

Strategy for Personal and Public Involvement (PPI) in Health and Social Care research



HSC Research & Development Division



Foreword

I am delighted to present the second edition of the HSC R&D Division's PPI Strategy. This strategy continues to recognise the importance of involving patients and the public in the research process and will build on the progress already made in implementing PPI in research in Northern Ireland, both in the work of the HSC R&D Division and its communities of practice.

My years as a PPI representative in research have been a learning experience. At first, I was nervous about my lack of medical knowledge, worried that I would be unable to grasp the concept of the submissions I might be asked to assess. I was also wary of being asked for my opinion against a background of specialist professional knowledge but I found that these fears were totally unfounded. The professionals were open to comment, aware that I approached situations from a different perspective and therefore generated some very worthwhile discussions.

It is extremely important that a different dimension can be presented to ensure the patient does not become merely a number.

Although I have been a carer at different times and have been close to some very distressing conditions, I am not aligned to any particular condition and this helps me have an impartial view of the submissions I am asked to assess. The views of the PPI representative are invited, discussed and taken on board in the final corporate decision and I believe this is beneficial for the final outcome.

Personally, I have found this a very rewarding experience. I have learned many things, not least the impact of financial constraints on the research area, but I also know the clinical knowledge and expertise is there to create a better future and a better quality of life for the citizens of tomorrow, as well as improvements for the patients of today.

I take this opportunity to encourage other members of the public to get involved in research, and urge researchers to involve service users and the public as partners in the research process as a matter of course.

Mrs Eileen Wright, PPI Representative

The context

Local and national policy increasingly emphasises the central role of service users and the public in shaping Health and Social Care (HSC).

Organisations now have a statutory duty to involve users and the public in the commissioning, planning and delivery of all HSC services.¹⁻⁵

This process is known as Personal and Public Involvement (PPI). It means including individuals in decisions about their specific care or treatment and consulting members of the public and the wider community on the design, delivery and location of local services.⁶⁻¹⁴

Effective PPI is central to the delivery of safe, high quality services and, as such, is a key element of clinical and social care governance.

Ensuring that PPI is a core responsibility of all HSC staff will improve the quality and safety of services, promote health and social wellbeing, address local and regional needs and priorities, strengthen local decision making and promote social inclusion.

As in other areas of HSC activity, PPI is dependent on core values that include:

- dignity and respect;
- inclusion;
- equity and diversity;
- collaboration and partnership;
- transparency and openness.

The strategic need for and benefits of PPI apply to all levels of HSC Research and Development Division (HSC R&D Division) activity and its associated communities of practice.¹⁵⁻¹⁷

Definition

In defining PPI in this strategy, **'personal'** refers to any individual with a specific condition who uses or has used a service. This will include patients, carers, parents, clients or their advocates.

Service users and the public each have unique perspectives they can bring to the research process as expert partners.¹⁸⁻²²

The term **'public'** refers to any member of the wider community including their collective organisations.

These generic terms encompass all those people who will ultimately be the end users of research.

'Involvement' means working with service users and the public by actively engaging them in all parts of the research process as partners rather than doing research 'on' them. This may be through consultation or collaboration at different stages of the research process or having users lead a research study.



Purpose

Integrating PPI into the research process ensures researchers prioritise topics that are important for service users, and formulate questions, processes and outcomes that are patient- and public-centric rather than solely researcher-led.

Engaging with PPI representatives as partners rather than research subjects has been shown to produce a range of benefits and impacts.²³⁻²⁷

Impact on study design:

- identification of more meaningful research topics and questions;
- greater ethical integrity;
- improved reliability of research tools;
- more practical research methods;
- increased numbers of patients participating in clinical trials;
- improved access to groups or services that may be difficult to reach;
- richer data;
- more relevant and accessible findings;
- quicker dissemination and translation into appropriate and timely interventions.

Benefits to researchers:

- greater knowledge and understanding of service users;
- greater satisfaction and enjoyment;
- career benefits;
- increased credibility.

Benefits to PPI representatives:

- new skills and knowledge;
- sense of empowerment and achievement;
- support and friendship;
- enjoyment and satisfaction;
- employment and financial reward.



Benefits to the wider community:

- greater trust in and acceptance of research;
- projects grounded and focused on benefits for the community;
- improved relationships between communities and professionals;
- new and improved services;
- changes in practice;
- partnerships to effect change.

Approach

To embed PPI into all aspects of HSC R&D Division activity, we aim to:

- promote public awareness of health and social care research and actively seek the involvement of the public in our activity;
- increase awareness among the clinical research community of the benefits of PPI and encourage researchers to engage with users, carers and advocacy groups at the earliest possible stage in the planning and development of their research projects;
- make researchers aware of mechanisms and systems for PPI that will provide the scope and capacity to help them to plan, conduct and disseminate research studies that are important and relevant to service users;

- facilitate researchers' access to service users and public input.

To achieve these aims, a three-pronged approach will be employed, focusing on the main areas detailed in Figure 1.



Figure 1: Three-pronged approach to embedding PPI into all aspects of HSC R&D Division activity

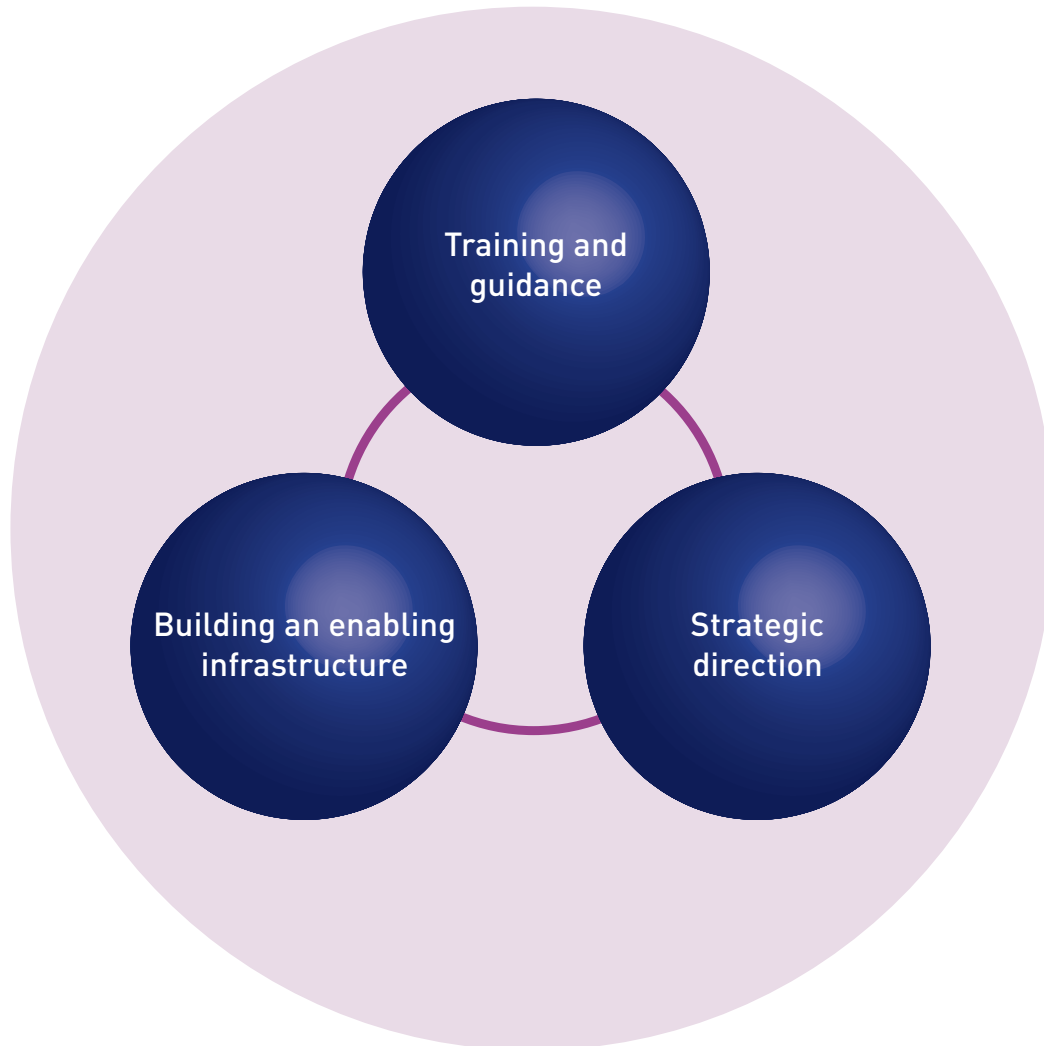


Figure 1



Training and guidance

Effective PPI requires that PPI representatives have the necessary skills and knowledge to become actively involved in all parts of the research process. Researchers should be confident and competent in facilitating this involvement.

Members of the public should also understand and have confidence in the value of research in improving HSC services and the benefits of involvement to themselves and others.

The HSC R&D Division has a responsibility to ensure appropriate training and guidance is in place to support PPI in all the activities it funds.

This will draw on a range of existing programmes and resources already available locally or elsewhere in the UK and, where appropriate, adapted to suit Northern Ireland.

Documents to support training and guidance should be practical, accessible, easy to read, and in a variety of formats to suit different learning needs, styles and research roles.

Deliverables

Over the next two years, we will:

- fund a training programme for researchers, service users and the public, and encourage the development of new training as necessary;
- produce local guidelines supporting PPI activity for PPI representatives and researchers;
- disseminate guidance and information on relevant websites or portals via global email;
- organise PPI conferences and study days;
- develop a public awareness campaign about the benefits of HSC research.



Training and guidance

Infrastructure

The HSC R&D Division has an important role in creating an infrastructure that will embed PPI in its various activities and enable researchers and PPI representatives to participate actively in these processes by removing unnecessary barriers and obstacles.

An effective infrastructure depends on collaboration and partnership with colleagues in the HSC, voluntary sector and research community.

The main elements of this enabling infrastructure will ensure access to a pool of PPI representatives who are willing and able to be involved in research activities, and the commitment of researchers who are skilled in facilitating this involvement.

Deliverables

Over the next two years, we will:

- contribute towards the creation of a directory of service user groups willing to be involved in research;
- continue to ensure that calls and funding schemes commissioned by the HSC R&D Division include a prerequisite for PPI and an appropriate question on application forms and monitoring reports;
- expand the pool of PPI representatives who support HSC R&D activities and continue to provide training for this group;
- ensure adequate reimbursement of PPI representatives for expenses incurred through involvement in line with relevant policy.



Strategic direction

It is important that the HSC R&D Division represents local views on national steering groups and takes an active role in disseminating or adapting national policy for use by local researchers. It should also provide leadership for PPI in the clinical academic research community.

The HSC R&D Division will liaise with local and national bodies and key stakeholders to ensure its strategic direction for PPI is evidence-based and aligned with the aims, roles and responsibilities of its organisational partners (Figure 2).

It will also acknowledge and build upon existing good practice and expertise through the establishment of effective and reciprocal working relationships with key stakeholders.

Where appropriate, the HSC R&D Division will provide funding for, or commission new initiatives in PPI in order to facilitate the identification of important local needs and appropriate models of care.

Deliverables

Over the next two years, we will:

- represent the HSC R&D Division on national and local PPI steering groups;
- liaise with local and national PPI stakeholders to disseminate and share best practice;
- work in partnership with the Northern Ireland Clinical Research Network and other relevant bodies to promote PPI in study design and adoption through the provision of courses and relevant guidance;
- dedicate funding to PPI initiatives;
- evaluate, with relevant partners, the impact of PPI on the HSC R&D Division and wider HSC system;
- disseminate examples of good practice or change resulting from PPI in research.



Figure 2: HSC R&D community



Figure 2

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Equality and human rights considerations

This policy has been screened for equality implications as required by Section 75 and Schedule 9 of the Northern Ireland Act 1998.

Equality Commission guidance states that the purpose of screening is to identify those policies likely to have a significant impact on equality of opportunity so that greatest resources can be devoted to these.

Using the Equality Commission's screening criteria, no significant equality implications have been identified. The policy will therefore not be subject to equality impact assessment.

Similarly, this policy has been considered under the terms of the Human Rights Act 1998 and was deemed compatible with the European Convention Rights contained in the Act.





Research and Development

For further enquiries please contact:
Dr Gail Johnston
Programme Manager
HSC Research & Development Division
Public Health Agency
12-22 Linenhall Street
Belfast
BT2 8BS

Tel. 028 9536 3490
Email gail.johnston@hscni.net

2nd Edition. Published by the Public Health Agency.
Belfast. 2014

www.publichealth.hscni.net