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

Report of findings from survey

TwoCan Associates

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In association with

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Executive Summary

The Involvement Matters project aims to identify and agree on priorities for action to improve Personal and Public Involvement (PPI) practices in health and social care research in Northern Ireland (NI). The practical steps have so far involved a survey of key stakeholders, which will be followed by a workshop/ workshops with stakeholders to agree priorities. This report summarises the responses to the survey.

249 people took part in the survey. The majority were members of the public (61%), a third of whom had previous experience of PPI. The remaining 39% were professionals with diverse roles within health and social care research.

The survey asked people about what was working well in terms of PPI in research, what could be done better, and their views on priorities for action.

The responses were very wide-ranging, and in summary related to the:

(a) Impact of PPI on research and health services

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

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

(d) Environment – how external factors can limit or enhance the success of PPI

The vast majority of the survey respondents commented on aspects of good practice which have been well established for many years. This raises questions about why poor practice is still frequently reported, and what more could be done to improve adherence to existing guidelines.

Some survey respondents did not understand the difference between PPI and other types of activity, such as campaigning or participation in research. Others gave responses that indicated they were working with the common misconception that PPI is a form of qualitative research. Raising awareness and sharing learning about how PPI relies on working with experiential knowledge (rather than data) might therefore be as important as sharing good practice. A number of survey respondents identified such people factors as being critical to meaningful PPI.

Finally, survey respondents who had a clear understanding of PPI and were keen to do it well, reported on the barriers within the research system that prevent them from doing so. It seems that the system currently makes demands on researchers for PPI, without always equipping them with the resources and skills to meet those demands. Lack of clarity around what is expected from PPI in different contexts, especially now in relation to ensuring diversity, also makes it difficult for researchers to be certain of what good practice looks like *in their specific circumstances*. Addressing these environmental factors might therefore create positive change that is system-wide, and act to promote good practice going forward.

BACKGROUND

The background to this project is described in two sections:

Section 1: Introduction

Section 2: Methods used

INTRODUCTION

Aim of the project

1.1 The aim of the Involvement Matters 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 (NI). A clear, shared agreement on priorities for action will ensure future efforts are targeted, meaningful and responsive to what matters most. The key priorities are expected to guide research and development initiatives, so that PPI becomes more impactful and sustainable across Northern Ireland.

1.2 The project has three main objectives:

a) To map current PPI activity in Health and Social Care (HSC) research in NI.

b) To identify practical steps known to improve PPI in research and also current barriers to more effective PPI.

c) To develop priorities for future PPI research and development initiatives in NI.

1.3 The approach has been loosely based on the priority setting process (PSP) used by the James Lind Alliance (JLA), and has been overseen by a JLA Adviser. The practical steps have therefore involved a survey of key stakeholders, followed by a workshop/ series of workshops to agree priorities.

About this report

1.4 This report summarises the responses to the survey. These have been analysed and written up by Dr Kristina Staley from TwoCan Associates (www.twocanassociates.co.uk). TwoCan Associates has been specialising in promoting and developing PPI practice in England for over 25 years. Kristina has also acted as an Information Specialist, responsible for analysing survey responses on multiple JLA PSPs.

1.5 A draft report was reviewed by the Project Leads within HSC Research & Development Division. The next steps will be a stakeholder event and the publication of a final report.

METHODS

2.1 A project Steering Group was established with 17 members to include PPI contributors, researchers, health and social care professionals, and representatives from the community and voluntary sector.

2.2 The Steering Group oversaw the design and delivery of the survey, drawing on:

- the James Lind Alliance approach
- the UK Standards for Public Involvement
- existing PPI literature and practice-based knowledge

2.3 The survey questions asked respondents for their views on:

- What works well in PPI?
- What are the challenges or barriers and what could be done better?
- What future priorities should be addressed to improve PPI?

A final open question asked for any further comments or shared experiences.

2.4 A draft survey was piloted with members of the Steering Group and their colleagues with experience of PPI, research delivery, and public engagement. This piloting phase helped refine question wording, ensured accessibility and clarity, and tested the overall length of the survey. Feedback from the pilot phase led to minor changes in language, the addition of explanatory text, and clearer signposting to optional demographic questions.

2.5 The final survey was hosted online using Microsoft Forms. It was disseminated widely across NI to capture a broad range of perspectives from people with lived experience, carers, members of the public with no experience of PPI, researchers, health and social care professionals, and community and voluntary sector organisations. Dissemination channels included:

- emails to HSC Research & Development (R&D) networks
- weekly R&D bulletin communications
- social media posts (X/Twitter and LinkedIn)
- stakeholder networks, including charities, community organisations, academic institutions, and professional groups
- Steering Group members sharing the survey within their own networks
- attendance at research seminars, conferences and PPI events throughout Northern Ireland

2.6 A webinar was held around the time of the survey launch to raise awareness of the project and encourage participation, particularly among those with no experience of PPI. Two roundtable discussions were held with members of the public and researchers and the notes from these have been included in the analysis of findings.

2.7 The survey was open from 9th September 2025 to 25th November 2025. During this period, response numbers and respondent characteristics were monitored. Ongoing promotion was adjusted to encourage participation from as wide a range of groups and sectors as possible.

2.8 Consistent with the aims of a Priority Setting Partnership, the survey is best understood as a consultation and collective reflection on experiences of PPI, rather than hypothesis-driven research. The survey responses provide a “bottom-up” view of what matters most to people involved in, or affected by, PPI in health and social care research.

2.9 Free-text responses formed the core of the dataset and were analysed thematically to:

- identify recurring issues, concerns, and areas of good practice
- surface shared priorities and critical reflections for future action
- capture diverse perspectives across different roles and lived experiences

2.10 Direct quotations are used in the report to illustrate key themes and are attributed to broad respondent category (e.g. PPI member, academic researcher) without identifying individuals. The recommendations for action identified by survey respondents are listed in a box at the end of each section. These are slightly edited versions of comments made directly by survey respondents.

FINDINGS

The results from the survey are reported in the following four sections of the report:

Section 3: Who took part in the survey

Section 4: Respondents' views on PPI in research in NI

Section 5: Respondents' views on PPI in health service development in NI

Section 6: Views of respondents with no experience of PPI

Who took part in the survey

3.1 249 people took part in the survey. The majority were members of the public (61%), a third of whom had previous experience of PPI. The remaining 39% were professionals who fell into one of the following categories:

- academic researcher
- representative of a funding organisation
- health or social care professional who leads or helps to deliver research projects
- clinician
- representative of a charity or community voluntary organisation
- independent research consultant
- PPI lead/ practitioner
- support worker within social services
- HSC employee role with data and reporting
- specialist nurse
- academic researcher who leads or helps deliver research projects in HSC
- facilitator of clinical research through project management
- Government
- nurse manager
- research administrator
- project manager for a digital health research centre

3.2 All respondents were asked about their gender, age, ethnic background, whether they had a disability, country of residence and religion. Members of the public were also asked whether they had experience of PPI, and if they would be interested in being involved in research in future. The characteristics of the respondents can be found in the Appendix 1.

3.3 Some of the responses had clearly been generated by AI, as they were similar in content and non-sensical, although they all used the language of PPI. The Project Lead who had access to personal data submitted as part of the survey, including the email addresses of respondents, confirmed these responses were invalid. On this basis 43 of the respondents were excluded from the analysis.

Respondents' views on PPI in research in NI

4.1 The survey asked people about what was working well in terms of PPI in research in NI, what could be done better, and their views on priorities for action. Respondents were encouraged to provide examples or stories of what they had observed as well as making general comments.

4.2 A number of responses were not about PPI. These included comments about participation in research, campaigning, support groups and public input into national research policy. Similarly, some responses appeared to be based on a misconception that PPI is a form of qualitative research, with comments for example, about how best to achieve a representative sample of involved members of the public. These responses were reviewed by the Project Leads as well as the Information Specialist, and were agreed to be beyond the scope of this exercise.

4.3 The responses that were about PPI very wide-ranging. They included examples of impact as well as discussions of the factors influencing the success of PPI. The responses have therefore 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

These will now be discussed in turn.

(a) Impact of involvement in research

4.4 Many of the researchers who responded to the survey described how PPI makes a difference to their research by: improving the quality of the process; ensuring ethical acceptability; helping with recruitment and retention; and, importantly increasing the relevance and usefulness of the findings.

> It ensures the research we do is clinically relevant, asking real questions aiming to provide answers to things which matter to patients. **Academic researcher**

> I used a PPI group with my PhD research looking at social inclusion for disabled children and young people. It was fundamental to hear these voices to help me with the best methods to collect my data, as well as prioritising outcomes. **Academic researcher**

> We produced a number of reports on attitudes towards suicide… in which we used an attitudes subscale called 'Suicide is attention seeking'… A group of families bereaved by suicide highlighted that using this wording was inappropriate and we were able to

> change this. As this was the name of the validated scale, we had not thought about how we were referring to it... **Health professional researcher**

4.5 Others reported that PPI can help with setting research priorities that are meaningful for a particular group of patients or community.

4.6 Some of the PPI members explained that PPI shifts the direction of research in ways that are important to them, ways that researchers might otherwise have missed.

> I can't begin to tell you the number of times I have heard academics / researchers saying 'I never thought of that' and the focus of the research broadens or takes on a new patient led perspective. **PPI member**

4.7 PPI members on grant review panels described how their involvement can improve researchers' communication, which can have a bearing on whether research projects get funded.

> I saw an excellent project, that would go nowhere, because it was hard to understand, even at a professional level. That was a good example of where public involvement would have come in. They would have worked with the project team and said "This is great, but really who can understand it apart from yourselves?" **PPI member**

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.

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

4.8 Some researchers said they found it easiest to do PPI when they already had "well-established connections" with PPI members, but wondered whether this was always ideal. Others stated that "the enthusiasm and willingness of the public" was an important factor influencing success.

> PPI members I have worked with are excellent, passionate and provide really useful insights. **Health professional researcher**

4.9 One PPI member reported that researchers do not always understand the reasons for working with the pubic versus working with people with lived experience. Knowing this is essential to ensure people with the most *relevant* lived experience are involved.

> The researcher must be clear that those who don't have actual experience of the issue might not be best placed to inform the design and delivery of the research project.
>
> **PPI member**

4.10 How researchers perceive people with lived experience and whether they welcome them as valued members of their team was reported to be significant to outcomes. Recognising and working with the expertise of PPI members was thought more likely to lead to impact, rather than simply asking for people's views and opinions.

> It means working with people as part of your team, seeing them as any other member of the team e.g. a statistician. **Voluntary sector staff**

> Rather than extractive view point sourcing. Give responsibility. Often folk… have successfully navigated more problems than the researcher. So play to their strengths.
>
> **Health professional researcher**

4.11 Similarly whether researchers are open to learning from PPI members and willing to respond to their input was described as the difference between PPI feeling like genuine collaboration, or simply being tokenistic.

> It is meaningful when researchers are open to change and willing to take on board the suggestions from PPI members. Sometimes, I find PPI to be a tick-box exercise and researchers want to talk about their work as opposed to listen… **PPI Lead**

> A genuine partnership needs a willingness to understand each other's expertise and respect diverse voices. **PPI member**

4.12 Some respondents used the terms co-production, co-design and co-creation to describe when PPI was meaningful, but these terms were not defined.

4.13 Several respondents concluded that working relationships between researchers and PPI members need to be based on mutual respect and trust to foster genuine collaboration.

> Mostly, when it happens it is conducted in a respectful and open way, allowing everyone to air their views and contribute to the research project. **Academic researcher**

> There are sometimes very strong hidden agendas on both sides, so honesty is extremely important. **Funding organisation staff**

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:

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

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

4.14 The vast majority of the survey responses were about the approach used for PPI and discussion of the specifics of good practice. These included ensuring:

- i. Clarity of purpose and proportional and appropriate approaches to PPI
- ii. Clear explanation of the expectations of PPI
- iii. Recruitment of the right people to PPI roles
- iv. Involvement at the early stages and continuously throughout a project
- v. Training and mentoring for researchers and PPI members
- vi. Support for PPI members and researchers
- vii. Good communication throughout a research project
- viii. Diversity amongst PPI members
- ix. Inclusive approaches to PPI
- x. Power is shared between researchers and PPI members
- xi. PPI members receive feedback on their contributions
- xii. PPI members are recognised and rewarded for their contributions

These will now be discussed in turn.

i. Clarity of purpose and proportional and appropriate approaches to PPI

4.15 Some researchers said they would welcome greater clarity about the following: the purpose of PPI in different contexts; its potential disadvantages as well as its advantages; and, which approaches are appropriate and proportional for different kinds of research project.

> As a clinician and a researcher I am confused about PPI. What counts, what doesn't count, who can be approached, who can't. **Health professional researcher**

> I think the word 'appropriate' is needed as PPI might need to be different, depending what is being proposed. **Academic researcher**

4.16 One researcher recommended a priority for action would be to make PPI simpler, focusing on purpose rather than processes, going as far to suggest developing new standards.

> The HSC formal processes of PPI are unapproachable, unwieldy and wrapped up in far too many processes and structures… More emphasis should be placed on the spirit of co-production/involvement and we should simplify evaluation/ accountability processes. Collaborate with the charity/voluntary sector to establish new standards.
>
> **Health professional researcher**

ii. Clear explanation of the expectations of PPI

4.17 Many respondents explained that it is essential for researchers to communicate their expectations of involvement to PPI members right at the start, as well as being open and transparent about any limits to PPI members' influence. This helps PPI members know where and when they can be most helpful, and avoids them feeling unheard. PPI was thought to not working well when there isn't clarity about PPI roles and their expected contributions.

> Ensuring that I understood what was being asked of me was a good tool to ensure that my engagement was as good as it could be. It was also important that those undertaking the research were clear what the limits of my involvement would be. This ensured that I did not expect changes or outcomes that were unrealistic. This avoided me feeling that I wasn't been listened to or that my input was not seen as important. **PPI member**
>
> Preparation with PPI members so they understand their role and expectations - GREAT checklists help with this. **Health professional researcher**

4.18 In the similar vein, a clear explanation of what PPI members can expect in terms of resources and support needs to be clearly communicated early on.

> Being candid about expectations, benefits and support - what can you as a researcher honestly provide, even if it's not a lot because you're restricted by funding, that's fine I just want to know. **PPI member**

4.19 Researchers stated that it is also important to manage the expectations of PPI members in terms of what the research can achieve, given that the pace of research can be slow and the translation of results/recommendations into practice takes even longer.

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.

iii. Recruitment of the right people to PPI roles

4.20 Survey respondents stated that recruiting people to PPI roles works well when:

- opportunities are advertised with a clear role, and information about time commitments, expectations, and tasks
- multiple methods of advertisement are used
- more than one PPI member is recruited so that they can cover for each other

4.21 Some respondents suggested that most PPI members want to get involved to make the future better for the people who come after them. For this reason they concluded that the potential benefits of any research need to be explained to motivate people to come forward. Other ways to encourage people were thought to be:

- enabling people to be involved in a way that suits them
- showcasing the impact of PPI on research
- making people feel confident they will be genuine partners in the project

4.22 However, the majority of respondents commented on the challenges with recruitment. One of these was the general lack of knowledge and understanding of PPI amongst patients and the public. Some believe this leads to the same PPI members being involved over and over again, even if they are not the right people for the role.

> Many patients are unaware they could be involved…It seems often patients will be chosen and approached for PPI… based on previous involvement - a closed door system.
>
> **Health professional researcher**

> Often the same PPI member is used repeatedly rather than looking for those with actual experience of issues. **Health professional researcher**

4.23 Some expressed concern that the people who come forward for PPI roles when these are openly advertised are not always the most suitable people. This approach encourages people to “self-select to become involved e.g. individuals with very strong held beliefs”. If these people are unknown to the researcher it can be difficult to assess their legitimacy. It can also bias recruitment to those who are ready and able to contribute, while people from underserved communities may not respond.

> Serious problems with "fake patients" when process can be remote.
>
> **Academic researcher**

> It is important to ensure that those engaged are able to clarify their particular interests or areas in which they've had personal experience. **PPI member**

> People who are typically hard to engage are unlikely to respond to a generic email, poster, or social media post. To be effective, information must be tailored to the needs and preferences of different groups. **Voluntary sector staff**

4.24 There seems to be an unresolved tension between recruiting people who are experienced and skilled at involvement and are known to the researcher, at the same time as ensuring equal opportunities for new people to be involved. One researcher explained that trying to work with both categories of people is challenging.

> I am seeing an influx of "pseudo-professional PPI", people who have had decades of experience as PPI contributors and have more research experience and publications than me. It can be hard to work with new public contributors if they sit in a meeting where others introduce themselves with a list of experiences and roles, and I have lost PPI members who feel a pressure to live up to this… **Academic researcher**

4.25 Researchers also voiced concerns that it is not easy to recruit people who can make a long-term commitment to staying involved over an entire research project. They also suspected people might be fearful of helping with research. They thought this might be helped by clearly communicating the personal benefits of being involved.

> It isn’t just about contributing to research—it’s also an opportunity for individuals to build skills, grow in confidence, and feel valued. **Voluntary sector staff**

> Reaching out to and attracting the public I believe is the hardest part. Unless a person is motivated by personal reasons… it's not easy to know about and get involved in research. I think institutions can do better in having community champions or members just like me to advocate for PPI in research. P

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.

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.

iv. Involvement at the early stages and continuously throughout a project

4.26 A large number of respondents from all categories thought that involving people at the earliest stages of a research project was essential for PPI to work well. This is was thought to be important for PPI members to:

- assess whether the research topic is an issue that needs research
- shape the research question
- influence research design, while decisions have not yet been finalised
- help researchers avoid wasting time and effort developing ideas and plans that aren't relevant or useful to the end users of their research

4.27 One the of the perceived barriers to early involvement is lack of funding for PPI at the stage of grant development (see 4.58). Some researchers also expressed concern that there are limited ways to formally acknowledge PPI members input early on, especially if the application is unsuccessful.

4.28 Many respondents stated that it is important not to limit involvement to the design stage, and to find ways for PPI members to continue to influence subsequent implementation and dissemination stages. One PPI member described limiting the scope of involvement as "paying lip service to PPI". Many thought PPI members should be given opportunities to do much more than comment on researchers' proposals.

> Consistency of involvement - PPI has to be present at application stage, but fairly sure the actual input at latter stages drops off. **Academic researcher**

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.

v. Training and mentoring researchers and PPI members

4.29 Many respondents concluded that when both researchers and PPI members receive training in PPI, this helps PPI to work well.

4.30 Training for PPI members was described by some respondents to include:

- research literacy, e.g. understanding of research terms and reasons for constraints on research methods

- sessions to ‘help people understand how they can contribute, by sharing experiences of providing feedback on research design’.
- guidance on research tasks e.g. how to review research applications

4.31 It was thought this kind of technical training would help PPI members to work in equal partnership with researchers. However, others concluded that PPI members would benefit more from understanding how their lived experience is of value.

> PPI members need educating that prior research experience is not required… that their 'lived experience' gives them the expertise needed to inform research.
>
> **Academic researcher**

4.32 In terms of training for researchers, suggestions included:

- how to write in Plain English, particularly for grant applications which benefits staff in funding organisations as much as PPI members
- best practice in PPI and what makes “good” PPI at different stages of research
- learning how to work with people who have experienced trauma
- facilitation skills

4.33 Some researchers reported that they felt there was limited guidance and training available for them and recommended training undergraduates as ‘this is really needed to change the culture around PPI and make it the norm”, **Academic researcher.**

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.

vi. Support for PPI members and researchers

4.34 Some respondents reported that providing support to PPI members is important to build their confidence, which directly impacts the quality of the PPI process.

> The times when I have been involved and have been most productive and it’s been a good experience, is when I had a clear point of contact for information/support should I need it. **PPI member**

4.35 Some said the level of support might need to be greater in different situations for example, if PPI members are asked to speak at a conference. Extra support might also be needed if people are asked to share emotional or traumatic experiences. Ensuring people know they do not have to talk about anything they do not wish to, also needs to be made more explicit.

> Paternalistic behaviour and lack of trauma-informed/psychologically safe environments can lead to harm for those getting involved. **PPI member**

> People can end up feeling vulnerable or exposed as there are not clear guidelines for them to think about what feels ok to share and what doesn't. The emotional toll of sharing (more difficult experiences) can be overlooked... **PPI member**

4.36 Another respondent highlighted that researchers may also need emotional support, especially when they experience practical and emotional challenges when working with people with high-level needs e.g. people with post-traumatic stress disorder or depression.

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.

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.

vii. Good communication throughout a research project

4.37 Large numbers of respondents emphasised the importance of providing information about research in a way that PPI members can understand. If the information is too technical, PPI members may feel unable to make any contribution. This requires taking time to explain research processes as well as the subject area.

> I'm able to understand the papers and information at each meeting, but I am an intelligent adult who has numerous qualifications as well as a background in nursing and healthcare education. I worry that less experienced people would not volunteer or if

> they did, might feel overwhelmed and not understand. **PPI member**

4.38 Making the language around PPI clearer was also thought to be important to ensure clarity of purpose for everyone working in PPI.

> There needs to be clarification between PPI and co-design. These terms are often used interchangeably and incorrectly. **PPI Lead**

4.39 Ongoing communication throughout a research project was deemed important to keep PPI members updated. This also makes people feel they are valued, which keeps them motivated to stay involved. This can be done in any number of ways e.g. meetings, newsletters, emails or social media.

> Keeping them updated, what works well with me was sending a text, to say I haven't forgotten about you… **Health professional researcher**

> Clear communication between myself and the research team. Let me know what's happening! **PPI member**

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.

viii. Diversity amongst PPI members

4.40 Some of the researchers described one approach to PPI that has proved successful, which is to establish a group of PPI members who meet regularly with the research team to provide continuous input across a research project. Ensuring that the group includes people with a range of experience is important to maximise opportunities for learning. Very many respondents suggested that more could be done to increase diversity amongst the membership of these groups. They expressed concerned that certain communities are often missing.

4.41 The communities mentioned as being particularly difficult to sign up for PPI included:

- young people
- children – rather than involving parents by proxy
- people in full-time employment
- people living in rural areas
- marginalised groups
- people in lower socio-economic groups
- older people
- people with dementia
- people in nursing homes and their families
- ethnic minority groups
- prisoners
- people who are neurodiverse
- people who are homeless
- people who use substances
- people with mental health problems

- people with learning disabilities
- people with physical disabilities

4.42 One respondent highlighted an additional challenge when people feel stigmatised by being identified as someone who is marginalised, e.g. as a person with a mental health problem. They concluded that more work needs to be done to overcome such barriers to encourage the involvement of people from these communities.

> There is so much more to people living with mental health issues… they should not be defined by their illness, they have so much they could be giving back if given the chance… we need to give people living with mental illness their empowerment back, so that they feel valued and safe within their local communities and want to then become involved. **Voluntary sector staff**

Recommendations for action were:

Establish connections between local community organisations and higher education institutions, to build trust and good working relationships.

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.

ix. Inclusive approaches to PPI

4.43 Many survey respondents commented that any approach to PPI needs to be flexible and adaptable to meet the preferences and access needs of the people being involved. Recommendations included:

- Offering face-to-face meetings and online options for people who find it difficult or do not wish to travel
- One-to-one options as well as group meetings
- Conversations by phone or text, through social media or online conferencing
- Simplifying information and taking time for people who take longer to understand and need more time to respond
- Holding meetings in convenient locations such as community centres or hospitals that are not too far away, rather than always expecting people to come to the researchers' organisations
- Holding meetings at suitable times
- Offering ways for people who may feel intimidated by research meetings to contribute through more informal channels
- Making it easy to contribute – avoiding the need to read long documents or carry out extensive preparation ahead of meetings
- Addressing transport needs
- Building confidence in the use of technology (e.g. online video calling) for people who haven't had previous experience

4.44 Some highlighted that the choice of approach needs to be tailored to the actual needs of the people involved, rather than any assumption of need. This requires careful planning and preparation before any PPI work begins.

4.45 Some researchers reported they experienced challenges in being truly inclusive, due to limited resources and the lack of suitable venues (e.g. finding disabled toilets with hoists). There was some concern that people with the most relevant lived experience might not be asked to be involved, because the barriers to their involvement might be perceived to be too great (e.g. for people with severe learning difficulties, or for people with dementia).

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.

x. Power is shared between researchers and PPI members

4.46 A small number of respondents discussed the importance of researchers sharing power, if PPI members are going to meaningfully influence decisions about research. This includes being able to influence decisions about the extent of their involvement.

> I've had bad experiences, when… during the session the PPI members felt unable to contribute meaningfully, because the clinicians had much more expertise and power.
>
> **PPI member**

4.47 Some thought that meetings between researchers and PPI benefit from skilled facilitation, to ensure PPI members can play a more active role in decision-making.

> It is about enhancing the depth of PPI and reducing "superficial participation"… For instance, at the initial stage of research design, we should invite them to join the core team and participate in key aspects such as the selection of research topics and methods… This will truly achieve the transformation from "consultation" to "cooperation". **PPI member**

xi. PPI members receive feedback on their contributions

4.48 Giving feedback to PPI members about how they have made a difference was thought to be essential to making involvement work well. This is because it demonstrates that PPI members' contributions are genuinely valued and provides evidence that researchers have heard and responded to their input. It can encourage people to stay involved and means they will be more willing to be involved again in future. It also provides a mechanism for PPI members to learn how to be a 'good critical friend' – learning what's valuable to share with researchers and the best way to share it.

> Offer feedback to PPI members so they can improve how they communicate with you the researcher (it also really boosts confidence for the PPI member!). **PPI member**
>
> Make sure you can demonstrate how involvement translates to impact so that it is not perceived as a tick box. Keeping people in the loop. **Health professional researcher**

4.49 Practical suggestions for doing this included "You Say, We Do" logs and impact record sheets. These require researchers to explain how they have responded to each recommendation, or at least give reasons for not doing so.

4.50 At the end of a project, some respondents raised concerns that PPI is sometimes forgotten. PPI members may not be part of the final stages of report writing and dissemination, and may only hear about the research findings when they see the published report.

4.51 Linked to this was a concern that PPI can come to an abrupt end, either when the study finishes or the involvement finishes. Closing the process seems important to show appreciation for the PPI and to be clear about next steps (see 4.55).

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.

xii. PPI members are recognised and rewarded for their contributions

4.52 The importance of paying PPI members for their time was raised by large numbers of survey respondents. Not paying people was thought to be a barrier to involvement for underserved communities, and therefore an important part of inclusive practice.

4.53 Problems with payment were mostly reported as practical issues, including:

- HSC Trusts having poor mechanisms in place for paying people or lacking the systems for example to pay for shopping vouchers or make mileage payments
- Not being able to pay people with cash if that's what PPI members would prefer
- Use of vouchers, and corporate and online vouchers not supporting the ethos of people wanting to help their community

4.54 A small number of respondents highlighted that it is essential for PPI members to be reimbursed for their expenses, specifically travel and childcare.

> The first step is to break down the barriers to participation. Currently, some groups are unable to participate due to limited resources… extend the compensation scope from transportation and lost work time, to childcare expenses, covering more potential participants. **PPI member**

4.55 As well as financial reward and reimbursement, some respondents stated that PPI members need to be recognised for their contributions in other ways, for example by acknowledging their input and/ or including them as authors on any dissemination materials.

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.

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

4.56 The success of PPI is not only dependent on the individual researchers and PPI members involved, but also on the context, and whether the external environment facilitates or hinders the implementation of good practice. The survey respondents highlighted several areas where the research system makes demands for PPI, but does not always provide the clarity, resources and support to enable a high-quality process. These include ensuring:

i. Sufficient funding and time for PPI

ii. Clear requirements for PPI across the research system

iii. Advice and support around PPI for researchers

iv. Recognising, rewarding and sharing good practice

v. Working with third sector organisations

These will now be discussed in turn.

i. Sufficient funding and time for PPI

4.57 One researcher mentioned that the PPI in Research Small Grant Scheme is very helpful for funding PPI activity. However, the vast majority of respondents reported that it can be difficult to find the funds to reimburse PPI members for their time and expertise, or to recognise their contributions in other ways. This has an impact on the relationships between researchers and PPI members, and the quality of the outcomes.

> The research network has zero ring-fenced core funding to support PPI, nothing for personnel to support PPI, nor for PPI contributor's expenses… It's a fantasy to think PPI can happen with no budget – but that seems to be an expectation. The PPI contributors themselves are amazing… but of course we shouldn't be reliant on goodwill. **PPI Lead**

> We need more recognition of PPI members through certificates / award systems / thank-you lunch etc. We cannot do our research without PPI – but research projects are underfunded to show how much we appreciate PPI insights. **Academic researcher**

4.58 One of the key stages where this becomes particularly problematic is during the development of grant applications. While funders require PPI in research design, there is no mechanism to fund this PPI *before* receiving a grant.

> Many researchers complain that they don't receive funding to have a robust PPI plan. Funders need to be engaged in the discussion around this, as it is not a cheap undertaking and we should not expect the public to do it for free. **Academic researcher**

4.59 Funders request that researchers involve more diverse PPI members, which is both time-consuming and costly. It seems unclear whether funders understand and accept this.

> If we want to include hard to reach populations in research, more accommodations are required which can be expensive e.g. transport, interpreters, more venues nearer people's homes etc. **Academic researcher**

4.60 Carrying out PPI to a high standard requires a considerable investment of time. The amount of time funders allow for PPI, e.g. in response to a funding call, was described as being too tight and limiting potential impacts. Many stated that pressures in the current research system do not give researchers sufficient time or money to do PPI well.

> What we know is it needs time and resource to build relationships across communities. However, if that is acknowledged – why is there no finance to do this? **PPI Lead**

> Time is often a barrier to establishing trusting relationships and balancing the demands of research timelines with people needing to be properly listened to, heard and valued.
>
> **PPI member**

> It takes so much time to do it correctly and the mad rush for things in academia makes it really difficult to do good work better. **Academic researcher**

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.

ii. Clear requirements for PPI across the research system

4.61 Some respondents thought that funders could encourage more PPI in research by:

- making explicit PPI requirements for HSC R&D funded research
- requiring a PPI plan for every research project and there are ways to evaluate the details of each plan
- requiring PPI members in the development of grant applications

4.62 Others thought that ethics committees could play a similar role:

> The majority of research studies still limit PPI involvement to reading the Participant Information Sheet. We need to make the ethics process more robust in terms of expectations around what constitutes PPI. **Academic researcher**

4.63 Importantly it was thought that the requirements for PPI must be appropriate to the context, and adapted accordingly.

> It seems to be seen as compulsory regardless of the circumstances, which runs the risk of PPI being treated as a tick box, rather than something valuable in most, but not all, circumstances. **Academic researcher**

4.64 One researcher explained there are tensions in trying to respond to the insights from PPI members, when there are external constraints that limit the possibility for change. They concluded that funders and other institutions in the research system also need to be willing and open to learning from PPI.

> It can be difficult to align priorities. What researchers want to produce does not always align with what individuals need - through pressures from funders, institutions etc.
>
> **Academic researcher**

iii. Advice and support around PPI for researchers

4.65 When PPI involves group work, then the quality of the outcome was reported to be dependent on having skilled facilitators, who can manage group dynamics and bring people into discussions who might not otherwise contribute. One respondent suggested that more funding is needed to build capacity in PPI support roles, to employ more staff who can enable researchers and PPI members to work together effectively.

> There is often no permanent funding for PPI roles within the research community…This makes it challenging to retain staff and to plan for longer-term initiatives.
>
> **Funding organisation staff**

iv. Recognising, rewarding and sharing good practice

4.66 Some respondents suggested that researchers who practice high quality PPI should be rewarded within the system e.g. through awards ceremonies. Finding ways to share the learning and experience of these skilled researchers could also help to improve practice more generally.

4.67 Other suggestions for ways to share learning included:

- PPI conferences
- Communities of support – connecting researchers who deliver PPI with professional PPI advisers
- Best practice sharing in open forums
- Collaboration across disease areas
- Joined-up practice across funders and support organisations

4.68 While some suggested making standard documents available (e.g. group agreements), others thought that too many tool-kits and websites already exist. They placed greater emphasis on continuous *experiential* learning to improve practice.

> We must continue to ask questions. Our provision of care and research can only be improved if we see PPI as a continuous life-long learning process for care providers, researchers and participants alike. **PPI Lead**

v. Working with third sector organisations

4.69 One factor that researchers reported to have increased the quality of PPI was being able to draw on the support of voluntary and statutory sector organisations.

> The projects I have been involved with targeted hard to reach groups such as the Traveller Community. PPI support from HSC R&D supported the environment to meet with people to build trust and made this process much smoother.
>
> **Health professional researcher**

4.70 Charities are also a much-valued source of support because they can:

- help with finding people with relevant lived experience
- provide advice on best practice
- provide access to their own established PPI groups
- help with involving people are often excluded from research

4.71 A representative of a voluntary organisation explained that the sector will need more financial support if it is going to be able to meet the increasing demand for support in this area.

> Voluntary sector organisations have the trusted relationships and local knowledge needed to engage communities effectively. However, their contribution is often overlooked when budgeting for PPI. Funding typically goes directly to participants… without dedicated funding, organisations are unlikely to provide the outreach and support needed. In the current challenging funding environment, they will understandably prioritise their core work and funded activities. **Voluntary sector staff**

Respondents' views on PPI in health service development in NI

5.1 There were far fewer survey responses related to this aspect of PPI. They included examples of impact as well as discussions of the factors influencing good practice. Some issues were raised that were unique to PPI in health service development. The responses have therefore been summarised under the following headings:

(a) Impact of PPI on health services

(b) Recommendations related to improving PPI practice in general

(c) Recommendations specific to improving PPI in this area

These will now be discussed in turn.

(a) Impact of PPI on health services

5.2 Respondents with experience of PPI in health service development described a number of ways that it can have a positive impact, including:

- ensuring services genuinely meet the needs of the people who use them
- identifying ways to improve service delivery and performance
- identifying ways to work better with each person using the services
- educating health and care professionals

> What may be viewed by the professionals as a first-class service, may not be meeting the needs of those using the service. With PPI… organisations are getting what it is truly like being in receipt of the services provided. (A fuller picture). **PPI member**

> In my experience, it is a very rewarding activity. Actioning ideas makes service users feel valued… From our carers event, new mutually supportive relationships have been formed. Also, carers have offered support using their skills and professional connections in ways that will enrich the service we provide. **PPI Lead**

(b) Recommendations related to improving PPI practice in general

5.3 The respondents raised many of the same issues as discussed above in Section 4 about PPI in research. These included recommendations to:

- build relationships based on mutual trust and respect
- be prepared to listen to what people say and act upon it
- make PPI meaningful and avoid tokenism
- ask people which issues they want to address, rather than asking them to get involved in projects identified by the Trust
- provide professional support from people with PPI expertise
- be proactive in advertising opportunities to get involved
- identify the people who have the most relevant experience to offer – avoid using the same generic group of patients
- ask people how they want to be involved
- provide training to PPI members to increase their confidence to contribute
- manage people’s expectations e.g. around the time it takes to change services

- offer a range of accessible/flexible ways to be involved e.g. online and face to face, meeting in convenient locations
- communicate clearly and avoid jargon
- increase diversity amongst those involved
- meet the communication needs of those who find it difficult e.g. people with learning difficulties
- ensure payment of expenses and for people's time, and publicly recognise their contributions
- provide feedback on what has happened in response to PPI
- raise awareness through positive, visible stories about how patients have been involved in improving services and healthcare

(c) Recommendations specific to improving PPI in this area

5.4 The issues raised which were specific to PPI in health service development included:

i. Finding different ways to engage service users

ii. Potential barriers to open and honest conversations

iii. Building in review processes to close the loop on involvement

These will now be discussed in turn.

i. Finding different ways to engage service users

5.5 In addition to the more traditional ways of involving people, some respondents suggested that greater numbers of service users could be reached while they are using civic spaces. For example, they thought suggestion boxes could be placed in community centres, hospitals, churches and nursing homes. This would allow people who are unlikely to attend meetings to make a contribution.

ii. Potential barriers to open and honest conversations

5.6 Some respondents identified barriers to open and honest conversations between service users and service providers, which would limit the potential for success. These were: a lack of trust in health professionals; and a lack of confidence in the views of service users. Both were discussed in the context of mental health services.

> There are a lot of clients who don't trust or believe the Community Mental Health Teams, so are therefore more reluctant to voice their opinions/views on the services/support they receive. **Voluntary sector staff**

> People with living with mental illness don't feel they are listened to, or taken seriously when they are trying to voice their opinion… just because we are professionals does not mean we are above those we support. We need to speak to people on a human level and cut out the medical jargon and excuses for the failings, and work with the people who know what works and what doesn't. **Voluntary sector staff**

5.7 Another concern was that health professionals seem to believe that the only people who come forward for this work are those who were dissatisfied with the service they received. By way of contrast, service users concluded that the people who volunteer only usually want to make things better for people that follow them, and that health professionals need to be made more aware of this.

iii. building in review processes to close the loop on involvement.

5.8 One health professional stated that while feedback is often sought from PPI members on services, much more could be done to re-engage with those people to explore whether the service re-design has addressed their suggestions, and whether it now meets their expectations.

6. The views of survey respondents with no experience of PPI

6.1 Survey respondents in this category raised issues around how raise awareness and general understanding of PPI, as well as the conditions they thought would be necessary to encourage people to take part. The responses have therefore been summarised under the following headings:

(a) Improving awareness and understanding

(b) Ensuring fairness in opportunities to be involved

(c) Ensuring an inclusive approach

(d) Giving feedback about impact

These will now be discussed in turn. All of the quotes in this section of the report have come from members of the public with no experience of PPI.

(a) Improving awareness and understanding

6.2 For some respondents in this category, the value of PPI, particularly around health service development, was very obvious.

> There is a real need to talk to real people about their experiences and about what is and isn't working for them. People love their health service, but they see waste and inefficiency as being a problem.

6.3 A large number thought that more needs to be done to raise the public's awareness of PPI and its value to research and services. They thought this might require first making research easier to understand and more inclusive, before explaining how it can be open to everyone's ideas. Practical suggestions to do this included:

- include stories in the print media explaining the need for PPI and how PPI has changed research
- involve PPI members in explaining how their lived experience has helped to bring about positive change
- hold introductory meetings across a series of locations that are easily accessed by the public
- give talks and lectures in libraries, to community groups and organisations, in schools and universities
- post articles on social media e.g. Facebook

6.4 Many emphasised the importance of using language that everyone can understand, given that PPI would be "jargon to most people".

(b) Fairness in opportunities to be involved

6.5 It was thought that opportunities to be involved should be advertised widely to ensure many people have a chance to contribute. If this was done regularly and publicly, it would make PPI relevant to everyday life and experiences. Practical suggestions for doing this included:

- working with charities
- posting on social media
- a one-stop-shop for information on all up-and-coming PPI opportunities
- advertising at GP offices, health & wellbeing receptions, opticians and supermarkets

(c) Ensuring an inclusive approach

6.6 The key principles of inclusivity and transparency were thought to be crucial to gain public trust and confidence in PPI.

> Inclusivity is very important. Everyone should get to play a part in shaping the services that they use. And throughout, transparency is key. The public lack trust in the powers that be and to regain that trust, transparency should be practiced from the offset.

> The university/ the research community has to come to the people not expect the people to come to them.

6.7 Suggestions for how to work with a range of people from different backgrounds and experiences included:

- Take action to overcome any barriers such as disability, language, childcare and accessibility needs
- Hold virtual meetings to help e.g. those with caring duties
- Hold meetings outside of the workday
- Meet people in public and community spaces, since large institutions can feel overwhelming for the average person
- Pay people fairly and promptly
- Use language everyone can understand
- Work with people in rural areas

(d) Giving feedback about impact

6.8 Some respondents thought that getting people to sign up to PPI and keeping them involved would require "Showing people they are listened to, by showing the impact or outcomes from their involvement".

7. DISCUSSION

7.1 The vast majority of the survey respondents commented on aspects of good practice in PPI, which has been worked on extensively for many years, culminating in the UK Standards for Public Involvement in 2019. Over 200 pieces of guidance on good practice have already been published, and a recent publication described the 'mountain of PPI toolkits' currently available. The important question this raises is why is poor practice still being frequently reported by the survey respondents, and what more could be done to improve adherence to the existing guidelines.

7.2 The survey respondents' recommendations for action around good practice were very wide-ranging, from setting strategic goals through to improving the work of an individual or research team (see the full list in Appendix 2). It is not clear how to prioritise amongst these as a research community, since all are important for high quality PPI.

7.3 More importantly, in terms of any practice development, the priority for any improvement work will be highly context specific. It will depend on what is being done well, and where there are specific gaps or evidence of poor practice. This development work also needs to be tailored to the institution, project or individuals and the factors that either enable them or hinder them from putting the guidance into practice. Priorities for action to improve practice are therefore best set by the individuals or organisations, in order to be responsive to their particular needs.

7.4 It is of note that a number of the survey respondents gave responses to indicate that they did not understand the difference between PPI and either taking part in research, or other types of activity such as campaigning and policy work. Amongst those that did have experience of PPI, many gave responses that indicated they were working with the common misconception that PPI is a form of qualitative research. For example, they suggested establishing publicly available databases to recruit representative members of the public, in keeping with sampling approaches underpinning qualitative research methods.

7.5 PPI is better understood as a process that allows people with lived experience to draw on their experiential knowledge to act as critical friends to researchers. PPI members have the foresight and wisdom to identify where there may be problems with research design and delivery and to find acceptable solutions. The focus is then on involving PPI members with experience that is *relevant* to the context. Raising awareness and sharing learning about the value of experiential knowledge - who has it, how to share it and how best to work with it (it is not the same as data), might therefore be widely applicable to improving practice and avoiding tokenism. A number of survey respondents identified such people factors as being critical to meaningful PPI.

7.6 Finally, the survey respondents who had a clear understanding of PPI and were keen to do it well, reported on the barriers within the research system that prevent them from doing so (the research system being the environment, infrastructure, and processes that support and enable research). It seems that the system currently makes demands on researchers for PPI, without always equipping them with the resources and skills to meet those demands. Lack of clarity around what is expected from PPI in different contexts, especially now in relation to ensuring diversity, also makes it difficult for researchers to be certain of what good practice looks like *in their specific circumstances*. Addressing these environmental factors might therefore create positive change that is system-wide, and act to help rather than hinder, good practice going forward.

Appendix 1: Demographic characteristics of survey respondents

Table 1. Survey respondent category

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

Table 2. Do you have previous involvement in PPI?

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

Note: This question was only asked to members of the public.

Table 3. Would you be interested in getting involved in research at a future date?

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

Note: This question was only asked to members of the public.

Table 4. What is your gender?

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

Table 5. To which of the following age categories do you belong?

Age group	**n**	**%**
16–24	11	4.4
25–34	29	11.7
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 6. What is your 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 7. Do you have a disability?

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

Table 8. What is your religion?

	n	%
Agnostic	1	0.4%
Buddhist	1	0.4%
Catholic	2	0.8%
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 9. Where do you usually live?

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

Table 10. Caring responsibilities

	n	%
Child(ren) under 18	79	31.7
An elderly person	44	17.7
Person with a disability (above 18 years old)	35	14.1
Child(ren) under 18 with a disability	0	0.0
None	122	49.0
Prefer not to say	6	2.4

Note: Respondents could answer more than one question, therefore column totals may exceed the number of people who responded to the survey

Appendix 2: List of survey respondents' priorities for action

- 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.
- 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:
- Improve communication and transparency in PPI.
- Set clear boundaries for PPI at the start and ensure these are respected by all people involved.
- 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.
- 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.
- 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.
- 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
- Assign full-time coordinators to help solve problems encountered during involvement.
- Provide peer support e.g. a buddy system for new PPI members.
- 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.
- 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.
- Establish connections between local community organisations and higher education institutions, to build trust and good working relationships.
- 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.
- 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.

- 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.
- 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.
- 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.