Involvement Matters- Improving Personal and Public Involvement in Research Knowledge Exchange Workshop Discussion Document

The table below summarises the condensed focus areas identified from the long list of recommendations generated through the project survey and presented in the interim report (see Appendix 1). In total, 51 suggested recommendations for action were identified and have been grouped into 10 focus areas to support discussion and action.

For each focus area, the table also highlights examples of existing guidance, tools, resources and training that are already available to support Personal and Public Involvement (PPI) in research. These resources are included to provide an overview of the current landscape and to help inform discussion. We are keen to ensure that we do not recommend actions which will simply duplicate work that already exists.

During the workshop, attendees will be divided into small groups. Each group will be asked to consider three focus areas in detail.

For each focus area, groups will be asked to discuss and provide responses to the following questions:

1. What overarching action is needed to address this PPI focus area?

2. What are the potential barriers to implementing this overarching action?

3. Who is collectively responsible for addressing this overarching action?

4. Who should take the lead?

The discussion from each table will help inform the development of clear, practical priorities for action aimed at strengthening Personal and Public Involvement in health and social care research in Northern Ireland.

Table 1. Condensed focus areas for discussion and resources / training on what already exists for each focus area

Condensed focus areas	***Overlapping Long-List Priorities (1–51)***	***What We Mean***	***What we already know***
			To support discussion at the workshop, this column highlights examples of existing guidance, tools and resources in the PPI space. These are included to give a sense of what is already available and to help us focus on identifying gaps, challenges and opportunities for improvement
1. Valuing the Impact of PPI	1, 2, 3, 4, 6, 41, 42, 43	Ensuring the impact and value of PPI is recognised, evaluated, and shared.	Understanding and demonstrating the impact of PPI is important for ensuring that involvement is meaningful and not simply symbolic. The following tools and frameworks support researchers and contributors to plan for, capture, and communicate the impact of PPI throughout the research process. Public Involvement in Research Impact Toolkit (PIRIT): A toolkit to help researchers plan, track, and report the difference public involvement makes in research, aligned with UK Standards for Public Involvement. GRIPP2 reporting checklist: A checklist (available in both long and short form to aid reporting of patient and public involvement in publications. The Public Involvement Impact Assessment Framework: designed to help researchers plan for and assess the

			impact of PPI, providing a structured approach to identifying both process and outcome impacts. Patient and public Impact log: A tool specifically designed to capture the impacts of PPI as they happen throughout the research project. PPI ignite impact framework: Provides PPI contributors, researchers and other stakeholders a model that can be used to plan for and capture the impact of PPI in a research project. “Impact” is one of the six UK Standards for Public Involvement. This standard aims to “Seek improvement by identifying and sharing the difference that public involvement makes to research”.
2. Avoiding Tokenistic PPI	5, 7, 8, 34	Ensuring PPI shapes the decisions made about research, and is not treated as a tick-box exercise.	Meaningful PPI requires more than consultation and should actively influence decisions made during research. The following resources provide practical guidance to help ensure involvement is embedded in a genuine and constructive way. “Governance” is one of the six UK Standards for Public Involvement. The Governance standard encourages public involvement in research governance can help research be more transparent and gain public trust. Shaping our Lives: user-led organisation specialising in inclusive involvement. Developers of the Ladder of Co-Production.

			HSC R&D Division's PPI in Research Support Small Grant Scheme provides funding for researchers to develop PPI advisory groups or panels that can help to develop their research projects and programmes.
3. Early and Sustained Involvement	18, 19, 20, 51	Involving people from the earliest stages of research and maintaining appropriate involvement throughout projects.	Involving people from the earliest stages of research helps ensure that studies address issues that matter to those with lived experience. Several resources exist to encourage PPI from the earliest stages of the research lifecycle. The issue with early and sustained involvement is not a lack of resources, but rather implementing the resources. Research Cycle: Engaging Patients and the Public (PEDRI): An infographic tool that highlights key points for involving the public at every stage, from design to dissemination. "Working together" is one of the six standards in the UK Standards for Public Involvement. These standards are a national framework for what effective PPI should look like. Diagram - how PPI can be embedded in the research process - ARC West. Diagram for young people - how PPI can be embedded in the research process - ARC West.

			HSC R&D Division's PPI in Research Support Small Grant Scheme and the SEED fund at QUB both aim to support early and sustained involvement.
4. Respectful and Accessible Communication	10, 11, 30, 31, 32, 40	Ensuring roles, boundaries, expectations, and communication are clear, accessible, and agreed from the outset.	Clear communication, shared expectations, and accessible information are essential for building positive relationships between researchers and contributors. Numerous resources exist on effective communication and inclusive engagement in PPI. NIHR - Working effectively with public contributors: NIHR resources offering useful guidance on communication in PPI. Imperial College London Resource Hub**:** Offers practical guides on virtual meetings, including Inclusion Insights for accessible, inclusive virtual meetings. Patient and public involvement in research: A literature review highlighting practical advice on communication and accessibility in PPI. NIHR - Ethical Practice Guidelines for Public Involvement and Community Engagement: Ethical guidelines for PPI outlining best practice for communication, boundaries and expectations throughout the PPI process. "Communications" is one of the six standards in the UK Standards for Public Involvement. This standard

			encourages all parties involved in PPI to “Use plain language for well-timed and relevant communications, as part of involvement plans and activities.” The Lived Experience Guide and Service-User-Carer-checklist are practical resources and contain key information for public contributors on what to consider and expect before getting involved in research projects.
5. Support for Relationship Building and PPI Support Structures	9, 26, 27, 28, 29, 49	Developing positive, respectful working relationships between researchers, PPI members, and communities. Ensuring practical support structures such as co-ordination, preparation and peer support are in place to sustain meaningful involvement	Developing strong working relationships between researchers, public contributors, and communities is central to meaningful involvement. Health Research Authority - Impact of public involvement on the ethical aspects of research: Highlights how positive working relationships between public contributors and research can positively impact research outcomes. “Working together” is one of the six UK Standards for Public Involvement. The Working together standard encourages everyone to work together towards a common purpose, and different perspectives are respected. Shaping our Lives: user-led organisation specialising in inclusive involvement. Developers of the Ladder of Co-Production. HSC Research & Development Division have compiled PPI resources for researchers and for patients, carers and members of the public.

6. PPI Training and Support for Researchers	21, 22, 24, 38	Supporting researchers and clinicians to develop the skills, confidence, and understanding needed for PPI in research.	Researchers may require support and training to feel confident in designing and delivering meaningful PPI activities. Several resources and training coursed provide opportunities and practical guidance to support researchers in developing these skills. However, gaps may exist in this training in terms of practical aspects of PPI, such as facilitating training, managing meetings or making accessible arrangements. Building Research Partnerships: HSC R&D Division provide training which can be attended by researchers and the public. This training provided a high level overview of public involvement and practical approaches to embedding PPI throughout the research life cycle. HSC R&D PPI resources for researchers: HSC R&D Division have compiled aa resource library to help researchers with PPI. Imperial College Patient Experience Research Centre offers PPI training for researchers. This training also provides an overview of PPI, why it is important and how it can be implemented throughout the research process. NIHR have compiled briefing notes for researchers on public involvement in Health and Social Care Research.

			HSC R&D have recently completed a PPI training needs analysis to understand what aspects of PPI HSC and academic researchers need help with. The report can be read here NIHR also provide a guide on working effectively with Public contributors which was developed by public contributors.
7. Training and Capacity Building for Public Contributors	23, 25	Supporting public contributors to build confidence, develop skills, and take on meaningful roles in PPI.	Public contributors may benefit from training and information to help them feel confident and supported when getting involved in research. The following resources provide guidance and learning opportunities to support meaningful involvement. Getting started: becoming involved: NIHR guidance and resources for public contributors. Building Research Partnerships: HSC R&D Division provide training which can be attended by members of the public. This training a high-level overview of PPI and practical approaches to embedding PPI throughout the research life cycle. HSC R&D PPI resources for patients, carers and members of the public: HSC R&D Division have compiled a resource library for public contributors. NIHR provide a plain English glossary on terms used in statistics and research terms.

			Resources and training for public involvement in research: NIHR resource hub for public contributors. Contains several resources and links for public contributors including a guide on embers of the public being offered payment for their involvement in research. NIHR have developed reviewer training for public contributors to help provide feedback on a research document or sit on a committee that assess several research documents. “Support and Learning” is one of the six standards in the UK Standards for Public Involvement. This standard encourages everyone involved in PPI to promote support and learning that builds confidence and skills for public involvement in research. Healthtalk.org: Provides resources to encourage people to become involved in research. Several case study videos are shown.
8. Raising Awareness of PPI Opportunities	12, 13, 14, 15	Improving awareness of PPI opportunities and supporting recruitment of people with relevant lived experience.	Improving awareness of PPI opportunities can help ensure that a wider range of people are able to contribute their experiences and perspectives to research. Several resources have been developed and published to help with improving awareness. Several organisations and institutions advertise opportunities where people can learn more about PPI opportunities.

			People in Research: allows people to sign up to learn more about future PPI opportunities. PPI Ignite Network has an active noticeboard which provides an overview of involvement opportunities. VoiceIn is a digital platform that makes it easier for people to get involved in health research.
9. Fair Payment, Reimbursement and Recognition	44, 45, 46, 47, 48, 50	Ensuring people are fairly paid, reimbursed, and recognised for their time, expertise, and contributions.	Several resources and guidance exist to help researchers cost involvement activities into grants and projects. Approximate amounts to be paid for different involvement activities are also summarised. The NIHR have also put together guidance for public contributors who are considering involvement in research. NIHR Payment Guidance for the Public: A guide for patients and carers on what to expect, including potential impacts on benefits. Payment for public involvement in health and care research: Health Research Authority guidance for researchers The NIHR has budget for involvement which aims to help researchers approximate costs associated with public involvement.

			NIHR – Payment guidance for members of the public considering involvement in research: Guidance for PPI contributors considering involvement. HSC R&D Division's PPI in Research Support Small Grant Scheme and the SEED fund at QUB both aim to support researchers with costs associated with PPI.
10. Effective Engagement with Under-Served Communities	16, 17, 33, 35, 36, 37, 39	Working proactively with under-served groups and communities to reduce barriers and support inclusive involvement.	Engaging and involving underserved communities is important for improving future PPI projects and initiatives. The following resources offer practical approaches. NIHR - Resource guide for community engagement and involvement in global health research. Care Quality commission - Reaching under-served people and communities: A framework to help engagement and involvement with different communities. Guide for Inclusive Research: A guide to support researchers in their work with groups underserved by research. NIHR Include Guidance: Guidance on providing better health and care through more inclusive research with under-served communities. NIHR - A practical guide to being inclusive in public involvement in health research: A practical guide to help PPI be more inclusive.

"Inclusive opportunities" is one of the six UK Standards for Public Involvement. This standard encourages all partnerships to be accessible and include a range of people and groups, as informed by community and research needs.

Appendix 1: Long list of focus areas taken from the interim report

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, as well as maintaining an independent, critical PPI voice.
6) Have PPI high up agendas, making it a necessity not just a tick box.
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 the PPI members by:
10) Improve communication and transparency in PPI.
11) Set clear boundaries for PPI at the start and ensure these are respected by all people 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, simple leaflets to show the importance of involvement and the benefits it can bring to those involved.
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 the communities that need more support to be included e.g. people in deprived communities, mentally ill, young/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 be formed.

19) Ensure consistency of involvement throughout research projects, 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 for all undergraduate training for all future researchers and healthcare providers.

23) Teach the public how to be ‘good’ PPI members.

24) Enable researchers/ clinicians with successful experiences to mentor their peers who are new to PPI.

25) Build PPI member’s experience and skills so they can take on greater responsibilities rather than merely remaining at the "consultation" level

26) Assign full-time coordinators 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 discussions 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 meaning 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 and 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) More outreach in community settings covering various population groups so more research voices are heard.

38) Guidance for research teams on how best to do community and outreach activities for PPI/E in their research.

39) Most projects need to employ a combination of approaches to be as inclusive as possible.

40) 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 being made (or not) 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) Incorporating fair compensation for PPI members' time at the grant application stage as well as 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/ parking upfront and then having to claim it back.

47) Change policy in NI on remunerating PPI members to bring this 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 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.