3rd DRAFT

INVOLVEMENT MATTERS – PARTNERSHIP & COLLABORATION FOR HEALTH AND SOCIAL CARE RESEARCH

Overview of Proposed Priority Setting Partnership (PSP) in association with the James Lind Alliance

July 2025

James Lind Alliance
In association with

HSC Public Health Agency
Research and Development

3RD DRAFT

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Background

The Northern Ireland Clinical Research Resilience and Growth (NICRRG) implementation plan was produced by a taskforce and published in 2022. The implementation plan recommended a series of actions to support recovery, resilience and growth in research in Northern Ireland following on from the COVID-19 pandemic. When we say ‘research’, we mean any activity that helps us learn more and make improvements in health and social care — this could include clinical trials, surveys, interviews, laboratory-based experiments, or studies that explore people’s experiences.

It was recognised that the successful recovery and growth of research needed strong Personal and Public Involvement (PPI) (as it’s referred to in Northern Ireland as a result of the integration of health and social care). Section 2 of the implementation was therefore dedicated to PPI and Priority Setting and a subgroup was formed to help take forward the actions. One of the actions was to develop a research priority setting exercise

Initially, a research priority setting exercise was to focus on clinical specialties within the Northern Ireland Clinical Research Network. A significant scoping exercise was undertaken and the subgroup determined that setting priorities for Personal and Public Involvement (PPI) would bring the most benefit to the Northern Ireland Health and Social Care research community.

What is Personal and Public Involvement (PPI) in research?

Within research, ‘Personal and Public involvement’ (also referred to as PPI or public involvement) means that research that is done ‘with’ or ‘by’ the public, not 'to', 'for' or 'about' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research, for example, the research topic or question, how the research is carried out, and how the results are shared and applied in practice.

Getting involved in research is different to being a ‘participant’ in a clinical trial or other research study. Public involvement is also different from ‘public engagement’, which is when information and knowledge about research is presented to the public (Health Research Authority 2024).

Why Personal and Public Involvement (PPI) in research matters

Everyone benefits from research but it is most powerful when it reflects the needs of patients, carers, service users and the public. When the public get involved in research, they work alongside researchers to help shape what research gets done, how that research is carried out, and how the results are shared and applied in practice.

Personal and Public Involvement (PPI) brings real-life experience and perspectives into the heart of research. When people with lived experience — patients, carers, service users, and communities — shape research priorities and decisions, the work becomes more relevant, meaningful, and impactful. Involving the public ensures that research is not only done *for* them, but *with* them, leading to outcomes that better reflect what matters most. Additionally, getting involved in research stops money from being wasted on research that doesn’t actually help people. PPI involves working collaboratively with researchers and makes a difference to the way health and social care is provided in the future.

PPI also builds trust, transparency, and a stronger connection between researchers and the public — improving the quality, credibility, and reach of health and social care research.

Purpose of this project

The primary purpose of this project is to identify and agree on key priorities for improving Personal and Public Involvement (PPI) practices in health and social care research in Northern Ireland. Identifying priorities for PPI is important because, while the benefits of PPI have been well documented, there is no clear, shared understanding of what questions and themes need to be addressed to improve PPI moving forward. Without this clarity, efforts to make PPI more effective may be inconsistent. By setting clear priorities, we are aiming to ensure that future actions are targeted, meaningful and responsive to what matters most. These priorities will help guide future research and initiatives so that PPI becomes more impactful and sustainable across Northern Ireland.

To do this, we’re bringing together a wide range of voices — including patients, carers and service users (who have or have not previously been involved in research) and the wider public, as well as representatives from the community and voluntary sector. We’re also including Public Involvement Leads, equality and diversity leads, health and social care professionals who are active in research, and members of the wider research community, including academic researchers.

Figure 1: Project overview

Project Vision - To develop priorities for Personal and Public Involvement (PPI) practices in Health and Social Care research in Northern Ireland

What we are aiming to do

1. To map current public involvement activity in Health and Social Care research in Northern Ireland (NI).

2. Identify practical steps known to improve public involvement in research and also note current barriers to more effective PPI.

3. To develop priorities for future PPI research and initiatives in Northern Ireland

How we will do it

Step 1: Identification and engagement with key interest groups.

Step 2: Survey with key groups and stakeholders across Northern Ireland

Step 3: Analyse responses to survey in step 2 and produce an interim report.

Step 4: Final priorities workshop to identify key priorities for PPI.

What we will produce

An overview of the of the PPI landscape within HSC research in Northern Ireland, and an understanding of barriers and enablers to effective PPI.

A final report with a list of key actionable priorities for future research or PPI initiatives.

Short-term outcomes

We will have knowledge of what works well in PPI in health and social care research in NI, and what could be better

A set of priorities for future research or initiatives to improve PPI practices in health and social care research across Northern Ireland will be identified. These priorities will be directly informed by feedback from a broad range of stakeholders, including patients, carers and service users, clinical and academic researchers, and the community and voluntary sector.

Longer-term outcomes

The priorities identified will be incorporated into health and social care research projects, funding calls, and the overall design of different research studies and projects.

Additionally, the priorities will help shape the direction of future research and wider PPI initiatives, ensuring that PPI is deeply integrated into research processes and decision-making. This sustained approach will ultimately contribute to making health and social care research more inclusive, equitable, and reflective of the needs of diverse communities.

Overall, the profile of PPI in health and social care research will be raised across the research community in Northern Ireland.

Project Oversight

A Project Steering Group will have oversight of the work, chaired by a JLA Adviser[1], with 12/14 members. Steering group members have been selected to draw on the range of perspectives from those with experience of public involvement in health and social care research in Northern Ireland. These include:

- People with experience of being involved in health and social care research (to include patients, service users and carers)
- Representatives from the Community and Voluntary Sector
- Public involvement Leads/ Practitioners
- Health and social care professionals who lead on or help deliver research
- Other members of the Northern Ireland research community (e.g. funders, representatives from the academic research community).

Methods:

Step 1: Identification and engagement with key interest groups

Potential partner organisations will be identified initially through the Steering Group member’s networks. This will inform the mapping exercise which will highlight current public involvement activity in Health and Social Care research in Northern Ireland. Before the launch of the survey potential partners will be contacted and informed of the priority setting partnership and why it is important to set priorities for PPI. Additionally, an information session will be held before the launch of the survey for potential partners

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[1] All priority setting partnerships conducted in association with the James Lind Alliance are chaired by a James Lind Alliance Advisor.

to find out more about the PSP and address any questions or concerns. The steering group will co-design a communication plan which will have several objectives:

- To present and generate awareness of the proposed plan for the PSP
- To encourage participation in the process

To initiate discussion, answer questions and address concerns

Step 2: Survey with key interest groups and people across Northern Ireland

We will then carry out the survey with key groups (represented by members of the steering group). This will include a survey and group discussions. The survey will explore the experiences, challenges and priorities for PPI in practice.

Step 3: Analysing and Reporting Responses and produce an interim report

We will sort and analyse the responses to the survey with input from the Steering Group, and summarise group discussions. We will compare these responses with current evidence and research guidelines (including the UK Standards for Public Involvement) to identify themes. The responses will be categorised based on:

- Practical actions known to improve public involvement (what works well).

  Priorities where there is a lack of clear actions or understanding (what could be better and what actions should be taken to improve PPI in health and social care research in NI).

Step 4: Finalising key priorities workshop[1]

An in-person workshop will be held with a wide range of partners (such as those represented by the Steering Group). The workshop will focus on identifying any remaining uncertainties or gaps in knowledge about public involvement in health and social care research and with the aim of agreeing a list of key priorities for further improving Personal and Public Involvement (PPI) practices in in health and social care research across Northern Ireland.

Publication of final report

We will publish a final report for this project. This will include an overview of the methods and findings, and the key list of priorities for future research or initiatives to improve PPI practice in health and social care research within Northern Ireland. Using insights from the survey, the report will also highlight barriers and enablers to effective PPI. The report will also be available in different formats, such as an easy to read, plain language summary and with infographics.

Sharing the report findings

Results will be shared with public contributors in a series of webinars and face to face presentations with local PPI groups. The key priorities for public involvement will also be shared widely with the wider research community in a variety of ways including, journal articles, conference presentations and webinars with the aim of reaching a wide readership across the UK and internationally. Once the project has been completed, there will be a launch event with an audience of key stakeholders, including public

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[1] Depending on the responses to the survey in step 2, there may be a second survey were the PPI uncertainties collected are narrowed down to a more manageable number before the finalising key priorities workshop.

contributors, representatives from universities, the charity and voluntary sector and the wider Health and Social Care community.

Proposed outcomes

The priorities identified will be incorporated into health and social care research initiatives, funding calls, and the overall design of different research studies and projects. Additionally, the priorities will help shape the direction of future research, ensuring that public involvement is deeply integrated into research processes and decision-making. Moreover, Universities, Research & Development offices and health and social care trusts will be encouraged to consider the priorities relevant to them. An additional outcome will be an understanding of barriers and enablers to PPI to help inform future PPI practices. This sustained approach will ultimately contribute to making health and social care research more inclusive, equitable, and reflective of the needs of diverse communities. Overall, the profile of Personal and Public Involvement (PPI) in health and social care research will be raised across in Northern Ireland.

Conclusions

Using a collaborative approach, the proposed Priority Setting Partnership, in association with James Lind Alliance, will develop priorities which when addressed will lead to more effective Personal and Public Involvement (PPI). Ultimately this will help to shape how health and social care research is commissioned, funded and conducted in Northern Ireland.

Funding

This project is funded by the Northern Ireland Clinical Research Resilience and Growth (NICRRG) Fund and is being led by the Health and Social Care Research & Development (HSC R&D) Division in association with the James Lind Alliance (JLA).

Appendix 1: Steering group members

Steering Group Member	Organisation
Alan Drennan	PPI Contributor
Anne McGlade	Social Care Council
Debbie McGrory	Health and Social Care, Research & Development
Fidelma Carter	Chest, Heart and Stroke
Helen McAneney	Northern Ireland Public Health Research Network
Ian Stafford	PPI Contributor
Janet Diffin	Health and Social Care, Research & Development
Jonathan Jackson	Northern Ireland Clinical Research Network
Laura Collins	PPI Contributor
Maeliosa McCrudden	Queen's University, Belfast
Margaret Grayson	PPI Contributor
Martin Quinn	Public Health Agency
Maryrose Tarpey	James Lind Alliance
Ruth Boyd	Northern Ireland Cancer Research Forum
Sonia Patton	PPI Contributor
Stephanie Cathcart	Chest, Heart and Stroke
William Crowe	Health and Social Care, Research & Development