr>
<th>Activity</th>
<th>Date</th>
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<tr>
<td>Proposal for consultation drafted by NISCHR CRC</td>
<td>December 2010</td>
</tr>
<tr>
<td>Proposal for consultation agreed by NISCHR CRC directors</td>
<td>December 2010</td>
</tr>
<tr>
<td>Proposal for consultation shared with Involving People advisory group</td>
<td>January 2011</td>
</tr>
<tr>
<td>Consultation task and finish group identified and invited</td>
<td>May 2011</td>
</tr>
<tr>
<td>Consultation task and finish group meet to develop the consultation</td>
<td>20th July 2011</td>
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<tr>
<td>proposal and plan next steps</td>
<td></td>
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<tr>
<td>NISCHR CRC develops bilingual consultation tool(s) further based on</td>
<td>July 2011</td>
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<tr>
<td>recommendations made at the task and finish Group meeting (with</td>
<td></td>
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<tr>
<td>assistance from South East Wales Trials Unit)</td>
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<tr>
<td>Bilingual online consultation survey (appendix 1 – English version)</td>
<td>23rd August 2011</td>
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<tr>
<td>circulated to stakeholders, that is, individuals identified as sharing</td>
<td></td>
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<td>an interest in active involvement in research:</td>
<td></td>
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<tr>
<td>- patients, carers and service users of the Involving People Network</td>
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<td>(n=172)</td>
<td></td>
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<td>- a selection of NISCHR CRC staff (n=11)</td>
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- members of the National Institute for Health Research PPI Delivery Professional Development Group (n=9)
- a selection of researchers from the NISCHR clinical research infrastructure (n=79)

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<thead>
<tr>
<th>Event</th>
<th>Date</th>
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<tr>
<td>Focus group conducted with 5 service user members of the Involving People Network, to gather views more fully (Appendix 2)</td>
<td>20th September 2011</td>
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<tr>
<td>Telephone interviews conducted with 4 researchers to gather views more fully (Appendix 2)</td>
<td>26th to 29th September 2011</td>
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<tr>
<td>(The consultation survey invited respondents to indicate whether they would be willing to be contacted by NISCHR CRC to share their views more fully. NISCHR CRC identified a selection of service users and researchers to consult further)</td>
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<tr>
<td>NISCHR CRC collates consultation responses and prepares summary report for task and finish group</td>
<td>October 2011</td>
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<tr>
<td>Consultation task and finish group meets to discuss and interpret the summary report and to draft the action plan for NISCHR CRC Involving People, 2010 to 2015.</td>
<td>17th October 2011</td>
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<tr>
<td>Agreement of summary report and action plan by NISCHR CRC directors.</td>
<td>November 2011</td>
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<tr>
<td>Dissemination of consultation summary report and action plan to stakeholders and the wider public, including via the NISCHR CRC and Involving People websites.</td>
<td>December 2011</td>
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2. Consultation responses

2.1. Who responded?

A total of 86 online survey responses were received (32% response rate). Two of these responses were received in the medium of Welsh. Respondents described themselves as following:

<table>
<thead>
<tr>
<th>Role</th>
<th>Count</th>
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<tr>
<td>Member of the public (patient, carer, service user)</td>
<td>37</td>
</tr>
<tr>
<td>Researcher</td>
<td>11</td>
</tr>
<tr>
<td>Research Manager</td>
<td>7</td>
</tr>
<tr>
<td>Health and Social Care Professional</td>
<td>13</td>
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<tr>
<td>Patient and Public Involvement Lead</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
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Thank you to all individuals who responded to the consultation.

2.2. Reading this report

This report deals with NISCHR CRC PPI objectives in the order in which they appeared in the online consultation survey.

Not every respondent completed a response to every question and not every response is outlined in this report.

Responses received in Welsh were translated prior to the writing of this report.

Additional comments gathered through the service user focus group and telephone interviews with researchers were also considered in the preparation of this report.

The purpose of this report is to reflect the breadth of responses received and the range of themes identified, and it is not an exhaustive list.
Objective 1: Supporting researchers to enable them to actively involve patients, carers and service users in their work

Summary of the topics covered in objective 1:
- Providing researchers with up-to-date advice and information, including guidelines on good practice.
- Coordinating recruitment of service users to be actively involved in research (including advertising opportunities for involvement and collating expressions of interest).
Online consultation survey question 1: We aim to provide sufficient advice and information to enable researchers to actively involve people in their work. In your experience, how sufficient is the advice and information we are providing?

86 individuals responded to this question, 40 of whom elaborated on their response.

Over two thirds of those who responded to this question viewed the advice and information we provide researchers as being sufficient, or more than sufficient.

- 12 individuals (14%) viewed this to be more than sufficient.
- 48 individuals (55.8%) viewed this to be sufficient.

Several individuals commented that the advice and information was clear, concise and informative.

Less than a third of those who responded to this question viewed the advice and information we provide researchers with as being insufficient, or not applicable to them.

- 6 individuals (7.1%) viewed this to be insufficient.
- 20 individuals (23.5%) answered with ‘I don’t know / Not applicable’.
A few individuals commented that there might still be a lot of researchers in Wales who do not know about the service we provide, and an individual noted that there does not appear to be much PPI on our website.

Other comments included:

- “make sure they realise it is governance to include patients”
- “I am aware that publicity material is circulated but am not aware of what the impact of this is”
- “I heard about ‘involving people’ on the grape vine. Despite spending HOURS filling in the IRAs form and talking to lots of people no one officially told me about them. Once I got in touch with them they were great, really helpful giving me prompt and useful feedback”

We are encouraged that, overall, response is positive with regard to the advice and information we provide researchers. However, we need to do further work to engage researchers, including developing relationships with NHS Research & Development departments and developing a strong Involving People presence on the PPI web pages of the NISCHR CRC website.
Online consultation survey question 2: We support researchers by coordinating the recruitment of service users to get actively involved in their work. In your experience how helpful is this to you?

86 individuals responded to this question.

Over three-quarters of those who responded to this question viewed our recruitment coordination service as being very helpful or helpful.

- 33 individuals (38.4%) viewed this service to be very helpful
- 32 individuals (37.2%) viewed this to be helpful.

Less than a quarter of respondents viewed the training we provide to service users as being either not helpful or not applicable to them.

- 5 individuals (5.8%) viewed this service as not helpful.
- 16 individuals (18.6%) answered ‘I don’t know / Not applicable’.

We are pleased that the majority of responses were positive with regard to our recruitment coordination service. We will continue to gather feedback from researchers who have engaged in this service, as part of our regular collection of feedback and we will develop the service accordingly (feedback will be reviewed annually, every August).
Objective 2: Supporting a diverse network of service users prepared for active involvement in research

Summary of the topics covered in objective 2

- Providing service users with training to prepare for active involvement in research.

- Ensuring service users who are actively involved in research are supported financially (for example covering expenses, offering payment for time, offering advice through a Citizens Advice Bureau 'Involvement Helpline').

- Providing service users with appropriate, bilingual information to help prepare for active involvement in research (including an Involving People Induction Pack, access to the Involving People library and monthly e-bulletins).

- Organisations, bodies and individuals we might work with to support the network.

- Organisations, bodies and individuals we might work with to increase the diversity of the network.

- Challenges we might face trying to support a diverse network.
Online consultation survey question 3: We provide training for service users to support their active involvement in research. In your experience how helpful is this service to you?

74 individuals responded to this question, 38 of whom elaborated on their response.

Almost three-quarters of those individuals who responded to this question viewed the training we provide to service users as being very helpful or helpful.

- 28 individuals (37.8%) viewed this service to be very helpful.
- 27 individuals (36.5%) viewed this to be helpful.

Several individuals commented that training enables individuals to contribute effectively to research development. For example:

- “It is very important that service users who support specific projects receive the appropriate training. This enables them to participate actively in the planning and empower them to talk about and handle the work on an equal level.”
- “It means that service users can obtain a clearer view of the research process, how R&D works and helps them/us become engaged.”
Less than a quarter of respondents viewed the training we provide to service users as being either not helpful or not applicable to them.

- 2 individuals (2.7%) viewed this service as not helpful.
- 17 individuals (23%) answered ‘I don’t know / Not applicable’.

An individual commented that the same training has been around for some time now and different approaches could be tried. Another individual suggested that there could be more training for researchers on different ways of involving people and ensuring researchers make their processes more accessible.

A selection of service users and researchers offered additional comments / suggestions via the focus group and telephone interviews, including:

- “NISCHR CRC may want to consider a period of time by which it would be acceptable for active members of the network to attend the core training sessions again, to refresh skills and knowledge.”
- “Requesting feedback from service users on the training they have attended a period of time following the training course, to see if it has had impact on the research development opportunities the service user is involved in. And also asking researchers if they believe the service user involvement in their research development has been improved as a result of training.”
- “Utilise contacts to make use of freely available venues and invite researchers and service users to deliver training in their areas of expertise.”
- “Evaluate the Involvement Workbook by finding out if service users are actually using it.”

The response to training is encouraging and we will continue to offer a suite of training to members of the network to prepare them in their active involvement. However more work is needed.

We will add ‘GCP (Good Clinical Practice) for Involving People Network’ to the training programme for actively involved members of the Network. We will collect service users’ and researchers’ feedback on training and its application to an individual’s active involvement in research, as part of our regular collection of feedback. We will review the training programme on an annual basis and we will signpost network members to freely available training in the community.
Online consultation survey question 4: We offer financial support for service users in their active involvement (expenses, payment for time and advice via the ‘Involvement Helpline’). In your experience how important do you think this support is?

74 individuals responded to this question, 43 of whom elaborated on their response.

Over 90% of those who responded to this question viewed the financial support we provide for service users as being very important or important

- 48 individuals (64.9%) viewed this service to be very important.
- 19 individuals (25.7%) viewed this to be important.

Many individuals commented that service users actively involved in research should not be ‘out of pocket’ and that this was a minimum in encouraging service user involvement. A number of individuals endorsed the appropriateness of payment for time, noting that service users should not be
seen as contributing less than academics/practitioners as their time is equally valuable.

Some additional comments:

- “They are committed volunteers and should not be out of pocket. If finance were a barrier people on low incomes would be excluded.”
- “Might encourage those who would otherwise not get involved at all.”
- “Whilst such costs may be covered by a research grant, monies are needed to facilitate development of grant proposals if research is to be truly inclusive.”

Less than 10% of the individuals who responded to this question viewed the financial support we provide for service users as being not important or not applicable to them.

- 2 individuals (2.7%) viewed this service to be not important.
- 5 individuals (6.8%) answered ‘I don’t know / Not applicable’.

One individual commented that ‘out of pocket’ expenses were very important but that honoraria ought to be discontinued since this receipt of honoraria changes the nature of the volunteer/organisation relationship, impairing the ability of the volunteer to remain ‘independent’. Another individual suggested that honoraria puts ones benefits in jeopardy.

Involving People will continue to ensure service users who are actively involved in research are supported financially, by covering expenses and offering payment for time, where appropriate.

We will continue to subscribe to the Citizens Advice Bureau ‘Involvement Helpline’, referring members to this service if they require reliable advice on their benefit or funding conditions in respect to any involvement that is offered. And we will publicise this service on the PPI web pages of the NISCHR CRC website and within the Involving People Induction Pack.
Online consultation survey question 5: Can you suggest any individuals, organisations or bodies we should work with to help us provide additional support to the Involving People Network?

41 individuals (48% of the total respondents) suggested individuals, organisations and bodies we could work with to help us provide additional support to the network.

Below is a sample of the comments / suggestions received:

- Community Health Councils, Health Boards where they have a community network in place.
- Disability Wales. Any organisations providing support for young disabled people e.g. Every Link Counts in the Bridgend area.
- Participation Cymru.
- County Voluntary Councils.
- Further Education Colleges - many run Health and Social Care courses and initiatives such as Welsh Baccalaureate which is concerned with social issues.

We were encouraged by the wealth of useful suggestions we received, and pleased that we are working already with some of these organisations and bodies.

We will establish contact with a number of suggested organisations in line with our action plan. And we will identify service user mentors to work with new members of the network to provide peer support.
Online consultation survey question 6: Can you suggest any individuals, organisations or bodies we should work with to help us increase the diversity of the Involving People Network?

42 individuals (49% of the total respondents) suggested individuals, organisations and bodies we could work with to help us increase the diversity of the network.

Below is a sample of the comments / suggestions received:

- “Most, if not all, County Voluntary Organisations have a Health and Social Welfare Officer who has contact with a great range of health related groups in their county. This also helps ‘Drill down’ to core users who I feel are extremely important.”

- “Disability Wales, local coalitions of disabled people. Maybe Abertawe Bro Morgannwg Community Health Council or closer to you would be Cardiff and the Vale Community Health Council.”

- “In terms of attracting more Welsh speakers from users, the following groups / forums have good contacts: - Menter Iaith – Merched y Wawr - Young Farmers Clubs – The Urdd (see the Lolfa directory for more information).”

- “Youth Groups - The Network tend to be older (often retired) people.”

- “LGBT groups - e.g. students. BME groups in urban areas - Cardiff, Newport, Swansea.”

We are pleased with the helpful suggestions that have been made and NISCHR CRC will take forward suggestions within the Equality and Diversity work stream.

We will scope the needs of NISCHR clinical research infrastructure researchers in relation to PPI in research and develop the Involving People Network to be able to meet these needs, including representation of conditions, disease, skills, age, disability, gender, race. And supporting the areas of research excellence in Wales as described by NISCHR Academic Health Science Collaboration (AHSC) and areas of research activity related to the NISCHR clinical research portfolio.
Online consultation survey question 7: In your experience, what challenges might we face when trying to support a diverse Network of service users to be prepared for active involvement in research?

54 individuals (63% of the total respondents) suggested challenges which Involving People, NISCHR CRC might face when trying to support a diverse network of service users. Several individuals suggested the challenge of supporting a range of people with diverse needs, including training needs and communication needs. A few individuals identified that some individuals may not be available to meet with researchers during working hours. And a number of people identified that support costs may be high if supporting a diverse range of people.

Additional comments / suggestions received:

- “In my experience disabled people, particularly those with a mental health impairment, will be reluctant to be involved. You may need to ‘reach out’ to such individuals to convince them of the value of getting involved.”
- “Time (information shared well before opinions are sought, face to face meetings to discuss the technicalities, travelling to places where the hard to reach groups meet, etc), commitment (needs more than one dedicated person to help support this, and often senior officers in organisations only offer lip service to true engagement).”
- “A smaller pool of people means a greater likelihood of being selected - the converse might mean that as selection happened less often volunteers could become a bit despondent about not being selected which actually brings a sense of ‘failure’ when it happens.”
- “Potentially more interested volunteers than involvement opportunities.”
- “Additionally, there is a risk of excluding specific groups of patients due to particular state of health or rigid regimes of treatment-such as the tendency, understandably, in Renal groups to have mainly representatives from the Transplant sector and not current dialysis patients who are often unable to participate if linked to a hospital slot or too exhausted to consider becoming involved. In addition, current CKD patients may simply unaware of the opportunity.”
A sample of service users and researchers offered additional comments / suggestions via the focus group and telephone interviews, including:

- “Do we have a clear picture of what is required in order to be representative of the population of Wales?”
- “Some work needs to be done to determine what sort of representation we already have on our network before we can see where the gaps of representation are. And need to ask researchers what they require with regard to service user involvement, and ensure that we have the right range of network members to satisfy the demand.”
- “Will need to read the broad literature available on diversity and equality and follow strategies which other organisations and bodies have adopted.”
- “However must consider the size of the network in terms of what level we are able to support within our available budget, and whether there is a sufficient amount of opportunities to offer to all individuals.”
- “Can’t represent everyone so could continue to target individuals to represent the issues and topics being researched at the time.”

We are grateful that a large number of potential challenges have been pointed out to us through this consultation.

The challenges will be borne in mind when scoping researchers’ needs in relation to PPI in research, and developing the Network to be able to meet these needs. The challenges will also be shared with the NISCHR CRC Equality and Diversity workstream for consideration in relation to future activities.
Objective 3: Working to embed active involvement in NISCHR CRC and the NISCHR clinical research infrastructure

Summary of the topics covered in objective 3:

- Supporting PPI at a strategic level across the NISCHR clinical research infrastructure, including challenges we might face.
Online consultation survey question 8: How important do you think it is that service users are represented at a strategic level within NISCHR CRC?

70 individuals responded to this question, 48 of whom elaborated on their response.

Over 90% of individuals who responded to this question viewed service user representation at a strategic level within NISCHR CRC to be very important or important.

- 46 individuals (65.7%) viewed this service to be very important.
- 18 individuals (25.7%) viewed this to be important.

A large number of individuals felt that PPI should be embedded at many levels of the NISCHR clinical research infrastructure. For example:

- “Patients are meant to be at the heart of everything that we do.”
- “Decision makers make decisions on the basis of personal experience’. If those on the NISCHR groups do not have personal experience of a wide range of different conditions (including poverty, poor housing, social exclusion), then the decision making process will be flawed.”
“Completion of a feedback loop with those at the sharp end of treatment and involvement.”

Less than 10% of individuals who responded to this question viewed service user representation at a strategic level within NISCHR CRC to be not important or not applicable to them.

- 2 individuals (2.9%) viewed this service to be not important.
- 4 individuals (5.8%) answered with ‘I don’t know / Not applicable’.

One individual challenged the importance of having service users on strategic committees commenting that we are all service users in some ways and specific advice needn’t impact at an all Wales level.
Online consultation survey question 9: Can you suggest any opportunities we might wish to explore to support PPI at a strategic level across the NISCHR clinical research infrastructure?

37 individuals (43% of the total respondents) suggested opportunities we might wish to explore to support PPI at a strategic level across the NISCHR clinical research infrastructure. And several helpful suggestions were received via the focus group and telephone interviews. A few individuals suggested service users should be involved at a strategic level within NISCHR, which is indeed already happening. Several individuals suggested that NISCHR CRC could recruit small task and finish groups to tackle specific pieces of work, and a couple of individuals suggested there could be regular meetings between service users involved in research at a project level and service users actively involved at a strategic level. A number of individuals suggested allocating time in the Involving People Annual Meeting to gather views from service users regarding PPI across the clinical research infrastructure.

Other comments included:

- “Identifying people who have a background and understanding of strategic planning.”
- “Development of core PPI SOP.”
- “Use of focus groups to review research strategies against what they view is the most needed research in light of incidence statistics, effectiveness of best treatments currently offered, cost of providing treatment and impact on quality of life.”
- “Broaden opportunity for a wider group of persons to input via a variety of mediums- allowing greater access.”
Online consultation survey question 10: In your experience, what challenges might we face when supporting PPI at a strategic level across the NISCHR clinical research infrastructure?

44 individuals (51% of the total respondents) suggested challenges we might face when supporting PPI at a strategic level across the NISCHR clinical research infrastructure. Several individuals suggested a challenge might be in ensuring that service users are prepared and equipped for PPI at a strategic level. For example ensuring individuals have appropriate knowledge of the clinical research infrastructure so they would not feel intimidated in such a role. A number of individuals felt that a challenge might be resistance from some researchers to engage in PPI. And several individuals suggested that the main challenge would be in supporting these activities financially.

We are grateful for the range of suggestions received in response to working to embed PPI in NISCHR CRC and the NISCHR clinical research infrastructure. In addition to supporting PPI across the NISCHR Registered Research Groups, Trials Units and Infrastructure Support Groups, and continuing to support PPI at a strategic level within NISCHR, we will recruit service users of the Network to join NISCHR CRC task and finish groups as and when required to take on specific pieces of work in relation to NISCHR CRC workstreams.

We will support these activities financially and provide the actively involved individuals with appropriate training and information to equip them for these roles. These individuals will be expected, with assistance from Involving People, to share their experiences and/or consult more widely with members of the network.
Objective 4: Raising awareness of PPI in research in Wales

Summary of the topics covered in objective 3:

- The Involving People Annual Meeting and its usefulness in raising awareness of PPI in research within the NISCHR clinical research infrastructure.
- Service user involvement in raising awareness of PPI in research in Wales.
Online consultation survey question 11: How useful do you think the Involving People Annual Meeting is in raising awareness of PPI in research within the NISCHR clinical research infrastructure?

How useful do you think the Involving People Annual Meeting is in raising awareness of PPI in research within the NISCHR clinical research infrastructure?

- Very useful
- Useful
- Not useful
- I don't know / Not sure

70 individuals responded to this question, 38 of whom elaborated on their response.

Almost two-thirds of the people who responded to this question viewed the Involving People Annual Meeting as a very useful or useful way of raising awareness of PPI in research within the NISCHR clinical research infrastructure.

- 24 individuals (34.3%) viewed it to be a very useful way of raising awareness.
- 21 individuals (30.0%) viewed it to be a useful way of raising awareness.

4 individuals (5.7%) viewed it as not useful, and 21 individuals (30%) answered ‘I don’t know / Not applicable’
Individuals were also asked if they could suggest other ways in which we might raise awareness of PPI in research in Wales. Several individuals suggested raising awareness within research centres, universities, hospitals and libraries across Wales.

Other suggestions included:

- “Locally (as appropriate) based workshops as everyone you would wish to encompass might not be able to attend an Annual Meeting especially with the geographic speed involved.”
- “Created interactive forum and networking opportunity.”
- “Encouraging each component of the infrastructure to have a PPI lead. Running training for researchers on ways of involving users (not the importance of it).”
- “Via local newspaper reports and possible magazine articles.”
- “The production of a directory that would indicate to current and potential researcher of the scope and advantages gained by NISCHR partnerships.”
Online consultation survey question 12: Do you have any suggestions on how members of the Involving People Network might assist us in raising awareness of PPI in research in Wales?

44 individuals (51% of the total respondents) suggested ways in which members of the Involving People Network might assist us in raising awareness of PPI in research in Wales. And several helpful suggestions were collected in the focus group and telephone interviews. Many individuals suggested showcasing good practice examples of PPI in research through a variety of mediums including newsletters, workshops and conferences. A few individuals suggested service users could meet with researchers face to face to offer examples of PPI in research.

Other suggestions included:

- “More involvement in delivering training maybe? We reach a lot of people.”
- “I think it ought to be possible to make more use of experienced volunteers as champions/ambassadors in the structures.”
- “Encouraged to raise PPI awareness through CHC and other organisations that members may work/ be involved in.”
- “Provide a simple credit card size card with a short explanation of what we are about that members can give out.”
- “When users are actively involved it is about getting them to ‘feedback’ to their own networks and others... even PPI research users’ newsletter of developments and involvements. Perhaps web site to promote this. If however people put themselves out, commit to joining a group as a user representative the biggest raising of awareness will come if their commitment is activated and utilised.”
- “A model of champions to promote messages about active involvement could work well as long as there were clearly defined roles for these individuals, otherwise every member of the network is effectively a champion. Consider tapping in to champions and ambassadors already actively involved in organisations and bodies.”
We are really encouraged by the range of helpful suggestions received. We will explore opportunities to engage with researchers across Wales as a NISCHR CRC workforce, with service user contribution where appropriate.

We will develop and share case studies and examples of PPI good practice in the NISCHR CRC Involving People newsletter, staff newsletter, electronic mailing list and Annual Report. And we will develop and maintain links with UK-wide collaborators, for example INVOLVE, exploring UK-wide PPI opportunities.
Online consultation survey question 13: Please provide any additional comments or suggestions.

25 individuals (29% of the total respondents) provided additional comments and suggestions, including:

- “Involving People has tried hard, especially during the past year, to invite Welsh speakers to their network and create appropriate resources and opportunities for them. We trust that it will be possible to build on this good work and extend the agenda to ensure representation from other minority groups.”
- “The team at Cathedral Rd base is exceptionally professional and supportive.”
- “Whilst I think the PPI annual meetings are great, I sometimes feel like to drive to recognise the diversity and value of the IP network comes at the expense of recognising the diversity of the people in the research networks. This in some ways encourages a ‘them and us way’ of thinking, whereas I think we need us and we.”
- “This is a very laudable organisation with a sound ethos I do feel that too few people are aware of its existence and that it requires substantial promotion in terms of raising the profile.”
- “The Involving People Network is a valuable tool to meet the requirement of Service User related research. It is a cost effective body that provided invaluable insights for researchers and professionals.”
- “Many patients derive great benefit form being involved in this way and it can be a very worthwhile experience. the ‘feel good factor’ of ‘giving something back’ when having benefitted from what is in the renal sector, lifelong treatment is tremendously rewarding. It also assists in promoting a positive mindset when managing a chronic & lifelong condition.”
APPENDIX 1 – Online Consultation Survey

NISCHR CRC Patient and Public Involvement Consultation

Introduction

The National Institute for Social Care and Health Research Clinical Research Centre (NISCHR CRC) is part of the health and social care clinical research infrastructure for Wales funded by NISCHR, Welsh Government.

Involving People, NISCHR CRC has a responsibility to recruit and train a network of Service users and provide these individuals with opportunities to be involved in research development within the NISCHR clinical research infrastructure.

*service users - we use the term service users in this survey to refer broadly to patients, carers, service users and the public.

This Consultation has been sent to individuals who, we believe, share our interest in Patient and Public Involvement (PPI). We value your input, including any thoughts, views and suggestions you might have in relation to some key PPI issues. The primary outcome of the consultation will be an action plan for PPI functions within NISCHR CRC for 2010 to 2015. This document will be agreed by NISCHR CRC Directors, based on the recommendations made by a Consultation Task and Finish Group. The recommendations will also be made available to NISCHR in order to inform strategy development.

We want to hear your views on:

- what we should be doing to achieve our strategic objectives
- who we should be working with to achieve our objectives
- any challenges we need to try to overcome

For background information please click here.

If you would like to read through this consultation before responding you can request a copy from Involving People by contacting Natalie Simon by email (involving.people@wales.nhs.uk) or by telephone (020 230 0203). However, the online consultation must be completed in one session.

If you have any questions about completing the consultation or would like to receive it in another format, or in the Welsh language, please contact Natalie Simon (contact details above).

Deadline for responses: 5pm on Wednesday 30th September 2011.

Thank you in advance.
NISCHR CRC Patient and Public Involvement Consultation

Objective 1 - Supporting researchers to enable them to actively involve people...

We aim to do the following:
- Provide researchers with advice and information (including guidelines on good practice when actively involving people in research).
- Coordinate recruitment of service users to be actively involved in research (including advertising opportunities, collecting interest and providing researchers with selection template documents).

1. **We aim to provide sufficient advice and information to enable researchers to actively involve people in their work. In your experience how sufficient is the advice and information we’re providing?**
   - More than sufficient
   - Sufficient
   - Insufficient
   - I don’t know / Not applicable

Please can you tell us why you think this?

2. **We support researchers by coordinating the recruitment of service users to get actively involved in their work. In your experience how helpful is this to you?**
   - Very helpful
   - Helpful
   - Not helpful
   - I don’t know / Not applicable
Objective 2 - Supporting a diverse Network of service users prepared for ac...

We do the following:

- Provide service users with free training.

- Ensure service users who are actively involved in research are supported financially (for example covering expenses, offering payment for time, offering advice through a Citizens Advice Bureau 'Involvement Helpline').

- Provide service users with bilingual information (including an Involving People Induction Pack, access to the Involving People library and monthly e-bulletins).

3. We provide training for service users to support their active involvement in research. In your experience how helpful is this service to you?

- Very helpful
- Helpful
- Not helpful
- I don’t know / Not applicable

Please can you tell us why you think this?
4. We offer financial support for service users in their active involvement (expenses, payment for time and advice via the 'Involvement Helpline'). In your experience how important do you think this support is?

- Very important
- Important
- Not important
- I don't know / Not applicable

Please can you tell us why you think this?

5. Can you suggest any individuals, organisations or bodies we should work with to help us provide additional support to the Involving People Network?

6. Can you suggest any individuals, organisations or bodies we should work with to help us increase the diversity of the Involving People Network?

7. In your experience, what challenges might we face when trying to support a diverse Network of service users to be prepared for active involvement in research?
Objective 3 - Supporting PPI at a strategic level across the NISCHR clinical research infrastructure

We will strive to support PPI at a strategic level across the NISCHR clinical research infrastructure (including within NISCHR CRC, NISCHR Registered Research Groups and NISCHR Infrastructure Support Groups and NISCHR Trials Units).

NISCHR liaise with NISCHR CRC in terms of PPI requirements at a NISCHR strategic level.

8. How important do you think it is that service users are represented at a strategic level within NISCHR CRC?

- Very important
- Important
- Not important
- I don’t know / Not applicable

Please tell us why you think this?

9. Can you suggest any opportunities we might wish to explore to support PPI at a strategic level across the NISCHR clinical research infrastructure?

10. In your experience, what challenges do you think we might face when supporting PPI at a strategic level across the NISCHR clinical research infrastructure?
Objective 4 - Raising awareness of PPI in research in Wales

We will strive to raise awareness of PPI in research within the NISCHR clinical research infrastructure and the wider public in Wales (for example through the Involving People Annual Meeting, through individual members of the Involving People Network and through engagement with researchers).

11. How useful do you think the Involving People Annual Meeting is in raising awareness of PPI in research within the NISCHR clinical research infrastructure?

- Very useful
- Useful
- Not useful
- I don't know / Not sure

Can you suggest other ways in which we might raise awareness of PPI in research within the NISCHR clinical research infrastructure?

12. Do you have any suggestions on how members of the Involving People Network might assist us in raising awareness of PPI in research in Wales?
## Additional comments

13. Please provide any additional comments or suggestions.
NISCHR CRC Patient and Public Involvement Consultation

Additional information

Please note that consultation responses will be treated confidentially by Involving People, NISCHR CRC and we will anonymise responses before they are interpreted by a Consultation Task and Finish Group.

*14. Which best describes you:
- Member of the public (patient, carer, service user)
- Researcher
- Research manager
- Health and social care professional
- Patient and Public Involvement Lead
- Other

Other (please specify)

*15. We may wish to contact individuals to gather views more fully. As above all responses will be treated confidentially and will be anonymised by Involving People, NISCHR CRC before interpretation by the Consultation Task and Finish Group.

Can we contact you to gather your views more fully?
- Yes (if yes please enter your preferred contact details below)
- No

Please provide your preferred contact details if you are happy for us to contact you

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### NISCHR CRC Patient and Public Involvement Consultation

#### What happens next?

- A Consultation Task and Finish Group will interpret an anonymised summary of responses prepared by Involving People, NISCHR CRC.

- The Consultation Task and Finish Group will make recommendations to the NISCHR CRC Directors for their consideration.

- NISCHR CRC Directors will make those recommendations available to NISCHR to inform PPI strategy development and will develop an Action Plan around the PPI functions of NISCHR CRC for the period of 2010 to 2015. This Action Plan will be made available to all stakeholders and the public in the winter, via the NISCHR CRC and Involving People websites.

Thank you very much for your contribution.
APPENDIX 2

PPI Consultation Focus Group and Telephone Interviews

Topics for discussion

Topic 1 – training for service user members of the Involving People Network

Involving People intends to continue offering the following core training days to prepare service user members of the Involving People Network for active involvement in research:

1) Involving People Induction
   At least twice a year, rotating across North Wales, South East Wales and South West Wales
   For service user members of the Involving People Network

2) Getting Involved and Influencing Research
   Three times a year, rotating across North Wales, South East Wales and South West Wales
   For service user members of the Involving People Network and researchers

3) Introduction to Research Methods
   At least twice a year, rotating across North Wales, South East Wales and South West Wales
   For service user members of the Involving People Network and researchers

Service user members of the network will be encouraged to attend the above core training, particularly the induction day. All members who attend an induction day will receive an Induction Pack, which will include an Involvement Workbook to enable individuals to log their research involvement activities, including training they have attended.

In addition GCP (Good Clinical Practice) for the Involving People Network has also been added to the training portfolio. This training will happen at least annually, depending on demand. Active service user members of the Involving People Network will be invited to attend this training, usually on the back of a request from a researcher.

Also, in the autumn of every year Involving People and the training team at NISCHR CRC will agree any additional training which can be delivered in the next financial year (from April to March), depending on comments and requests received from researchers and service user members of the Network.
Focus Group - Please spend 3 minutes noting down any comments you have on the above training plans.

Telephone Interviews – Please express your views on the above training plans.

Think about the following:
- Is this training plan acceptable to you?
- Do you have any suggestions on how we can evaluate training?

A facilitated group discussion will follow for the focus group.

**Topic 2 – the challenges which Involving People might face when trying to support a diverse network of service users to be prepared for active involvement in research**

Involving People has a role in ensuring that diverse and minority groups are actively involved in research so that research and development, and the subsequent impact on service delivery reflects the needs and interests of the populations they seek to serve.

Involving People will strive to develop, maintain and support a network of individuals which is representative of the population of Wales, in line with the equality and diversity agenda within NISCHR CRC, including language awareness.

Focus Group - Please spend 3 minutes noting down any comments you have on the above topic.

Telephone Interviews – Please express your views on the above topic.

Think about the following:
- Size of the network
- Different priorities for different populations
- Geography
- Communication needs
- Support costs
A facilitated group discussion will follow for the focus group.
Topic 3 – service user representation at a strategic level within NISCHR CRC (how important it is, exploring opportunities to do this and addressing challenges we might face)

The Involving People advisory group was established at the outset of the Involving People Project to provide advice and support to the Involving People Team, to develop the Involving People agenda across the research infrastructure and to steer the development of an effective Involving People Network.

The Group was suspended in February 2011 as we progress this consultation. In January 2011 the Group consisted of approximately 20 individuals. The majority of members are patients, carers and service users and these individuals have experience of a range of conditions / diseases across health and social care. NISCHR Registered Research Groups are represented on the Group as well as UK-wide representatives, including INVOLVE.

Consultation responses to date have provided some useful suggestions regarding arrangements for service user involvement at a strategic level within NISCHR CRC. Some of these are outlined below as options:

1) An open forum with very open structure and accountability. The forum would enable discussion and consultation on a wide range of topics related to NISCHR CRC, for example topics raised by NISCHR CRC task and finish working groups. With this arrangement a service user chair and a service user vice chair would be appointed and rotated every couple of years, but membership would be open (though limited with regards to numbers) so that all members of the network would have the opportunity to input at different times. The chair and vice chair would be expected to report informally to the Involving People team so that their suggestions and views could be shared across NISCHR CRC. The forum would also play an active role in developing plans for the annual meeting.

2) Meetings between a number of active service user members of the Network (those who are involved in research opportunities) and members of the Involving People team to discuss progress and issues relating to PPI in research. A service user chair and service user vice chair would be appointed and rotated every couple of years, and membership would be through application, with rotation written in to the terms of reference. The chair and vice chair would be expected to report informally to the Involving People team so that their suggestions and views can be incorporated in to the work of Involving People, NISCHR CRC.

3) Re-establishment of the Involving People advisory group with new terms of reference so that the group could be more ‘fit for purpose’. For example membership would be through application and members would be expected to be actively involved in research opportunities. The group would be smaller and meet less regularly (perhaps twice a year) and members would be consulted for their advice on a wide range of topics related to NISCHR CRC, for example topics raised by NISCHR CRC task and finish working groups. The service user chair and service user vice chair would be expected to report informally to the Involving People team so that suggestions and views could be shared across NISCHR CRC.
4) Regular (as needed) consultations with all members of the Involving People Network. For example online consultations, telephone and postal input on a wide range of NISCHR CRC topics.

Focus Group - Please spend 3 minutes noting down any comments you have on the above topic.

Telephone Interviews – Please express your views on the above topic.

Think about the following:
- Is it important that service users are represented within NISCHR CRC? And why so, why not?
- What are your thoughts on the above options? Please think about the options in terms of:
  - equality of opportunity (ability to consult widely, communication tools, accessibility)
  - membership (representation geographically and across topics of research, only those actively involved or wider?)
  - frequency of meetings
  - location of meetings
  - timeliness of input (ability to consult with service users in a timely fashion)
  - accountability
  - costs to NISCHR CRC including expenses and honorarium

A facilitated group discussion will follow for the focus group.

Topic 4 – exploring service user involvement in raising awareness of PPI in research in Wales

Involving People, NISCHR CRC will continue to gather feedback from service users and researchers on active involvement in research development. This is a form of awareness raising as long as the information is shared with stakeholders, including the Involving People Network. Therefore Involving People intends to include a regular feature within its newsletter / e-bulletin on feedback, for example a case study. This requires support from members of the Network and from researchers to develop the case studies.

Involving People, NISCHR CRC will continue to invite service users to speak about their involvement in research at the annual meeting.

Involving People will work closely with the communications team in NISCHR CRC to develop press releases and publications to raise awareness of active involvement in
research in Wales. This may require support from members of the Network and from researchers in developing stories and pieces.

Involving People, NISCHR CRC may also develop a model of champions of active involvement in research, where service users who are experienced at active involvement in research are invited to share their experiences with other members of the Network. Champions might include champions in language awareness and champions across the various topics of research. This might be through the annual meeting and the Involving People Induction Day training etc.

Focus Group - Please spend 3 minutes noting down any comments you have on the above plan.

Telephone Interviews – Please express your views on the above plan.

Think about the following:
- Is this plan acceptable to you?
- Is this plan sufficient?
- Do you have any suggestions on what else service users might do?

A facilitated group discussion will follow for the focus group.