Involving People Action Plan

April 2010 – March 2015

This action plan is informed by the analysis of responses to a consultation on the Patient and Public Involvement (PPI) functions within the National Institute for Social Care and Health Research Clinical Research Centre (NISCHR CRC).

This action plan will be made operational through the Involving People work plan.
Background
The National Institute for Social Care and Health Research Clinical Research Centre (NISCHR CRC) is part of the NISCHR clinical research infrastructure.

The clinical research infrastructure is funded by NISCHR, part of the Welsh Government Health and Social Services Directorate. NISCHR develops, in consultation with partners, policy on research and development (R&D) to reflect the health and social care priorities of the Welsh Government.

NISCHR CRC provides a number of important all Wales functions including an all Wales expert research workforce to support and develop research activity within health and social care. NISCHR CRC also leads for NISCHR on training and development and maintenance of the NISCHR clinical research portfolio.

One of NISCHR CRC’s functions is to 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 Registered Research Groups (RRGs) and subsequent funded projects. **Involving People, part of NISCHR CRC, is tasked with this function.**

Consultation on the Patient and Public Involvement (PPI) functions within NISCHR CRC

A consultation on the PPI functions within NISCHR CRC was conducted between July and October 2011. A task and finish group convened to develop the consultation with the aim of identifying how NISCHR CRC can ensure effective PPI in high quality, relevant and people focused research within the research infrastructure of Wales.

An online consultation survey was circulated to 271 stakeholders (people who were identified as sharing an interest in PPI in research). Responses were received from 86 individuals (32% response rate), including members of the public, researchers, researcher managers, health and social care professionals and PPI Leads. A selection of service users were invited to a focus group, and a selection of researchers were interviewed on the telephone, so that views could be gathered more fully.
In October 2011 the consultation task and finish group developed a summary report to outline the breadth of responses received and the range of themes identified in the consultation, and this action plan, informed by the summary report, outlining the continuation and improvement of Involving People services. In November 2011 NISCHR CRC directors reviewed the consultation summary report and action plan and acknowledged and approved the recommendations within both documents.

The consultation summary report can be downloaded from the bilingual NISCHR CRC website.

**Involving People Function:**

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.

*Service users – the term service user is used in this document to refer broadly to patients, carers, service users and members of the public.*
Objective 1: Supporting researchers to enable them to actively involve patients, carers and service users in their work:

a) Exploring opportunities for PPI in research

- Nurturing relationships with individuals across the NISCHR clinical research infrastructure, including regular face to face meetings with researchers within NISCHR RRGs, Trials Units and Research Infrastructure Support Groups (ISGs), to explore PPI opportunities. This includes identifying and scoping opportunities for PPI at a strategic level, and at a research project development level.
- Developing relationships with NHS Research and Development (R&D) departments to explore PPI opportunities.
- Engaging researchers through a strong Involving People presence on the bilingual NISCHR CRC website and improving access to the bilingual Involving People webpages, with further information for researchers.
- Developing and maintaining links with researchers across the UK, for example INVOLVE. Exploring and promoting UK-wide PPI opportunities.

b) Providing researchers with up-to-date advice and information, including guidelines on good practice

- Reviewing the ‘Guidelines for researchers’ resource annually to ensure the resource is up-to-date and informed by feedback gathered from researchers and service users working together in research development. Highlighting feedback which describes the impact of PPI on research.
- Developing and maintaining a researcher section on the bilingual Involving People website, with downloadable resources.
- Developing and maintaining links with key partners across the UK, for example PPI Leads, keeping abreast of good PPI practice, developing NISCHR CRC Involving People resources accordingly.
c) Coordinating recruitment of service users to be actively involved in research

- Scoping researchers’ needs in relation to PPI in research and developing the Involving People Network to be able to meet these needs. Including relevant representation of conditions, diseases, skills, age, disability, gender and race. 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.

- Developing appropriate and informative involvement opportunity advertisements / selection packs.

- Circulating opportunity advertisements to the Involving People Network, and where necessary, utilising the Involving People database to identify individuals to whom the opportunity should be targeted, for example to individuals representing specific characteristics / interest areas / skills. It may sometimes be necessary to identify a wider pool of individuals to recruit from through established links with organisations / partners, for example County Voluntary Councils.

- Collecting expressions of interest and providing researchers with this information, in an anonymised format, so that researchers can select appropriate individuals.

- Gathering feedback from researchers who have engaged in this coordination service, as part of Involving People’s regular collection of feedback, and developing the service accordingly (feedback is gathered from researchers and service users at various stages of the involvement opportunity, and is reviewed annually, in August).
Objective 2: Supporting a diverse network of service users prepared for active involvement in research

a) Providing service users with training to prepare for active involvement in research

- Delivering the core training course ‘Involving People Induction Day’. Encouraging all members of the network to attend this training, providing each delegate with financial support to attend the training and an Involving People Induction Pack. Delivering this course at least bi-annually and rotating across North Wales, South East Wales and South West Wales.

- Encouraging all members of the network to attend two further core training sessions on the NISCHR CRC training programme ‘Getting Involved and Influencing Research’ and ‘Introduction to Research Methods’, providing financial support to enable members to attend. These courses are delivered at least bi-annually and rotate regionally across North Wales, South East Wales and South West Wales.

- Responding to researcher requests to financially support active members of the network (those actively involved in research) to attend Good Clinical Practice (GCP) training, on the NISCHR CRC training programme.

- Responding to researcher requests to financially support active members of the network (individuals actively involved in research) to attend additional training to prepare members for their active involvement.

- Collecting service users’ and researchers’ feedback on training and its application to an individual’s active involvement in research, as part of the regular collection of feedback.

- Reviewing the training programme and feedback received on an annual basis, each December, and developing the programme accordingly. Providing an opportunity for service users of the network to be involved in this review.

- Signposting service users to training available in the community.
b) Ensuring service users who are actively involved in research are supported financially

- Where possible, arranging, booking and paying for necessary travel and accommodation prior to involvement activities to ensure individuals are not ‘out of pocket’.
- Timely reimbursing individuals for any expenses incurred by their active involvement in research.
- Offering payment for time, where appropriate, to individuals who are actively involved in research.
- Subscribing to a Citizens Advice Bureau ‘Involvement Helpline’, referring members of the network to this service if / when they require reliable advice on their benefit or funding conditions in respect of the involvement that is offered. Publicising this helpline on the bilingual Involving People website and PPI webpages of the bilingual NISCHR CRC website and within the Involving People Induction Pack.

c) Providing service users with appropriate, bilingual information to help prepare for active involvement in research

- Providing members of the Involving People Network with a monthly bilingual newsletter with information on training opportunities, active involvement opportunities, relevant news and a network members section. Providing a quarterly special edition newsletter outlining members’ achievements and show casing examples of active involvement in research.
- Developing and maintaining a strong Involving People presence on the bilingual NISCHR CRC website and improving access to the bilingual Involving People website, with downloadable information resources for service users.
- Making available a library of literature relating to PPI in research for active members of the Involving People Network and publicising this resource via the bilingual Involving People website.
- Supporting service users of the network to evaluate the bilingual Involving People Induction Pack, including the Involvement Workbook.
- Identifying service user mentors to work with new members of the network to provide peer support. Mentorship will be limited to selected experienced service users on the network, who will be offered training and support in order to effectively deliver this role.

d) Reviewing service user PPI activity levels

- Reviewing on an annual basis, every September, the PPI activity levels of service users of the network to gather a picture of which service users are and are not being recruited to PPI activities.
- Scoping researchers’ needs in relation to PPI in research and developing the Involving People Network to be able to meet these needs. Including relevant representation of conditions, diseases, skills, age, disability, gender and race. Supporting the areas of research excellence in Wales as described by NISCHR AHSC and areas of research activity related to the NISCHR clinical research portfolio.
- Working with service users who are continually not being recruited to PPI opportunities and identifying service user mentors to nurture these individuals.
Objective 3: Working to embed active involvement in NISCHR CRC and the NISCHR clinical research infrastructure

a) Active involvement in Research Development Groups (RDGs) of the NISCHR Registered Research Groups, Trials Units and research Infrastructure and Technical Support Groups:

- Exploring and developing PPI opportunities within these Groups, by nurturing relationships through regular face to face meetings with contacts.

b) Active involvement within NISCHR CRC

- Recruit members of the Involving People Network to join task and finish groups as and when required by NISCHR CRC to take on specific pieces of work in relation to NISCHR CRC workstreams. These individuals may be expected, with assistance from Involving People to share their experiences and / or consult more widely with members of the network.

c) Active involvement at a strategic NISCHR level

- Support the active involvement of Involving People network members at a strategic level in NISCHR groups as and when required.
Objective 4: Raising awareness of PPI in research in Wales

a) Through the Involving People Annual Meeting

- Delivery of the Involving People Annual Meeting to a mixed audience of service users and researchers. Delivering focused themes and messages to researchers and service users via different workshops, and allowing service users the opportunity to share views and ideas via a forum session.
- Disseminating the proceedings of the Involving People annual meeting on the PPI webpages of the bilingual NISCHR CRC website and the bilingual Involving People website.

b) Exploring opportunities to engage with researchers across Wales through the NISCHR CRC workforce, with service user contribution where appropriate.

c) Developing and sharing case studies and examples of PPI good practice in the Involving People newsletter, the NISCHR CRC staff newsletter, NISCHR CRC electronic mailing list and the NISCHR CRC Annual Report.

d) Developing and maintaining links with UK-wide collaborators, for example INVOLVE, to explore UK-wide PPI opportunities.