Involvement Matters: Shaping the Future of Personal and Public Involvement (PPI) in Health and Social Care research

Survey Results: Summary of Recommendations for Action for PPI in Northern Ireland

HSC Public Health Agency
Research and Development

What did we do?

We surveyed people in Northern Ireland to find out what was working well with Personal and Public Involvement (PPI) in Health and Social Care research, what could be done better, and what actions they felt could help strengthen PPI in the future.

Who did we hear from?

249 people took part in the survey:
- 61% were members of the public, and a third had previous experience of PPI.
- 39% were professionals with diverse roles within Health and Social Care research.

What did people tell us?

The responses were very wide-ranging and included examples of impact, as well as discussions of the things that influenced the success of PPI.

Recommendations for action to improve PPI practices have been summarised under the following headings:
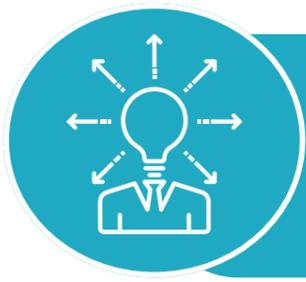
(a) Impact of PPI on research

(b) People – how people's awareness and attitudes affect PPI

(c) Approach – how the approach to PPI influences success

(d) Environment – how external factors impact the success of PPI

Impact of PPI on Research

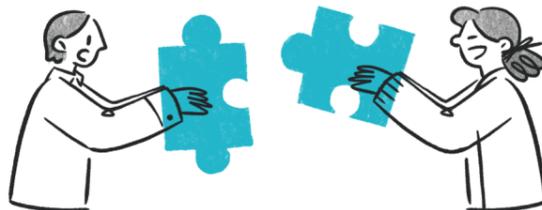**Recommendations for action were:**

- Develop robust frameworks to demonstrate PPI impact.

- Develop guidance on evaluating PPI and demonstrating the impact of PPI.

- Make sure the impact of PPI is evaluated and disseminated.

People's awareness and attitudes affect PPI

Recommendations for action were:

- Ensure researchers recognise the importance of, and benefit to be gained from PPI.

- Create meaningful PPI partnerships with research teams, as well as maintaining an independent, critical PPI voice.

- Have PPI high up agendas, making it a necessity not just a tick box.

- Ensure researchers listen to people before deciding on outcomes.

- Ensure everyone understands their unique role and respects each other's skills and knowledge.

- Build good working relationships between researchers and PPI members, and between the PPI members by:

  1. Having meetings outside of formal meetings
  2. Allowing time for PPI members to get to know researchers
  3. Providing spaces for PPI members to get to know each other
  4. Holding 1-2-1 calls prior to group meetings.
  5. Organising pre-event social activities and mechanisms for informal communication
  6. Ensuring everybody honours time commitments and deadlines whilst being flexible

The approach to PPI influences success

The vast majority of the survey responses were about the approach used for PPI and discussion of the specifics of good practice.

Clarity of purpose for PPI and proportional and appropriate approaches to PPI

Recommendations for action were:

- Improve communication and transparency in PPI.

- Set clear boundaries for PPI at the start and ensure these are respected by all people involved.

Recruitment of the right people to PPI roles

Recommendations for action were:

- Help researchers to recruit the most relevant people to PPI activities.

- Increase public awareness of PPI and the value of people's contributions.

- 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.

Recommendations for action (continued):

- Increase information in clinics to raise awareness amongst patients about how they can be involved in shaping research.

- 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.

- Enhance digital accessibility and literacy to enable a broader segment of the public to get involved.

Involvement at the early stages and continuously throughout a project

Recommendations for action were:

- Bring PPI members into research from the very beginning while ideas are still be formed. Ensure consistency of involvement throughout research projects, that are not onerous for researchers.

- Make it mandatory local policy for academics to do PPI at early stages for all projects.

Training and mentoring researchers and PPI members

Recommendations for action were:

- Share examples of training materials that helped support good PPI – practical guides and examples that can be adapted to different contexts.

- Make PPI training mandatory for all undergraduate training for all future researchers and healthcare providers.

- Teach the public how to be 'good' PPI members.

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

- Build PPI member's experience and skills so they can take on greater responsibilities rather than merely remaining at the "consultation" level.

Support for PPI members and researchers

Recommendations for action were:

- Assign full-time coordinators to help solve problems encountered during involvement.

- Provide peer support e.g. a buddy system for new PPI members.

Recommendations for action (continued):

- Support PPI members to prepare ahead of meetings, to ensure understanding and allow time for questions and discussions outside of meetings.

- Provide training and guidelines to help people think about the implications of sharing their experiences and how to take care in that process.

Good communication throughout a research project

Recommendations for action were:

- Avoid jargon and use plain language. Provide a list of keywords and their meaning for each meeting.

- Create easy-to-understand leaflets or videos explaining study goals.

Diversity amongst PPI members

Recommendations for action were:

- Establish connections between local community organisations and higher education institutions, to build trust and good working relationships.
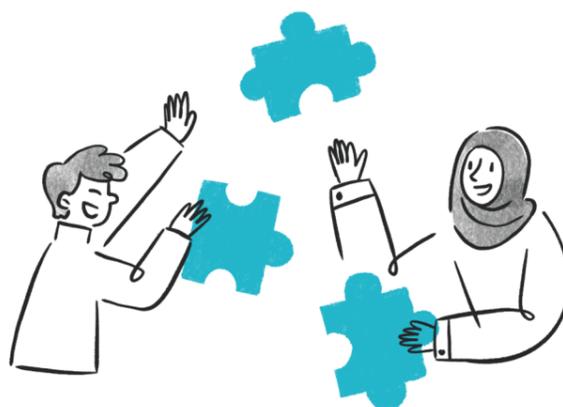
Recommendations for action (continued):

- Educate people about power and privilege and how these play out and what needs to happen to ensure more equitable access and inclusion.

- Provide funding to those leading health and social care research to actively address barriers that exclude marginalised groups.

- Work with people who are excluded to ask what would make involvement easier for them.

- More outreach in community settings covering various population groups so more research voices are heard.

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

Inclusive approaches to PPI

Recommendations for action were:

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

- Guidance and training for researchers on how best to meet the communication and access needs of the people they work with.

Power is shared between researchers and PPI members

Recommendations for action were:

- Commit to giving feedback to PPI members about how their involvement is influencing decisions being made (or not) on an ongoing basis.

- 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.

- Follow up with PPI members about the final results and impact of the research they have been involved in.

PPI members are recognised and rewarded for their contributions

Recommendations for action were:

- Incorporating fair compensation for PPI members' time at the grant application stage as well as any research project activities.

- Make the way people get paid more flexible for people with different financial needs.

- 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.

Recommendations for action were:

- 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.

- Provide advice on payment processes, e.g. when right to work checks are needed.

- Map the resources available to support PPI in NI and advertise this widely.

- Increase availability of dedicated funding for PPI.

- 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.

To access the full interim report, <u>please click here</u> or scan the QR code below:

PPI Resources

To find out more about PPI in Health and Social Care research, <u>please click here to view our animation</u>.

<u>View or PPI Resource Library for Researchers</u>

<u>View or PPI Resource Library for the Public</u> or <u>find out more about getting involved in Health and Social Care research</u>.

To stay updated on the 'Involvement Matters' project <u>please click here</u> or scan the QR code below: