HSC Public Health Agency
Research and Development

Involvement Matters: Partnership and Collaboration in Health and Social Care Research

Final report

June 2026

TABLE OF CONTENTS

FOREWORDS

Together we should all be seeking to support and facilitate Health and Social Care Research, of the highest standard, in Northern Ireland. This can only be realised through excellence in research; research that brings benefit to patients, workforce and indeed the Health and Social Care as a whole. Fundamental to this is the collaborative work done with personal and public partnerships and researchers in the decision-making process.

The Public Involvement and Priority Setting panel, a subgroup of the Northern Ireland Clinical Research and Resilience Group (NICRRG), recognised the important work already underway in Personal and Public Involvement (PPI) in Health and Social Care research. They saw Involvement Matters as an opportunity to strengthen this involvement by identifying areas for improvement. We are very grateful to the NICRRG for funding this project.

Thank you to our James Lind Alliance facilitator, Maryrose Tarpey, for her guidance in adapting the framework in relation to PPI to help identify priorities for action.

Thank you also to the Involvement Matters lead, Dr Alan McMichael and the rest of the core team Dr Janet Diffin, Dr William Crowe and Debbie McCrory for their passion in enabling the project.

Involvement Matters has been a truly collaborative project in relation to involvement in Health and Social Care Research; which is especially gratifying to us as PPI and Clinical Research contributors.

Involvement Matters has identified 14 key priority action points. Together we look forward to the implementation of these action points, fulfilling the aim of the project to increase effectiveness of PPI in how research is funded, commissioned and conducted in Northern Ireland.

Margaret Grayson, PPI contributor, Co-chair of Public Involvement & Priority Setting Sub-Group

Prof A. Jonathan Jackson, Consultant Optometrist & Director Northern Ireland Clinical Research Network

FOREWORDS

Meaningful Personal and Public Involvement (PPI) is an important part of ensuring that Health and Social Care research addresses the issues that matter most to patients, service users, carers and communities. It helps to improve the quality, relevance and impact of research, and strengthens the relationship between research and the people it is intended to benefit.

Over the years, Health and Social Care Research & Development Division have had a strong commitment to PPI. Building on this, I am delighted to introduce this report from the Involvement Matters project. This work represents the first exercise of its kind in Northern Ireland to explore the barriers and enablers to conducting Personal and Public Involvement in Health and Social Care research, and to identify shared priorities for action for the future.

The findings presented in this report are the result of a truly collaborative effort. I would like to thank the many public contributors, researchers, Health and Social Care professionals, community and voluntary organisations and stakeholders who generously gave their time, experience and expertise to help shape this work. Their willingness to share insights and learn from one another has resulted in a rich and important body of evidence that will help guide future developments in PPI across Northern Ireland.

One of the strongest messages emerging from this project is that strengthening PPI is a shared responsibility. No single individual or organisation can deliver this change alone. Rather, it will require continued partnership, leadership and collaboration across the research community to ensure that PPI becomes increasingly inclusive, meaningful and embedded within research culture.

Importantly, this report does not mark the end of the journey. Instead, it provides a strong foundation upon which to build. The priorities for action identified through this work present an opportunity to strengthen capacity, promote shared learning, and support a culture in which the voices and experiences of patients, service users, carers and communities are recognised as essential to high-quality research.

I am confident that the relationships, momentum and shared commitment generated through Involvement Matters will continue to have a positive impact on Health and Social Care research in Northern Ireland for many years to come.

Rhonda Campbell

Assistant Director, HSC Research & Development Division

Rhonda Campbell.

PLAIN LANGUAGE SUMMARY

We carried out the Involvement Matters project to learn what is working well in Personal and Public Involvement (PPI) in Health and Social Care research across Northern Ireland, and what could be better.

PPI means that researchers work together with patients, carers, service users, and members of the public to shape research and how it is carried out. This helps make research more meaningful to the people it is hoped to benefit.

Although there are many examples of good PPI practice across Northern Ireland, we wanted to better understand what helps meaningful involvement happen, and what is needed to strengthen PPI in the future.

To do this, we brought together a group of people to guide the project. This included patients, carers, researchers, and representatives from Health and Social Care organisations, universities, and community and voluntary sector. We also carried out a survey and a one-day workshop to gather experiences, ideas, and suggestions from a wide range of people.

Together, we decided on a set of priorities for action. These priorities for action highlight the importance of involving people early in the research process, providing training and support which was easy to access, improving how organisations work together, and building trusting relationships with communities. They also show it is important to share learning, resources, and examples of good practice.

The findings from the Involvement Matters project will help shape future approaches to PPI in Health and Social Care research across Northern Ireland. We hope the priorities for action will support stronger partnerships between researchers, public contributors, Health and Social Care organisations, and communities, leading to more meaningful, inclusive, and long-lasting public involvement in research.

A NOTE ON LANGUAGE

Across the United Kingdom and Ireland, different terms are used to describe public involvement in Health and Social Care research. In much of the UK, the term Patient and Public Involvement and Engagement (PPIE) is now used, whilst in Ireland, Public and Patient Involvement (PPI) is used. However, in Northern Ireland, we use the term Personal and Public Involvement (PPI). This term was first introduced in 2007 to describe the concept of involving people and local communities in the planning, commissioning, delivery and evaluation of the Health and Social care services they receive [1]. The use of “Personal” recognises the integration of Health and Social Care in Northern Ireland, and the contributions of people with lived experience beyond those who identify as patients, including carers, family members, and the wider public. PPI is the only abbreviation used throughout this report and we use the term public contributors to describe individuals who get involved in research.

We recognise that different individuals and organisations use different terms, such as patients, service users, the public, or people affected by a condition or service. No single term will feel right for everyone and we have therefore chosen people with lived experience as a broad and inclusive term, while acknowledging that language preferences vary and should always be respected.

We use the term public contributors when referring to individuals working in partnership with researchers to shape, deliver, analyse, and share research findings. When we refer to involvement, we mean the active involvement of people in the decisions made about research, not as research participants or recipients of services.

This report reflects the views and language agreed by public contributors during the Involvement Matters project.

INTRODUCTION

What is Personal and Public Involvement in Health and Social Care research?

In research, Personal and Public Involvement (PPI) means research that is carried out with or by members of the public, rather than to, for, or about them. It involves an active partnership between patients, carers, service users, members of the public and researchers.

Involving people in research in this way can help shape:

- What research questions are asked
- How research is designed and conducted
- How findings are interpreted, shared, and used in practice

PPI is different from taking part in a research study as a participant. It is also different from public engagement, which focuses on sharing information about research. Instead, PPI is about working together and influencing decisions throughout the research process. At its core, PPI is about doing research in partnership with people, and recognising the value of lived experience alongside professional and academic expertise.

Health and Social Care research affects everyone, but it is most effective when it reflects the realities of people’s lives. PPI brings real-world insight into research, ensuring that studies are relevant, ethical, and grounded in what matters most to those who use and deliver services.

PPI also helps prevent time, funding, and effort being spent on research that does not address real needs [1,2]. By involving the public early and throughout the research lifecycle, research is more likely to lead to positive change in Health and Social Care. Importantly, PPI encourages trust, transparency, and accountability [2-4]. It strengthens relationships between researchers, services, and communities, and helps ensure that the benefits of research are shared more fairly across society [5-7].

The Northern Ireland context

Northern Ireland has a number of well-established and active PPI groups and professionals supporting public involvement in Health and Social Care research. For example, groups such as Public Involvement Enhancing Research, the Northern Ireland Cancer Research Consumer Forum, and the Patient and Carer Education Partnership group at Queen's University Belfast, work consistently with researchers to support meaningful PPI.

Moreover, a number of project-specific PPI groups have also been established to support research projects and programmes of work, such as the preconception PPI group and the Northern Ireland Lewy Body Dementia Research Advisory Group at Queen's University Belfast, and the Healthy Ageing and Alzheimer's Research UK (NI) Research Advisory Group Panel. The community and voluntary sector also plays an important role, with organisations such as Diabetes UK, Alzheimer's Research UK (NI), the Northern Ireland Kidney Research Fund, and Northern Ireland Chest Heart and Stroke, supporting PPI advisory groups and individual contributors to get involved in research.

The Public Health Agency has responsibility for leading the implementation and monitoring of PPI policy across Health and Social Care, and for ensuring that Health and Social Care Trusts meet their PPI statutory and policy responsibilities. Most Health and Social Care trusts have dedicated PPI leads who advocate for involvement and support the integration of PPI into research and service development. Additionally, the Patient Client Council is an independent statutory body in Northern Ireland that champions the voice of patients, clients, and carers within Health and Social Care and aims to ensure the public's views shape local healthcare policy and delivery.

In the context of research within Northern Ireland, Health and Social Care Research & Development Division is responsible for delivering the current PPI strategy for Health and Social Care research. PPI is also an important requirement within funding processes. Researchers applying for funding through the Health and Social Care Research & Development Division are expected to clearly demonstrate how PPI has informed the development and delivery of their projects. At a UK wide level, larger research funders such as the National Institute for Health and Care Research (NIHR) also have a requirement for PPI within the research projects and programmes that they fund. Moreover, the Shared Commitment to Public Involvement in Health and Social Care research has stated that public involvement is important, expected and possible in all typed of health and social care research.

Several other organisations within Northern Ireland have more recently made a wider commitment to PPI. For example, Queen’s University Belfast has recently become a new University Lead site with PPI Ignite. These recent developments reflect the expectation that PPI is not optional, but a core component of high-quality research.

There is clearly a strong foundation of PPI activity and expertise across Northern Ireland, providing valuable opportunities to build on existing good practice. However, some gaps do exist as not all Health and Social Care trusts have dedicated PPI leads, and the focus of their role may not necessarily be on Health and Social Care research. This gap was recognised within the Northern Ireland Clinical Research Resilience and Growth implementation plan (2022) which was published in response to the pressures that the Health and Social care system faced during the COVID-19 pandemic. A recommendation was to scope out the creation of PPI leads for research within Health and Social Care Trusts and primary care to help increase awareness among the public of value and impact of research, and create more opportunities to get involved.

Overall, the implementation plan recognised that successful recovery and growth of research relied upon having strong PPI. Section 2 was therefore dedicated to PPI and Priority Setting. A sub-group was subsequently formed to guide delivery of the actions within Section 2 and identify priorities for strengthening PPI in Health and Social Care research in Northern Ireland. This was considered to be important for the following reasons:

- To focus effort and resources on what matters most to people who are already involved or want to get involved in research.
- To identify common PPI challenges and opportunities across the research system.
- To identify how to best support consistent and high-quality involvement aligned with the UK Standards for Public Involvement.
- To ensure that responsibility for PPI is shared across researchers, academia, organisations, funders, and wider Health and Social Care systems.

With support from Health and Social Care Research & Development Division, the sub-group secured funding from the Northern Ireland Clinical Research Resilience and Growth programme to identify priorities for action for PPI through the Involvement Matters project.

About Involvement Matters

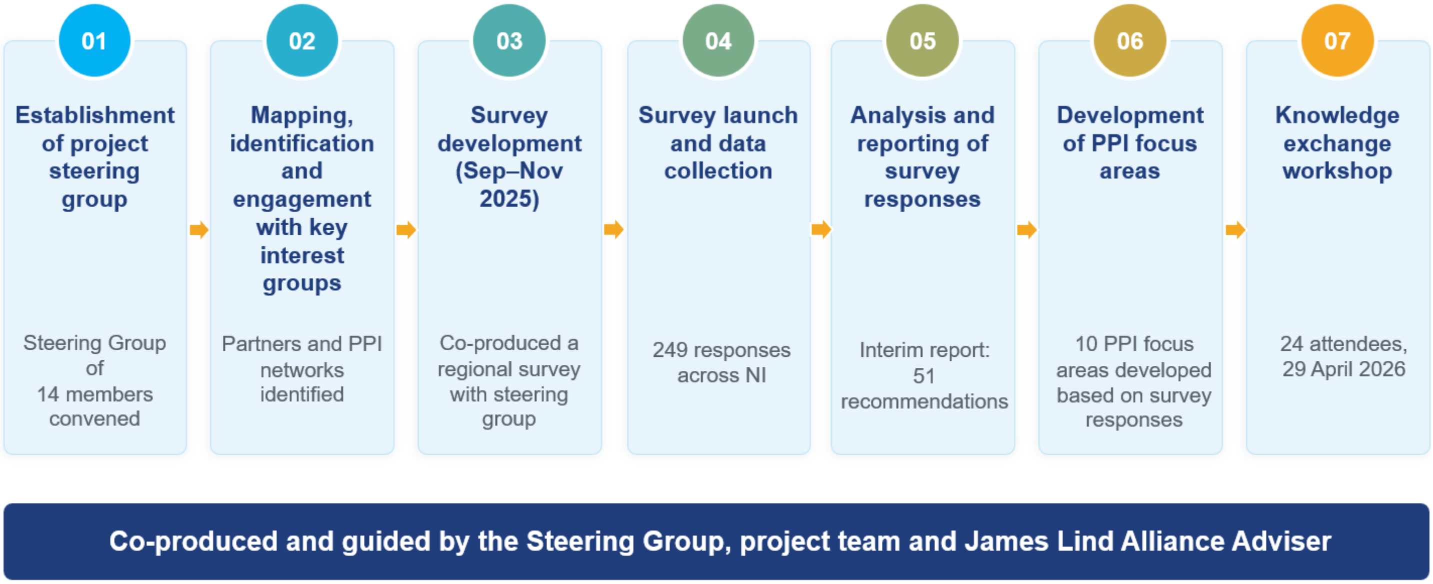
Involvement Matters is a Northern Ireland wide initiative conducted in association with the James Lind Alliance. The project focused on what works well, what could be improved, and what the priorities should be for PPI in Health and Social Care research.

The James Lind Alliance is best known for supporting Priority Setting Partnerships that identify and prioritise unanswered treatment uncertainties. However, the James Lind Alliance framework has also been successfully adapted to address broader questions about research practice and methodology [8,9]. In a similar way, Involvement Matters adapted the James Lind Alliance approach to focus on uncertainties and challenges related to PPI itself, while respecting the core principles of transparency, inclusivity, and equal partnership that underpin the principles of the James Lind Alliance. The primary aim of the Involvement Matters project was to identify a set of priorities for action that can guide and improve PPI practice in Health and Social Care research across Northern Ireland.

WHAT DID WE DO?

Figure 1 provides a visual overview of the steps taken throughout the project. The following sections provide an overview of each step in more detail.

FIGURE 1. OVERVIEW OF THE INVOLVEMENT MATTERS PROCESS



Step 1: Establishment of project steering group

A Steering Group was established to provide the oversight and strategic direction for the project. The Steering Group was chaired by the James Lind Alliance Adviser, Maryrose Tarpey, and comprised 14 members. Members were selected to reflect a broad range of perspectives relevant to PPI in Health and Social Care research in Northern Ireland.

Members of the Steering Group included:

- People with lived experience of involvement in research (including patients, service users, and carers)
- Representatives from the community and voluntary sector
- Public involvement leads and practitioners
- Health and Social Care professionals
- Members of the wider research community

The Steering Group co-produced the project plan and guided each step of the project as detailed below. The list of steering group members can be found in Appendix A. A project team within Health and Social Care Research & Development Division guided the delivery of the project.

Step 2: Mapping, identification and engagement with key interest groups

Potential partner organisations and networks were identified through Steering Group members' professional and community links.

A communications plan was co-developed with the Steering Group at this stage to:

- Promote awareness of the Involvement Matters initiative
- Encourage participation from a wide range of individuals and organisations
- Support inclusive engagement across sectors and communities

A mapping exercise was also undertaken to scope existing PPI groups and networks across Northern Ireland to share the survey with. Prior to the survey launch, potential partners identified through the Steering Group and mapping exercise were contacted to raise awareness of the project, explain its purpose, and encourage completion of the survey. A webinar was held on the 16th September 2025 to provide an overview of the project, outline how people could get involved, and address any questions or concerns.

Step 3: Survey development

The survey was co-produced and designed collaboratively with the Steering Group. Its purpose was to gather perspectives on:

1) What currently works well in PPI
2) Challenges and barriers to effective PPI
3) What the focus should be on for improving PPI in Health and Social Care research

The survey was open to members of the public with or without prior public involvement experience, Health and Social Care professionals, university researchers and people in the community and voluntary sector. The PPI related questions in the survey are shown in Table 1. PPI questions were open ended to allow respondents to share experiences, reflections, and suggestions in their own words. The language and structure of the survey were intentionally broad and accessible to enable responses from people with varying levels of familiarity with research and PPI. A series of demographic questions were also included to gather data on ethnicity, gender identification, age group, religion, disability and caring responsibilities. Results from the demographic questions are shown in Appendix B.

Table 1. Personal and Public Involvement survey questions included in the survey

	Survey questions
1	What do you think works well when it comes to involving patients, carers, service users and the public in Health and Social Care research? (You can share any examples you've seen or been part of, big or small.)
2	What do you think could be done better in PPI? (Have you come across any challenges, barriers, or things that didn't work as well? For example, were some voices missing, was it hard to get involved or get people involved, or was there confusion around expectations?)
3	What do you think are the most important priorities for improving public involvement in Health and Social Care research? (This could be ideas for future public involvement initiatives, or suggestions on what new practices would help to make involvement easier, better, or more meaningful.)
4	Is there anything else you'd like to share about Personal and Public Involvement (PPI) in Health and Social Care research in Northern Ireland? (This could be a story, an idea, or anything you would like to mention.)

Step 4: Survey launch and data collection

The survey was hosted online using Microsoft Forms and was open from 9th September to 25th November 2025. The survey was disseminated widely across Northern Ireland through:

- Steering Group member networks
- Health and Social Care research and professional networks
- Community and voluntary sector organisations
- Public involvement groups
- Online newsletters, websites, and social media channels

This broad approach aimed to capture views from a diverse range of people, including carers, patients, people who have or have not been involved in research before, researchers, Health and Social Care professionals, and representatives from the community and voluntary sector. To help explain PPI to those less familiar with the concept, and to describe what the benefits are, an animation was developed and linked to within the survey.

Who completed the survey?

A total of 249 survey responses were received, representing a broad range of perspectives from across Northern Ireland. As illustrated in Figure 2, the majority of respondents were members of the public (n = 153; 61%), with the remaining 39% (n = 96) identifying as professionals, including researchers, clinicians, and individuals working within Health and Social Care.

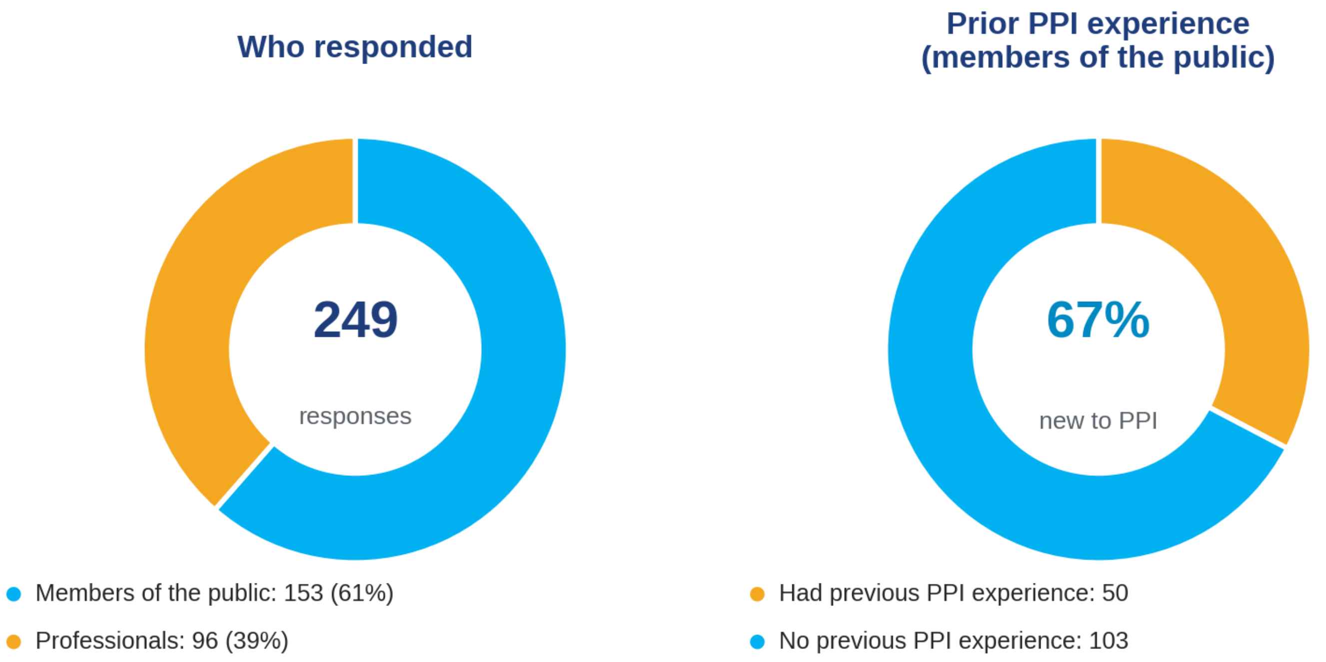


Figure 2. Respondent type and prior PPI experience among members of the public.

Members of the public were also asked if they had previous PPI experience. Of those who responded to this question, 67% (n = 103) reported no prior involvement, compared to 33% (n = 50) who had previous PPI experience. As highlighted in Figure 3, the most commonly reported barrier to involvement in research was not being asked or invited to get involved (n = 77). Many respondents also reported not being aware of relevant opportunities that already exist (n = 49) or not knowing how to get involved (n = 39). Survey respondents also felt they lacked sufficient knowledge about research (n = 25) or did not understand what PPI means (n = 21).

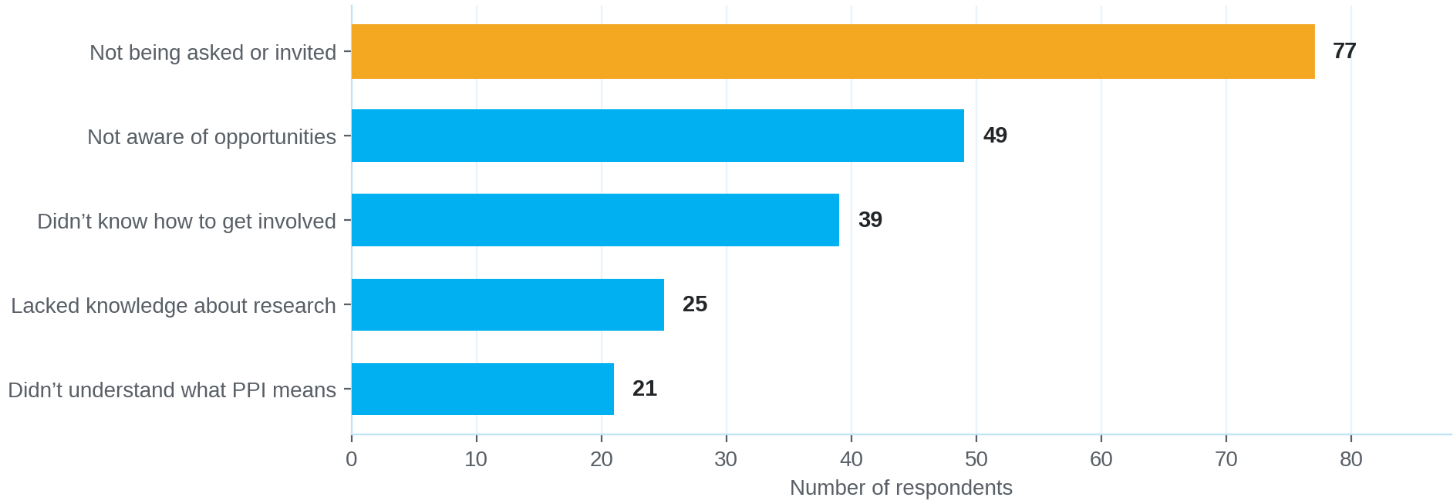


Figure 3. Most commonly reported barriers to getting involved in research.

A wide range of age groups was represented, with the largest proportion of respondents aged between 55 and 64 years (n = 63; 25.3%). Most respondents were based in Northern Ireland (n = 234; 94%), reflecting the regional focus of the project. A proportion of respondents also reported caring responsibilities, including caring for children (n = 79; 31%), an elderly person (n = 44; 18%), or an adult with a disability (n = 35; 14%).

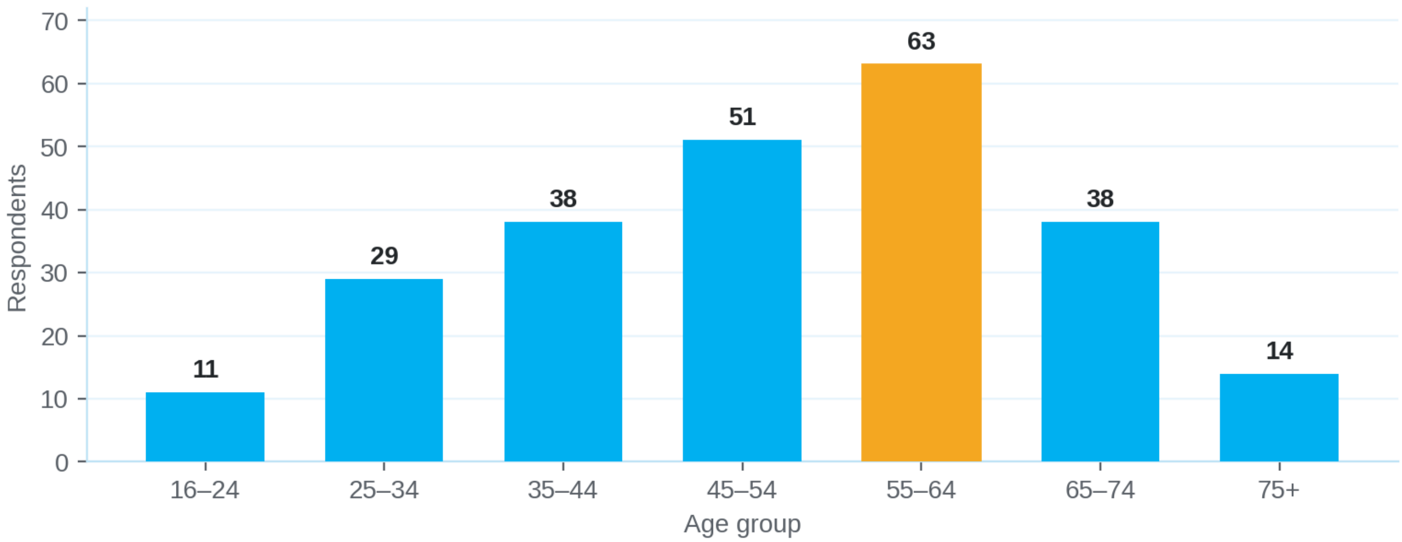


Figure 4. Age distribution of survey respondents.

Overall, the survey captured a diverse range of perspectives, including individuals with and without prior experience of PPI, providing a strong foundation for identifying relevant and meaningful priorities for improving involvement in Health and Social Care research. All demographic characteristics are shown in Appendix B.

Step 5: Analysis and reporting of survey responses

Health and Social Care Research & Development Division partnered with Dr Kristina Staley (of TwoCan Associates) who analysed the survey responses and produced an interim report. Responses to the survey were analysed using a thematic approach to identify key ideas, patterns, and recurring topics across all survey responses. Given the open-ended nature of the survey questions, this approach allowed survey respondents' views to be captured in their own words and ensured that a wide range of perspectives were reflected in the analysis.

Summarising the survey responses identified several trends. Among those survey respondents who had no previous PPI experience in Health and Social Care research, there was the misconception that PPI was taking part in research or other types of activity such as campaigning or policy work. Additionally, the notion that PPI was a type of qualitative research was also evident. Of those survey respondents who had previous PPI experience, there was a recognition that PPI is a key part of Health and Social Care research, which should be embedded from the start to avoid it being tokenistic. Despite numerous PPI resources already existing to help with PPI, respondents were suggesting the development of further resources and tools, which highlights a lack of awareness of existing PPI resources.

Throughout the interim report, each section was summarised with recommendations for strengthening PPI. In total, there were 51 recommendations for improving PPI in Health and Social Care research (Appendix C). Particular attention was given to preserving the language and emphasis used by survey respondents, recognising the importance of lived experience in shaping the findings. The interim report and a summary of the recommendations for action were made publicly available in February 2026.

Step 6: Development of PPI focus areas

In order to inform and guide discussions with stakeholders at a final knowledge exchange event, the project team and Steering Group worked together to identify similar or overlapping recommendations. Recognising the challenge of how to further prioritise the 51 recommendations outlined in the interim report, since all are important for high quality PPI, the recommendations were condensed into ten PPI focus areas (Table 2). These ten PPI focus areas formed the basis of discussions at the knowledge exchange workshop with the aim of identifying overarching priorities for action.

Table 2. The final ten PPI focus areas taken forward to the knowledge exchange workshop.

PPI focus area	What we mean
Valuing the impact of PPI	Ensuring the impact and value of PPI is recognised, evaluated, and shared.
Avoiding tokenistic PPI	Ensuring PPI shapes the decisions made about research, and is not treated as a tick-box exercise.
Early and sustained involvement	Involving people from the earliest stages of research and maintaining appropriate involvement throughout projects.
Respectful and accessible communication	Ensuring roles, boundaries, expectations, and communication are clear, accessible, and agreed from the outset.
Relationship building and PPI support structures	Developing positive, respectful working relationships between researchers, PPI members, and communities, and ensuring practical support structures such as co-ordination, preparation and peer support are in place to sustain meaningful involvement.
PPI training and support for researchers	Supporting researchers and clinicians to develop the skills, confidence, and understanding needed for PPI in research.
Training and capacity building for public contributors	Supporting public contributors to build confidence, develop skills, and take on meaningful roles in PPI.
Raising awareness of PPI opportunities	Improving awareness of PPI opportunities and supporting recruitment of people with relevant lived experience.
Fair payment, reimbursement and recognition	Ensuring people are fairly paid, reimbursed, and recognised for their time, expertise, and contributions.
Effective engagement with under-served communities	Working proactively with under-served groups and communities to reduce barriers and support inclusive involvement.

Step 7: Knowledge exchange workshop

The knowledge exchange workshop was held on 29th April 2026 and brought together a diverse group of stakeholders to review and build upon the recommendations within the interim report. The workshop was chaired by Maryrose Tarpey, a James Lind Alliance Adviser. The 24 workshop attendees included members of the public, people with lived experience, researchers, Health and Social Care professionals, and representatives from the community and voluntary sector. A full list of workshop attendees can be found in Appendix D.

Prior to the workshop, all attendees were provided with the ten PPI focus areas (Table 2). Attendees were also made aware of existing resources relevant to each focus area, to support informed discussion and to avoid duplication of priorities for action.

Attendees at the Involvement Matters knowledge exchange workshop, 29 April 2026.

Attendees were organised across four tables and worked in small groups to discuss the PPI focus areas outlined in Table 2. Each table discussed three focus areas, and group discussions were supported by a facilitator whose role was to guide discussion and ensure that all attendees had an opportunity to contribute.

Drawing on their own experiences and perspectives, each group was encouraged to use the following questions to prompt discussion:

- What overarching action is needed to address this PPI focus area?
- What are the potential barriers to implementing this overarching action?
- Who is collectively responsible for addressing this overarching action?
- Who should take the lead?

Importantly, the workshop moved beyond discussion to focus on action. It provided an opportunity to ensure that the final priorities for action were grounded in both the survey responses and the collective experience of workshop attendees. Each group summarised the key points discussed for each of the three focus areas, and feedback was sought from the whole group via a facilitated discussion. The consolidated notes from the workshop group discussions can be read here.

Cross-cutting themes emerging from the workshop

Reflecting on the workshop discussions, several cross-cutting themes emerged which are illustrated below:

Early, Sustained & Meaningful Involvement

- A consistent message across all discussions was the importance of involving people at the earliest possible stage of the research process. Early involvement was viewed as essential to avoiding tokenistic approaches and ensuring that PPI is embedded meaningfully within research design and delivery.
- Attendees also highlighted the importance of maintaining communication and involvement throughout the research lifecycle.
- There was strong support for introducing PPI earlier within academic pathways, including at undergraduate and postgraduate levels, to help raise awareness of PPI.

Training, Capacity Building & Support

- The need for training and support was identified as a key priority for both researchers and public contributors. Attendees highlighted the importance of practical skills development, including communication, facilitation, relationship building, and partnership working.
- Training was viewed as needing to be tailored to different disciplines, career stages, and levels of experience. Co-produced training approaches, mentorship, peer support, and "buddy" systems were also identified as valuable mechanisms for supporting both researchers and public contributors.

Relationships, Trust & Inclusive Involvement

- Building and sustaining relationships was identified as central to meaningful PPI, particularly when engaging with underserved communities. Attendees emphasised the importance of trust, flexibility, and working collaboratively with existing community networks and trusted partners.
- Issues relating to power dynamics, language, accessibility, and psychological safety were also discussed. Attendees highlighted the need to create respectful and inclusive environments that enable meaningful participation from a diverse range of people and communities.

Implementation, Recognition & Impact

- Across all discussions, attendees identified a gap between existing PPI guidance and how PPI is implemented in practice. There was a strong emphasis on moving from principles to action, supported by clearer accountability, leadership, and organisational commitment.
- Attendees also discussed the distinction between, and importance of, fair recognition and reimbursement for involvement, and the need to better demonstrate and communicate the impact of PPI through evaluation, storytelling, and case studies of good practice.

KEY PRIORITIES FOR ACTION

While the workshop generated a wide range of ideas and suggested actions, fourteen key priorities for action across the four cross-cutting themes emerged. Together with a shared sense of collective responsibility, these set out where effort should now be focused to strengthen PPI in Health and Social Care research across Northern Ireland. The priorities are presented for ease of reference and discussion and are not intended to represent a ranking or order of importance. If organisations are considering addressing the priorities, they should also give full consideration to the 51 recommendations within the interim report.

Early, Sustained & Meaningful Involvement

These priorities recognise the importance of involving people early, maintaining relationships over time and ensuring that involvement is meaningful and valued.

Develop PPI peer mentorship opportunities for both researchers and people who want to get involved in research.

Proactively promote and signpost to existing PPI resources for both researchers and people who want to get involved in research.

Identify the most consistent and accessible approach to promote PPI opportunities within Health and Social Care research in Northern Ireland.

Promote the early involvement of people in Health and Social Care research through the availability of pre-application PPI support and funding for researchers.

Training, Capacity Building and Support

These priorities highlight the importance of developing knowledge, confidence and practical skills to support meaningful involvement in research.

Develop a co-produced 'train the trainers' training package for people who want to get involved in Health and Social Care research.

Develop PPI training for researchers which focuses on developing practical skills for inclusive and sustained involvement, including communication, facilitation, and partnership working.

Embed PPI education and awareness within undergraduate and postgraduate programmes.

Establish a regional PPI in research shared learning and coordination group to promote better alignment, collaboration, and shared learning between Health and Social Care, universities, funders, and the community and voluntary sector.

Relationships, Trust & Inclusive Involvement

These priorities emphasise the importance of collaboration, psychological safety and ensuring that involvement opportunities are accessible and inclusive.

Promote the need to consider the impact of power dynamics, hierarchy, language, and psychological safety on involvement experiences.

Develop an agreed pathway to engage with community and voluntary partners to promote PPI opportunities to people underserved by Health and Social Care research.

Encourage senior researchers, institutional leaders, and decision-makers to actively support and champion meaningful PPI within the research culture and practice of their organisations.

Implementation, Recognition & Impact

These priorities focus on translating principles into practice and recognising and celebrating the contribution that Personal and Public Involvement makes to research.

Strengthen the monitoring and reporting requirements set by funders of Health and Social Care research to ensure PPI plans are being delivered on effectively.

Develop and share case studies examples of effective PPI practice and impacts across different types of Health and Social Care research.

Deliver PPI learning or showcase events to celebrate and share good practice in Health and Social Care research across Northern Ireland and recognise the contributions of people who have been involved in research.

DISCUSSION

This project represents an important opportunity to reflect on PPI in Health and Social Care research in Northern Ireland. To our knowledge, this is the first time that people have come together to collectively identify priorities for action to strengthen PPI practice in Health and Social Care research across Northern Ireland.

Overall, the findings from both the regional survey and knowledge exchange workshop suggest that Northern Ireland has many existing strengths on which to build further. Survey respondents and workshop attendees consistently highlighted examples of good practice in PPI, a strong commitment to meaningful involvement, and the existence of established PPI groups, networks, and expertise across the region. However, despite these strengths, several issues were identified as needing to be addressed if PPI is to become more consistent, inclusive, and sustainable across the research landscape.

A key finding throughout the project was the importance of early, sustained, and meaningful involvement. Survey respondents and workshop attendees consistently highlighted that PPI should not be viewed as a single activity undertaken to meet funding requirements, but rather as an ongoing partnership approach embedded throughout the research lifecycle. A key discussion point at the workshop was the need for funders to ask for better reporting on how PPI has remained embedded throughout a project’s lifecycle. Early involvement, particularly during the pre-award stage, was viewed as essential to avoiding tokenistic approaches and ensuring that research is shaped by the experiences and priorities of those it is intended to benefit.

The findings also highlighted the importance of training, support, and relationship building. Both researchers and public contributors identified a need for practical training focused on communication, facilitation, co-production, and partnership working. Importantly, there was an emphasis that training should extend beyond early career researchers and contributors, and should also include senior researchers, institutional leaders, and others involved in shaping research culture and decision-making. Mentorship, peer support, and opportunities for shared learning were viewed as valuable approaches to building confidence and capacity across the system. There is a critical need for case studies to highlight previous examples of how PPI was successfully implemented. This was also a key finding of the recent training needs analysis survey carried out by Health and Social Care Research & Development Division.

Another important theme emerging from the project was the need for greater coordination and visibility of existing PPI resources and opportunities. Workshop attendees recognised that a wide range of valuable resources, networks, and expertise already exist across Northern Ireland. For instance, Health and Social Care Research & Development Division have compiled PPI resource libraries for researchers, and patients, carers and members of the public. Moreover, the National Institute for Health and Care Research has numerous resources and training for public involvement in research. However, awareness and accessibility of these resources were perceived as inconsistent. There was strong support for more coordinated approaches to signposting, collaboration, and sharing opportunities across organisations and sectors. It is vitally important that we do not duplicate efforts by developing more resources or toolkits given the numerous amount that already exist.

The project also highlighted the importance of inclusive involvement and relationship building, particularly when engaging with people underserved by research. Discussions at the workshop among public contributors and researchers emphasised the need to build trust over time, work with existing community networks, and ensure that involvement approaches are flexible and accessible. Discussions also highlighted how influential power dynamics, hierarchies and language can be on an individual's well-being and ability to get involved in a research project. There was a general consensus that friendly plain language should be used throughout all communications. These findings reinforce the importance of creating respectful and supportive environments that enable meaningful involvement from a diverse range of individuals and communities.

Difficulties relating to payments being made to public contributors in recognition of the time and effort spent on projects were discussed during the workshop. Attendees shared examples of the challenges associated with navigating different organisational processes, policies, and regulations relating to payment, honoraria, and reimbursement. Attendees at the workshop felt that the proposed PPI shared learning group could provide a valuable platform for organisations to share learning, experiences, and practical approaches relating to such financial issues.

Finally, it was clear that the responsibility for strengthening PPI does not sit with any single organisation or individual. Instead, the findings suggest that meaningful progress will require continued partnership working and collaboration across Health and Social Care organisations, universities, funders, the community and voluntary sector, and public contributors themselves. Importantly, priorities for action are likely to differ across organisations and settings depending on existing strengths, gaps, and the local context. The priorities for action identified through this project are therefore intended to support reflection and guide future improvement and development work, rather than act as a prescriptive set of actions for any single organisation or sector. This fits with the consensus at the workshop that that no single organisation is solely responsible for implementing the priorities identified through this project. However, workshop attendees highlighted that Health and Social Care Research & Development Division may be well placed to act as a conduit to support collaboration, coordination, and shared learning across the system.

In the short term, this project has helped identify key priorities for action and has provided an opportunity for stakeholders to collectively reflect on both the strengths and challenges associated with PPI in Health and Social Care research within Northern Ireland. The project has also supported greater dialogue and knowledge exchange between individuals and organisations involved in PPI across different sectors.

In the longer term, the priorities identified through this work will help inform future training initiatives, funding processes, organisational approaches to PPI, and the design and delivery of Health and Social Care research. The findings will also contribute to a more coordinated and sustainable approach to PPI across Northern Ireland, helping to ensure that research is increasingly inclusive, relevant, and informed by lived experience. It is hoped that this project contributes to the continued development of a research culture in which lived experience, partnership working, inclusion, and meaningful involvement, are recognised as central to high-quality Health and Social Care research.

ACKNOWLEDGEMENTS

Collectively, the Health and Social Care Research & Development Division core project team would like to sincerely thank everyone who contributed to this project.

In particular, we would like to thank the members of the Steering Group for their guidance, insight, and continued support throughout the project. Their commitment to co-production and meaningful involvement was central to shaping this work. We would also like to thank Maryrose Tarpey of the James Lind Alliance for her input and facilitation skills through the project and Kristina Staley (of TwoCan Associates) for analysing the survey responses and producing the interim report.

We are also extremely grateful to all survey respondents and workshop attendees who generously shared their experiences, perspectives, and ideas. The openness, honesty, and enthusiasm of contributors played a vital role in identifying the priorities and recommendations outlined within this report.

We would also like to acknowledge the support of the James Lind Alliance for providing methodological guidance and independent facilitation throughout the project, as well as all partner organisations and stakeholders who supported the dissemination of the survey and workshop activities. Moreover, this important PPI initiative would not have been possible without generous funding from the Northern Ireland Research Resilience and Growth (NIRRG) programme.

Finally, we would like to thank all those working to strengthen Personal and Public Involvement in Health and Social Care research across Northern Ireland. This project highlighted the significant commitment, expertise, and passion that already exists across the region, and we hope the findings from this work will help support continued collaboration and progress moving forward.

Above all, we would like to thank the public contributors whose lived experiences, insights, and willingness to engage meaningfully with this work helped shape the direction of the project from beginning to end.

Funding disclosure

This initiative was supporting by a contribution from the Northern Ireland Research Resilience and Growth (NIRRG) Fund. Further information on the NICRRG programme can be found here.

REFERENCES

[1] https://www.health-ni.gov.uk/topics/personal-and-public-involvement-ppi

[2] Harrison, J. D., Auerbach, A. D., Anderson, W., Fagan, M., Carnie, M., Hanson, C., ... & Weiss, R. (2019). Patient stakeholder engagement in research: a narrative review to describe foundational principles and best practice activities. Health Expectations, 22(3), 307-316.

[3] Jagosh, J., Bush, P. L., Salsberg, J., Macaulay, A. C., Greenhalgh, T., Wong, G., ... & Pluye, P. (2015). A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. BMC public health, 15(1), 725.

[4] Mathieson, A., Brunton, L., & Wilson, P. M. (2025). The use of patient and public involvement and engagement in the design and conduct of implementation research: a scoping review. Implementation science communications, 6(1), 42.

[5] Ivany, C., Hudson, T., Schneider, P., Farrukh, H., Swinton, M., & Ghert, M. (2023). Patient engagement in research; benefits, challenges, importance, and implications. medRxiv, 2023-03.

[6] Gafari, O., Bahrami-Hessari, M., Norton, J., Parmar, R., Hudson, M., Ndegwa, L., ... & Stokes, M. (2024). Building trust and increasing inclusion in public health research: co-produced strategies for engaging UK ethnic minority communities in research. Public Health, 233, 90-99.

[7] Warner, G., Lampa, E., Tökés, A., Osman, F., & Sarkadi, A. (2020). Meaningful patient and public involvement to advance healthcare equity, quality and accessibility. European Journal of Public Health, 30(Supplement_5), ckaa166-1228.

[8] Stewart, D.C., Worrall, A., Elliott, J., Smith, M., Tierney, T., Blackwood, B. and Maguire, T., 2022. Priority III: top 10 rapid review methodology research priorities identified using a James Lind Alliance Priority Setting Partnership. Journal of Clinical Epidemiology, 151, pp.151-160.

[9] Retention in Randomised Trials (PRioRiTy II) (priority setting in association with the JLA); Retention in Randomised Trials (PRioRiTy II) (priority setting in association with the JLA) | NIHR JLA.

APPENDIX A — STEERING GROUP MEMBERS

Steering group member	Organisation
Alan Drennan	PPI Contributor, PIER member
Alan McMichael (Project lead)	Health and Social Care Research & Development Division
Anne McGlade	Social Care Council
Debbie McGrory (Project team)	Health and Social Care Research & Development Division
Fidelma Carter	Northern Ireland Chest, Heart and Stroke
Helen McAneney	Northern Ireland Public Health Research Network
Ian Stafford	PPI Contributor, PIER member
Janet Diffin (Project team)	Health and Social Care Research & Development Division
Katherine O’Neil	iREACH Health, Belfast
Jonathan Jackson	Director Northern Ireland Clinical Research Network (NICRN, BHSCT)
Laura Collins	Family Carer and PIER member
Maeliosa McCrudden	Queen’s University Belfast
Margaret Grayson	PPI Contributor, PIER member
Martin Quinn	Public Health Agency
Maryrose Tarpey	James Lind Alliance
Ruth Boyd	Northern Ireland Cancer Research Consumer Forum
Sonia Patton	PPI Contributor, PIER member
Stephanie Cathcart	Northern Ireland Chest, Heart and Stroke
William Crowe (Project team)	Health and Social Care Research & Development Division

APPENDIX B — SURVEY RESPONDENT DEMOGRAPHICS

The following tables summarise the demographic characteristics of the 249 survey respondents.

Respondent type	n	%
Member of the public	153	61.5
Professional (e.g. academic / clinician)	96	38.5
Total	249	100

Table B1. Survey respondent category

Previous involvement	n	%
Yes	50	20.1
No	103	41.4
Total responding	153	100

Table B2. Do you have previous involvement in PPI? (Note: 96 respondents did not answer.)

Interest	n	%
Yes	64	25.7
Maybe / not sure	48	19.3
No	3	1.2
Total responding	115	100

Table B3. Would you be interested in getting involved in research at a future date?

Gender	n	%
Woman	172	69.1
Man	70	28.1
Prefer not to say	3	1.2
Total	249	100

Table B4. What is your gender?

Age group	n	%
16–24	11	4.4
25–34	29	11.7

Age group	n	%
35–44	38	15.3
45–54	51	20.5
55–64	63	25.3
65–74	38	15.3
75 or over	14	5.6
Prefer not to say	3	1.2
Total	249	100

Table B5. To which age category do you belong?

Ethnic background	n	%
White	234	94.0
Mixed ethnic group	4	1.7
Icelandic	1	0.4
Chinese	2	0.8
Black Caribbean	1	0.4
Black African	1	0.4
Arab	1	0.4
Prefer not to say	3	1.2
Total	249	100

Table B6. What is your ethnic background?

Disability	n	%
Yes	52	20.9
No	187	75.1
Prefer not to say	7	2.8
Missing	3	1.2

Table B7. Do you have a disability?

Religion	n	%
Agnostic	1	0.4
Buddhist	1	0.4
Catholic	2	0.8

Religion	n	%
Christian	155	62.3
Humanist	1	0.4
Muslim	3	1.2
Non-Christian	1	0.4
None	67	26.9
Other	1	0.4
Prefer not to say	13	5.2
Protestant	1	0.4
Spiritual but not religious	2	0.8
Missing	1	0.4

Table B8. What is your religion?

Location	n	%
Northern Ireland	234	94.0
England	7	2.8
Republic of Ireland	3	1.2
Wales	1	0.4
Outside the UK / Ireland	1	0.4
Prefer not to say	1	0.4

Table B9. Where do you usually live?

APPENDIX C — THE 51 RECOMMENDATIONS

The following 51 recommendations were drawn from the survey responses and presented in the interim report. They were subsequently condensed into the ten PPI focus areas shown in Table 2.

1. Develop robust frameworks to demonstrate PPI impact.
2. Develop guidance on evaluating PPI and demonstrating the impact of PPI.
3. Make sure the impact of PPI is evaluated and disseminated.
4. Ensure researchers recognise the importance of, and benefit to be gained from, PPI.
5. Create meaningful PPI partnerships with research teams, while maintaining an independent, critical PPI voice.
6. Have PPI high up agendas, making it a necessity and not just a tick-box exercise.
7. Ensure researchers listen to people before deciding on outcomes.
8. Ensure everyone understands their unique role and respects each other’s skills and knowledge.
9. Build good working relationships between researchers and PPI members, and between PPI members themselves.
10. Improve communication and transparency in PPI.
11. Set clear boundaries for PPI at the start and ensure these are respected by all involved.
12. Help researchers to recruit the most relevant people to PPI activities.
13. Increase public awareness of PPI and the value of people’s contributions.
14. Educate the public about PPI, e.g. through digital resources, online information/videos, and simple leaflets showing the importance of involvement and the benefits it can bring.

15. Increase information in clinics to raise awareness amongst patients about how they can be involved in shaping research.
16. Target advertisement of involvement opportunities to communities that need more support to be included, e.g. people in deprived communities, people who are mentally ill, and young and older people.
17. Enhance digital accessibility and literacy to enable a broader segment of the public to get involved.
18. Bring PPI members into research from the very beginning, while ideas are still being formed.
19. Ensure consistency of involvement throughout research projects, in ways that are not onerous for researchers.
20. Make it mandatory local policy for academics to do PPI at early stages for all projects.
21. Share examples of training materials that helped support good PPI — practical guides and examples that can be adapted to different contexts.
22. Make PPI training mandatory within undergraduate training for all future researchers and healthcare providers.
23. Teach the public how to be ‘good’ PPI members.
24. Enable researchers and clinicians with successful experiences to mentor peers who are new to PPI.
25. Build PPI members’ experience and skills so they can take on greater responsibilities rather than remaining at the “consultation” level.
26. Assign full-time co-ordinators to help solve problems encountered during involvement.
27. Provide peer support, e.g. a buddy system for new PPI members.

28. Support PPI members to prepare ahead of meetings, to ensure understanding and allow time for questions and discussion outside of meetings.
29. Provide training and guidelines to help people think about the implications of sharing their experiences, and how to take care in that process.
30. Avoid jargon and use plain language.
31. Provide a list of keywords and their meanings for each meeting.
32. Create easy-to-understand leaflets or videos explaining study goals.
33. Establish connections between local community organisations and higher education institutions, to build trust and good working relationships.
34. Educate people about power and privilege, how these play out, and what needs to happen to ensure more equitable access and inclusion.
35. Provide funding to those leading health and social care research to actively address barriers that exclude marginalised groups.
36. Work with people who are excluded to ask what would make involvement easier for them.
37. Carry out more outreach in community settings covering various population groups, so more research voices are heard.
38. Provide guidance for research teams on how best to do community and outreach activities for PPI/E in their research.
39. Recognise that most projects need to employ a combination of approaches to be as inclusive as possible.
40. Provide guidance and training for researchers on how best to meet the communication and access needs of the people they work with.

41. Commit to giving feedback to PPI members about how their involvement is influencing decisions, on an ongoing basis.
42. Make it mandatory for researchers to respond to PPI members’ recommendations with an explanation of whether and how these have been implemented, or a reason why they have not — to avoid PPI becoming merely a formality.
43. Follow up with PPI members about the final results and impact of the research they have been involved in.
44. Incorporate fair compensation for PPI members’ time at the grant application stage, as well as for any research project activities.
45. Make the way people get paid more flexible for people with different financial needs.
46. Ask PPI members about any financial barriers to involvement and remove these, e.g. having to pay for travel or parking upfront and then claim it back.
47. Change policy in NI on remunerating PPI members to bring it into line with other parts of the UK, and ensure there is a budget to meet need.
48. Provide advice on payment processes, e.g. when right-to-work checks are needed.
49. Map the resources available to support PPI in NI and advertise this widely.
50. Increase the availability of dedicated funding for PPI.
51. Build in more time to allow researchers to build authentic and meaningful working relationships with PPI members, especially those who are often excluded from research.

APPENDIX D — KNOWLEDGE EXCHANGE WORKSHOP ATTENDEES

Attendee	Organisation / role
Aidan McCormick	PPI contributor
Aileen Major	Northern Ireland Cancer Trials Network
Alan Drennan	PPI contributor
Alan McMichael	Health and Social Care Research & Development Division
Claire Kerr	Queen’s University Belfast
Claire Cleland	Health and Social Care Research & Development Division
Colm Darby	Queen’s University Belfast
Debbie Keatley	PPI contributor
Donna Maguire	PPI contributor
Jamie Ellis	Ulster University
Janet Diffin (facilitator)	Health and Social Care Research & Development Division
Joanne Sansome	Research Assistant and Disability Rights Activist
Joe Duffy	Queen’s University Belfast
Karen McConnell	Queen’s University Belfast
Katherine O’Neil	iREACH Health, Belfast
Kevin Fee	PPI contributor
Loreena Hill	Ulster University
Maeliosa McCrudden (facilitator)	Queen’s University Belfast
Margaret Grayson	PPI contributor
Martin McCrory	Public Health Agency
Martin Quinn	Public Health Agency
Michael McAlinden	Health and Social Care Research & Development Division
Nicole Blackburn	Ulster University
Noel Wilson	PPI contributor
Rebecca Orr	Queen’s University Belfast / General Practitioner
Ruth Boyd (facilitator)	Northern Ireland Cancer Trials Network
Sinead Donnelly	Queen’s University Belfast

Attendee	Organisation / role
Stephanie Cathcart	Northern Ireland Chest, Heart and Stroke
William Crowe (facilitator)	Health and Social Care Research & Development Division

Public Health Agency

Research and Development

Scan the QR Code to find out more about getting involved in Health and Social Care research

For further information please contact Cara McClure (Cara.McClure@hscni.net) or visit https://research.hscni.net

---

This report should be cited as:

Health and Social Care Research and Development Division (2026). Involvement Matters: Partnership & Collaboration for Health and Social Care Research, Belfast: Public Health Agency.