

Shaping the Future of Personal and Public Involvement in Health and Social Care Research

Why Involvement Matters?

Health and Social Care research has the greatest impact when it addresses the questions and priorities that matter most to the people it aims to serve. Increasingly, researchers are recognising that patients, carers and members of the public should not simply be participants in research, but active partners in shaping it. Involvement Matters was established to develop a series of priorities which will strengthen Personal and Public Involvement in research across Northern Ireland.



Bringing people together

At the heart of Involvement Matters was the belief that meaningful change happens through partnership.

A regional Steering Group was established, bringing

together public contributors, researchers, clinicians, representatives from universities, Health and Social Care organisations, charities and the voluntary and community sector. Together, the group guided every stage of the project and ensured that decisions reflected a broad range of perspectives.

The project adopted a structured priority-setting approach, drawing inspiration from the [James Lind Alliance](#) methodology while adapting the process to focus specifically

on improving Personal and Public Involvement rather than identifying clinical research priorities.

Over several months, researchers, public contributors and members of the wider community were invited to share their experiences through a regional survey, focus groups and a knowledge exchange workshop. People who completed the survey were asked to reflect on what had worked well, the challenges they had encountered and the changes they believed would have the greatest impact on improving Personal and Public Involvement in research. In total 249 people completed the survey.

The project identified [14 priorities for strengthening Personal and Public Involvement across Health and Social Care research in Northern Ireland.](#)

These priorities highlighted several recurring themes. People emphasised the importance of involving people earlier in the research process, providing appropriate training and support for both researchers and public contributors, building trusting relationships, recognising and valuing lived experience and ensuring that involvement is inclusive, meaningful and sustainable.

Perhaps most importantly, the priorities represented a shared vision developed collectively by people with different experiences but a common ambition—to improve the quality and impact of research through meaningful partnership.

Co-producing Involvement Matters

One of the defining features of Involvement Matters was that Personal and Public Involvement was not simply the subject of the project—it was central to how the project itself was designed and delivered.

Public contributors were involved throughout the project as equal partners, helping to shape key decisions from planning through to dissemination. Rather than being consulted at individual points, they worked alongside researchers and professionals to ensure that the project reflected the experiences and priorities of those it was intended to benefit.



Throughout the project, public contributors helped to:

- Shape the project approach through membership of the regional Steering Group, contributing to project planning, governance and decision-making.
- Co-produce the regional survey, helping to refine the wording, structure and accessibility of survey questions before launch.
- Develop project communications, including reviewing and refining the script for a [PPI animation](#) explaining PPI which to ensure messages were clear, engaging and accessible to a wide audience.
- Help distribute and promote the survey to a wide range of groups, institutions and individuals. This was reflected in the number of people who completed the survey (n=249).

- Interpret the findings, contributing to discussions on how the survey results should be grouped and helping refine the transition from a long list of recommendations into a smaller number of PPI focus areas for the [Knowledge Exchange Workshop](#).
- Shape the final priorities, working alongside researchers and professionals during the workshop to agree the priorities for action.
- Review and improve project outputs, including providing feedback on the [final report](#), and supporting communications before publication.
- Support dissemination, helping promote the findings through webinars, presentations and wider engagement activities. For instance, public contributors helped draft abstracts for the Research Development forum and conference. [PIER member](#) Margaret Grayson who was also a key member of the project steering group co presented the results of Involvement Matters at the [UK Clinical Research Facility conference](#).

Embedding PPI throughout the project strengthened both the process and the outputs. Public contributors challenged assumptions, highlighted practical considerations, improved the accessibility of project materials and ensured that the recommendations reflected real-world experiences alongside professional perspectives. This collaborative approach reinforced the project's central message: meaningful involvement is achieved not simply by asking for opinions, but by working in genuine partnership throughout the research process.

Turning priorities into action

The [publication of the Involvement Matters report](#) was never intended to be the end of the journey.

Instead, it marked the beginning of a new phase focused on implementation.

To support the next phase of work, the Involvement Matters Learning and Collaboration Group is being established to bring together public contributors, researchers and organisations from across Northern Ireland. The Group will provide a forum for sharing learning, showcasing examples of good practice, supporting collaboration and maintaining momentum as organisations and begin guiding the implementation of the priorities identified through the project.

Alongside the Learning and Collaboration Group, the findings have informed regional discussions on training and capacity building, contributed to wider work supporting implementation of the [UK Standards for Public Involvement](#) and provided organisations with a shared framework for strengthening PPI within their own research environments.

The project has also helped strengthen relationships across organisations, creating new opportunities for collaboration and shared learning that extend beyond the life of the original priority-setting exercise.

Lessons learned

One of the clearest lessons from Involvement Matters is that meaningful involvement cannot be achieved by one organisation alone.

Improving Personal and Public Involvement requires collaboration across organisations, investment in relationships and a willingness to learn from both public contributors and researchers. The project also reinforced that involving people early is essential. Public contributors should help shape research from the outset rather than being asked to comment once key decisions have already been made.

Looking ahead

The publication of Involvement Matters represents the beginning of an ongoing programme of improvement rather than a final destination.

The challenge now is to translate the priorities into action and continue building a research culture in which meaningful Personal and Public Involvement is recognised as an integral part of high-quality research.

By continuing to work together through the Involvement Matters Learning Group and wider partnerships, Northern Ireland has an opportunity to build upon the strong foundations established through Involvement Matters and ensure that future research is shaped with people, rather than simply for them.

You can find more information on the project at the following links

[Involvement Matters web page](#)

[PPI Resource Library for patients, carers and members of the public](#)

[PPI Resource Library for Researchers](#)

[Getting involved in research](#)

[Personal and Public Involvement training](#)