

Framework for

QUALITY IMPROVEMENT IN PUBLIC AND PATIENT INVOLVEMENT

in health and social care research



This process was led by Prof Mary McCarron (Trinity College Dublin), Prof Philip McCallion (Temple University, Philadelphia), Sarah Bowman (Trinity College Dublin) and Michael Foley (Trinity PPI Ignite Office).

Thank you to all of the workshop participants who were involved during the process:

Laura Brady; Aoife Brennan; Melody Buckley; Michelle Connolly; Naomi Donaldson; Jennifer Duggan; Sarah-Marie Feighan; Michelle Flood; Kate Frazer; Carmel Geoghegan; Meghan Gilfoyle; Stacey Grealis; Agnes Higgins; Zoe Hughes; Sinead Hynes; Robert Joyce; Cameron Keighron; Síofra Kelleher; James Larkin; Kerry Lawless; Anne Lawlor; Manjula Manikandan; Molly Manning; Anne-Marie Martin; Ciara Molloy; Maura Moloney; Marian O'Mahony; Ciara O'Reilly; Eileen O'Sullivan; Lydia O'Sullivan; Eilis O'Toole; Anna Pappan; Fiona Riordan; Nuala Ryan; Stephanie Skeffington; Clodagh Toomey; Niki Warner.

Workshop facilitation was provided by PPI Ignite Network members and supporters: Michael Foley (Principal Facilitator); Abhisweta Bhattacharjee; Sarah Bowman; Elaine Burns; Sarah Fox; Avril Kennan; Lorna Kerin; Virginia Minogue; Derick Mitchell; Clodagh O'Donovan; Emmy Racine.

Guidance was provided by the PPI Ignite Working Group on Quality and Impact: Mary McCarron (Lead); Sarah Bowman; Elaine Byrne; Sean Dinneen; Michael Foley; Avril Kennan; Lorna Lopez; Anne MacFarlane; Philip McCallion; Fiona Manning; Virginia Minogue; Derick Mitchell; Kate Morris; Edel Murphy. Trinity PPI Ignite Office is part of the national PPI Ignite Network. It is supported by the Health Research Board, the Irish Research Council and Trinity's Office of the Dean of Research, Office of the Dean of Health Sciences and School of Nursing and Midwifery.

© Trinity College Dublin and the PPI Ignite Network, 2023

This work is licensed under a Creative Commons Attribution (CC BY) 4.0 International License.

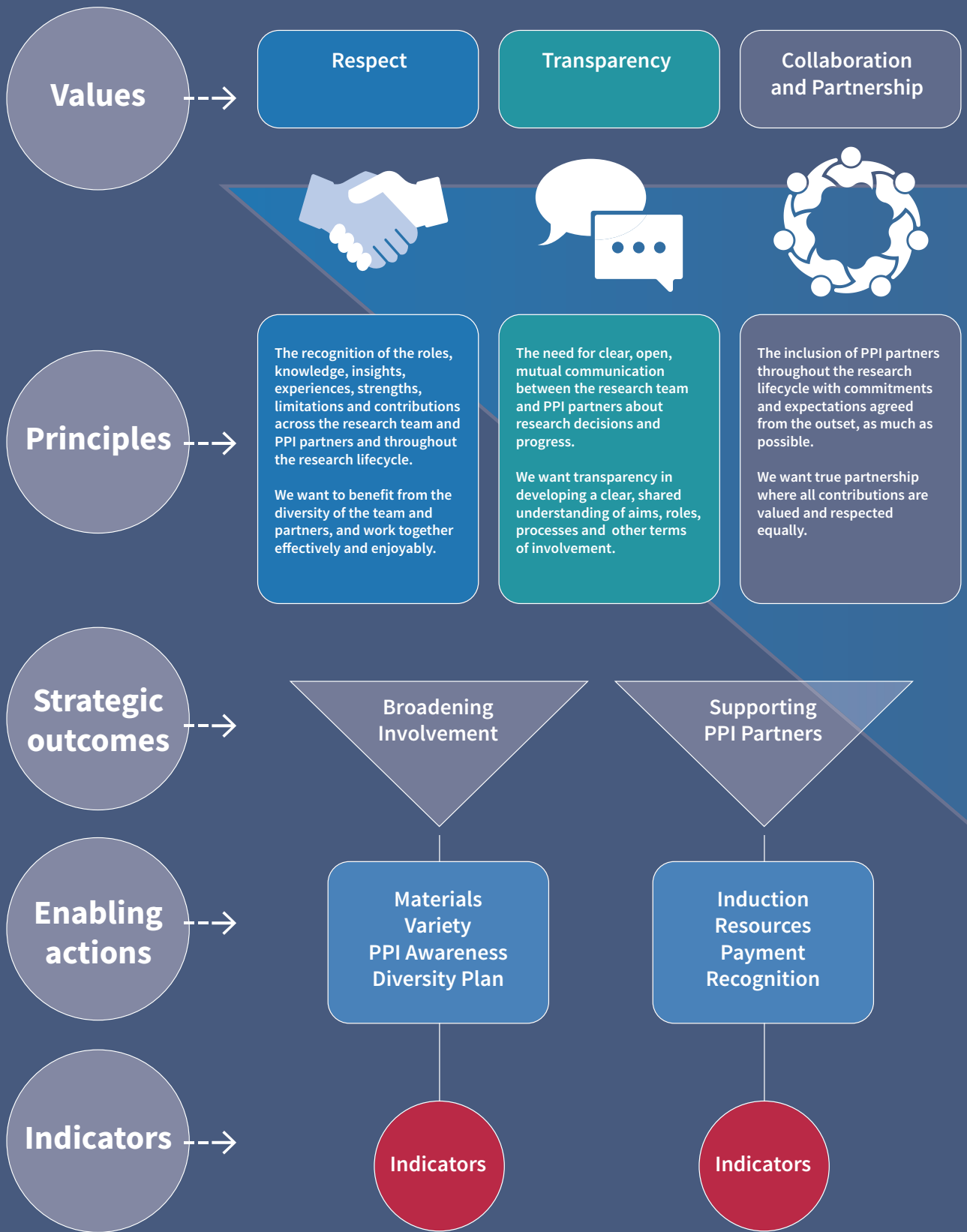


Framework for

QUALITY IMPROVEMENT IN PUBLIC AND PATIENT INVOLVEMENT

in health and social care research

Trinity College Dublin and the PPI Ignite Network 2023



Equity and Inclusion

Empowerment and Power Sharing

Flexibility

Trust



The active identification and removal of barriers and creation of entry points throughout the research lifecycle.

We want real co-design and partnership to take place that values equally people's diversity of opinions, experiences, abilities, backgrounds and expertise.

The inclusion as early as possible in funding decisions, strategy and decision-making, the co-design and co-production of research.

We want a wide range of involvement strategies to ensure that this happens.

The recognition of the time and other commitments involved in PPI and that this is acted upon in the research plan.

We want to co-design appropriate changes and responses to the experiences and to the views of PPI partners.

The building of reciprocal trust; this takes time to develop, is relationship based and needs to be consistently worked on.

We want everybody's opinion to be fully heard and we want confidentiality to be negotiated and respected.

Supporting Researchers

Establishing Relationships

Aligning Organisation Culture

Training
Mentoring
Promotion

Plans
Seed Funds
Agreements
Maintenance

Staffing
Commitment
Power Sharing
Oversight

Indicators

Indicators

Indicators

Contents

Introduction	02
Context for Development of Quality Improvement Framework	05
Values & Principles	09
Purpose of this Framework	11
Self-Assessment for Quality of PPI	12
Quality Improvement Outcomes for PPI	16
BROADENING INVOLVEMENT	17
SUPPORTING PPI PARTNERS	20
SUPPORTING RESEARCHERS	23
ESTABLISHING RELATIONSHIPS	26
ALIGNING ORGANISATIONAL CULTURE	29
Conclusion & Next Steps	33
Appendix 1 – Template for Rubric Mapping	34

Introduction

This Framework for Quality Improvement in Public and Patient Involvement (PPI) in health and social care research has been developed by the PPI Ignite Office in Trinity College Dublin for the national PPI Ignite Network. It has been created ‘to build capacity for high-quality PPI’, a stated aim of the Network. It strives for a shared understanding of what quality means in relation to PPI activity in Ireland by first identifying an agreed set of values and principles that underly high-quality PPI and then for PPI partners and researchers to define how those values and principles might look in practice.

Public and Patient Involvement in Research

Public and patient involvement (PPI) in health-related research means that the public and patients are potentially involved across the research cycle, from setting the research agenda to achieving wider societal impact. In straightforward terms, it is research which is carried out ‘with’ or ‘by’ patients or members of the public rather than ‘to’, ‘about’ or ‘for’ them.

The involvement of PPI voices across research is endeavouring to shape research which will address the issues and concerns of those with a lived experience of a long-term condition, an illness, a disability or an identity that is not well-served by current systems or approaches. For some, PPI relationships are driven by a desire to redress past inequalities where, for example, people with disabilities were being researched but had no role in shaping that research. For others, PPI relationships are about creating further levels of public scrutiny on how research money, which often comes from either donations or from the exchequer, is spent. For others still, PPI is part of people’s democratic or civic right to be able to participate in processes that may impact

their lives. The types of activities that PPI partners can do include:

- Discussing research priorities and ensuring that research can have a pathway to impact patients’ lives;
- Advising on research participant recruitment processes;
- Writing or editing communications so that they are more suitable to research participants, including creating meaningful consent forms for participants;
- Considering ethical issues that may arise in a study and suggesting solutions to reduce risk and build benefit for participants;
- Participating in certain data gathering activities;
- Triangulating or analysing data
- Writing or editing plain language summaries of research so that they can reach a wider audience;
- Endorsing and supporting relationship building with communities and other stakeholders;
- Co-presenting findings at seminars and conferences;
- Advocating for the adoption of recommendations from research findings.

Quality in Research and PPI

Quality in research can be judged through its accuracy, trustworthiness, credibility and the level at which it has been ethically conducted. Involving members of the public can help to ensure that research focuses on outcomes that are important to the public. It can also assist in tailoring research to the needs of specific communities. For example, when seeking research participants from a particular community, involving members of that community in shaping the study design can help to improve recruitment and retention of participants by ensuring that communication and research methods are sensitive to the needs, customs and circumstances of that community.

Defining quality in PPI activities, however, has been less clear cut. While practitioners of PPI activities, be they PPI partners or researchers, can identify when those activities are working well or badly, there is not always a shared understanding of what 'good quality' in PPI activities in Ireland actually looks like.

Quality Improvement in Health

Quality improvement (QI) has become a feature of a number of health services which seek to systematically and continually improve patient outcomes and the services that support them. The use of QI recognises that services are never static and that an improvement in one area can create new needs and opportunities in other areas. Services continue to strive

towards better quality and so 'good quality' remains a moving target.

QI involves identifying areas for improvement, developing and implementing interventions to address these areas, and monitoring the effects of these interventions to evaluate their success.

QI in health can also involve using data to monitor improvements, identify trends and make informed decisions about future improvements. This may include the use of quality metrics and indicators, such as patient satisfaction surveys or clinical outcome measures, to track progress over time and ensure that interventions are having the desired effect.

In order to understand what should be improved and how, there needs to be a shared understanding of what is important. A QI project may be underpinned by policy, by stated priorities or targets, or by a set of values and principles that show what is important and how people consider something to be good or worthwhile.

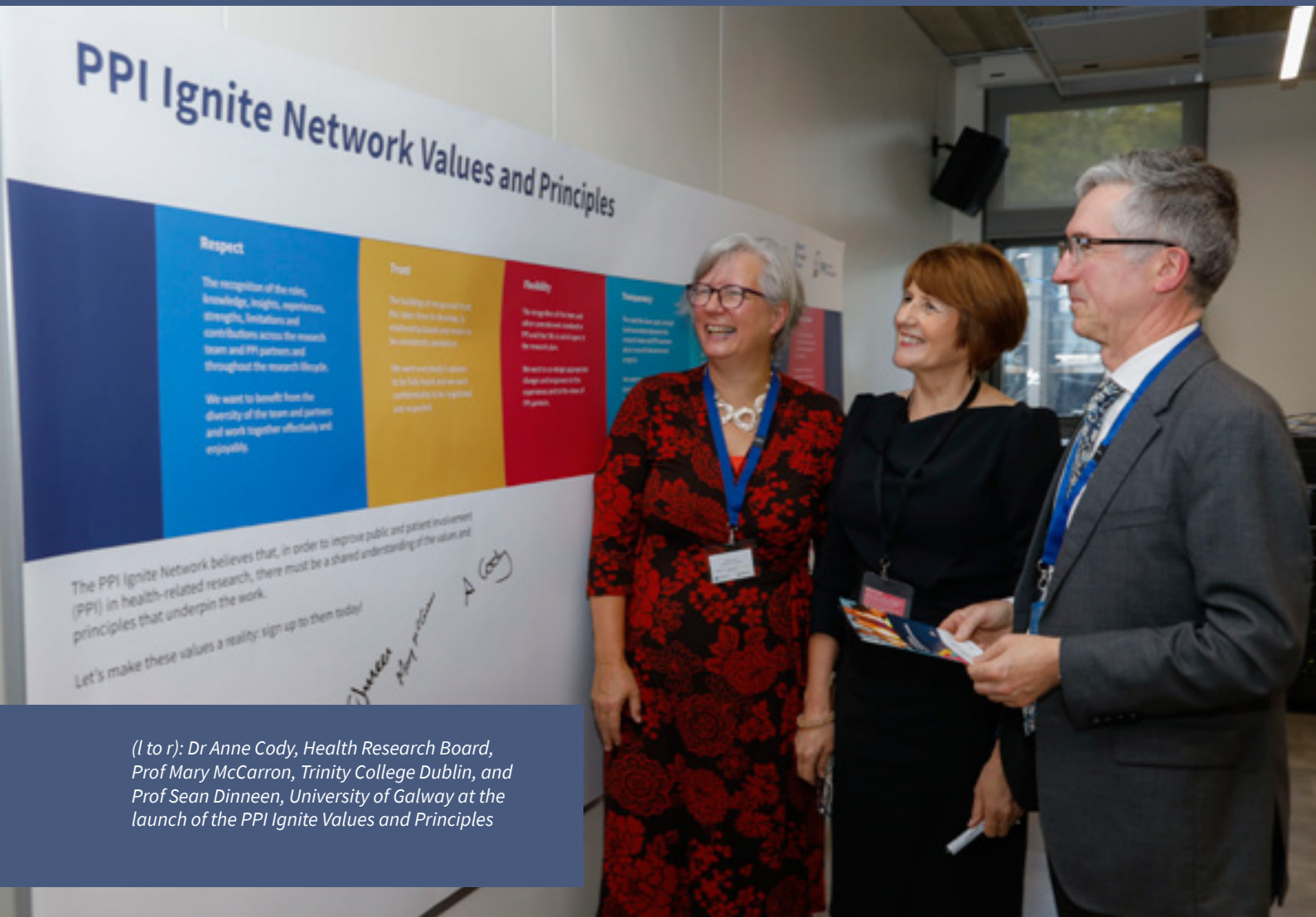
A PPI QI Framework

While PPI can be diverse in its activities, partners, processes and outcomes, there is a desire for good practice to flourish and for people to develop productive and fulfilling relationships that serve to improve the research cycle and to address wider societal challenges.

This Framework aims to identify areas where an improvement can lead to better PPI approaches and a set of potential indicators by which a stakeholders can judge whether a process can be considered of good quality and coherent with the values that underpin good PPI.

This framework has been developed through a series of collective intelligence workshop that took place between 2021 and 2023 on behalf of the PPI Ignite

Network. Led by Prof Mary McCarron, Prof Philip McCallion, Sarah Bowman and Michael Foley from the Trinity PPI Ignite Office, these workshops with PPI partners and PPI-experienced researchers identified values and principles that could underpin good quality PPI in Ireland, how these values and principles could work in practice and what were the indicators that could be used to understand whether progress was taking place.



(l to r): Dr Anne Cody, Health Research Board, Prof Mary McCarron, Trinity College Dublin, and Prof Sean Dinneen, University of Galway at the launch of the PPI Ignite Values and Principles

Context for Development of Quality Improvement Framework

The PPI Ignite Network is tasked with improving the quality of PPI in Ireland. The objectives of the Network under Quality Improvement are as follows:

- Explore both values and processes affecting PPI contribution amenable to Quality Improvement (QI) activities;
- Develop an agreed National PPI QI Framework with due attention to equality, diversity and inclusion;
- Develop self-assessment or evaluation materials to promote a QI culture within PPI;
- Review specific aspects of the Framework that are amenable to improvement, e.g. reimbursement of PPI contributors;
- Establish a mechanism where PPI contributors can debate and discuss both positive and negative experiences of involvement in PPI activity and feed back into the Network.

Led out by Trinity PPI Ignite Office on behalf of the Network, a Working Group was convened with members from across the Network and the national partner agencies. The approach to develop a values and principles-based QI framework was agreed and Collective Intelligence workshops were devised to achieve this.

Design of Collective Intelligence Workshops.

While 'collective intelligence' has different contextual meanings, the UK charity Nesta defined it for the purposes of tackling social challenges as the following:

Collective intelligence is created when people work together, often with the help of technology, to mobilise a wider range of information, ideas and insights to address a social challenge. Although people have been working together since the dawn of time, collective intelligence has evolved quickly since the start of the digital age.

The use of technology was, in 2021, still a necessity due to the health implications of face-to-face workshops; a series of online workshop experiences were designed.

Participants were nominated from the PPI Ignite Offices and from national partners of the PPI Ignite Network with a view to having diversity in terms of level of experience in PPI, context within which people were involved, socio-cultural backgrounds. While the initial aim was to identify 20 PPI partners and 20 researchers with PPI experience, the final numbers in attendance were 17 PPI partners and 20 researchers.

Workshop 1 & 2 - Values

The first two online Collective Intelligence workshops were run on the 3rd and 10th November 2021 respectively. These workshops were designed to create a consensus on what were the fundamental values that were driving good PPI practice in Ireland.

The dynamic of the workshops was that, in breakout groups with a facilitator, each participant told a story which they felt exemplified good or poor PPI. The other participants, listening to this story, then reported what values underpinned each story for them. This breakout group then provided some statements that put a context on how they understood their top three values. Once all groups had been brought back together, the facilitator from each group then presented the top three values from their group along with context statements. Having listened to what was reported back from each group, each individual participant then had an opportunity to input up to five values into a Mentimeter poll to reflect their individual priorities.

From what was reported and what individuals entered into the poll, it became clear that a consensus had emerged. Certain values, such as equity and inclusion were closely allied and so were amalgamated. This provided six values overall.

The results of the workshops were circulated for comment to all participants.

Workshop 3 – Principles

The third online workshop took place online on 19th January 2022. The aim of this workshop was to provide a principle that would contextualise each value from the previous workshops. This would allow participants to state what they meant by an abstract value such as ‘respect’ in the context of PPI.

The dynamic of this workshops was that participants were put into one of six breakout rooms with a facilitator displaying a Miro board to capture their input. As a team, each breakout room would discuss a value and the contextual statements about it that came up in the initial workshops. These values and statements had been supplied in advance to all attendees. They would then move on to another value and then another value until they had completed six ‘rounds’ where they had input into the principle for each value.

During Round 1 to 3, the group provided advisory notes on what should go in the principle statement. During Round 4, the team wrote the principle statement for the value assigned to them during that round, based on their own views, the contextual statements and the advisory notes from previous teams. During Round 5, each team read the statement and reflected on its implications and whether, with that in mind, they might change it. During the final round, the teams would review all of the input from the assigned value they were given and suggest tweaks to the final principle statement.

All participants were then convened together and the principle statements were presented with participants invited to vote on whether they would be happy to endorse each principle and which version of the principle they would prefer. It was also agreed that the values of Trust and Transparency, which had been amalgamated following the initial workshops, would be considered as two standalone values. This meant that there were now seven values.

These values and statements were then circulated to all participants for comment. A final version of the values and principles were signed off by the PPI Ignite Network and officially launched in November 2022.

Workshop 4 – Key Outcomes in Quality

The fourth workshop took place online on 8th September 2022. The aim of the workshop was to understand how, if the values and principles were translated by organisations, for what would be the key outcomes that those involved in quality improvement for PPI should be striving.

The dynamic of this workshops was that participants were put into one of three breakout groups with a facilitator using a Miro board to capture input from the group. Each group was given two or three values and principles. In Round 1 of discussions, they suggested five main differences those values would make to a research project. In Round 2, they were moving on to another two or three values and principles and considering five changes they might make to organisations or institutions. During Round 3, they were moving on to the final two or three values and principles and, having read what was already captured, what kinds of activities might need to occur if this change was to take place. The facilitators then reported back to the main group.

The results from across all Miro boards were collated and five thematic areas emerged which formed the quality improvement outcomes, with the

element under each outcome forming reflective questions for users of the quality improvement framework. These outputs were shared with participants for comment.

Workshop 5 & 6 – Quality Indicators

The fifth online workshop took place on 25th January 2023 with another series taking place on 15th May, 25th May, 26th June, 29th June with the aim of capturing the indicators that would assist those who are striving for ways to illustrate and capture the improvement that are taking place.

The dynamic of the January workshop was, based on the outcomes and reflective questions identified in Workshop 4, to ask participants for objectives, actions and performance indicators. While this yielded some indicators, they were quite abstracted and it was decided that another workshop which asked participants to consider how would we know each outcome was being achieved and what we could either count, measure or describe to show that the outcome was being achieved.

Workshop 6 was run multiple times in order to suit as many people from the initial process as possible to input into this final workshop. These workshops yielded suggestions of types of indicators that a project or organisation could consider that would help to evidence the move towards the achievement of the quality improvement outcomes.

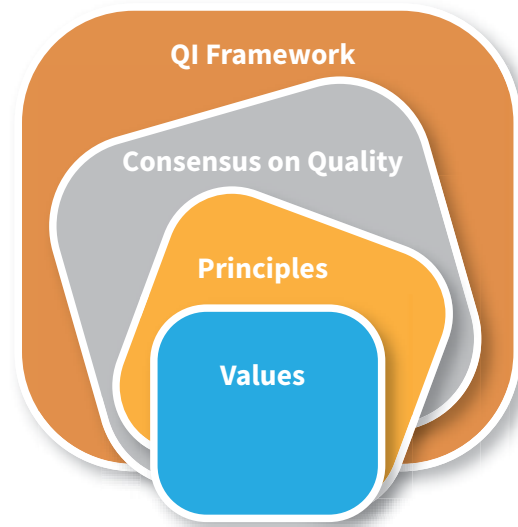
Quality Improvement Framework



Introduction

As there was not an explicit, previously agreed definition of quality in PPI in the Irish context, it proved important to build a shared consensus upon which to create a framework. At the heart of this is the creation of a set of shared values and principles which, in their observance, reflect what is commonly recognised by Irish PPI partners and researchers as good practice.

The development of these values and principles occurred through a series of Collective Intelligence Workshops which included both PPI partners and researchers and was based on their interpretations of their stories of good PPI and the values that drive it.



Agreed PPI Ignite Values

It was then necessary to develop a set of principle statements in order to contextualise what was intended by the promotion of those values and guiding best practice in PPI.



PPI Ignite Network Values and Principles

The PPI Ignite Network believes that, in order to improve public and patient involvement (PPI) in health-related research, there must be a shared understanding of the values and principles that underpin the work. We invite all researchers, PPI contributors, institutions and funders to consider how to uphold these values and principles when engaging in or supporting PPI activity.

Transparency

The need for **clear, open, mutual communication** between the research team and PPI partners about research decisions and progress.

We want transparency in developing a **clear, shared understanding of aims, roles, processes and other terms of involvement.**



Respect

The **recognition of the roles, knowledge, insights, experiences, strengths, limitations and contributions** across the research team and PPI partners and throughout the research lifecycle.

We want to **benefit from the diversity of the team and partners**, and work together effectively and enjoyably.



Empowerment & Power Sharing

The inclusion as early as possible in **funding decisions, strategy and decision-making, the co-design and co-production of research.**

We want a **wide range of involvement strategies** to ensure that this happens.



Trust

The **building of reciprocal trust; this takes time to develop, is relationship based** and needs to be consistently worked on.

We want **everybody's opinion to be fully heard** and we want **confidentiality to be negotiated and respected.**



Collaboration & Partnership

The **inclusion of PPI partners** throughout the research lifecycle with commitments and expectations agreed from the outset, as much as possible.

We want true partnership where **all contributions are valued and respected equally.**



Flexibility

The **recognition of the time and other commitments involved in PPI** and that this **is acted upon in the research plan.**

We want to **co-design appropriate changes and responses** to the experiences and to the views of PPI partners.



Equity & Inclusion

The active identification and **removal of barriers and creation of entry points** throughout the research lifecycle.

We want real co-design and partnership to take place that **values equally people's diversity of opinions, experiences, abilities, backgrounds and expertise.**



Purpose of this Framework

This framework has been developed in order to create a shared understanding of what constitutes quality PPI, as defined by those who experience it. Its primary goal is to shape how PPI is delivered and to ensure that the values identified are driving the attitudes, behaviours and actions of all concerned, and that those values are supported by research performing or research hosting organisations and research funders.

It is hoped that the framework will support discussions about:

- how to plan and approach PPI activity;
- how to build and sustain meaningful PPI relationships;
- how to judge the quality of PPI activity; and
- how to recognise where PPI activity can be improved.

While it is acknowledged that other values and principles frameworks and quality improvement frameworks exist, this was built upon the lived experience of PPI partners and researchers in Ireland, highlighting their experience of both best practice in Ireland and circumstances where PPI activity did not meet their expectations. It is accepted that, if this framework is effective, those circumstances will change and that future Irish frameworks will reflect that evolution.

This PPI Quality Improvement Framework provides a **rubric**, based on the values and principles, where a research team or PPI partner can consider the level at which a project is operating in accordance with the values and principles that were identified as most important. This rubric acknowledges that teams should be striving to be more thoughtful in their PPI work and to be intentional about creating a positive experience for PPI partners.

It also identifies five **outcomes** which are considered important as ways in which PPI should be developed in order to realise the values and principles, **reflective questions** to consider how these outcomes can be achieved and a set of prospective **indicators** that may be used in order to evidence movement towards these outcomes.

Self-Assessment for Quality of PPI

The following rubric, which has been built on feedback from participants in this process, allows for teams to consider the level at which their work is coherent with the values and principles that are driving quality in PPI.

	Progressing	Reasonable	Excellent
RESPECT			
We recognise the roles, knowledge, insights, experiences, strengths, limitations and contributions across the research team and PPI partners and throughout the research lifecycle.	There is some discussion about using different skills and experiences in shaping research projects.	The team know one another well and there continues to be ongoing discussions about people's roles and involvement.	From the beginning, the team co-designs a statement highlighting everyone's expectations from the project, what they are bringing to it and any limitations they may have. This is revisited at appropriate intervals for revision.
We benefit from the diversity of the team and partners and work together effectively and enjoyably.	Activities allow for different roles or perspectives to emerge.	Activities play to the strengths and motivations of each team member.	A diverse team has been convened and ongoing discussions take place on how to work together and how diversity affects the project or activities.
TRUST			
We actively build reciprocal trust; acknowledging that it takes time to develop, is relationship based and needs to be consistently worked on.	Efforts are made for team members to get to know one another and to share their skills and experiences.	Dedicated discussions take place among the team on how to improve relationships.	The team have a clear set of processes in place aimed at strengthening relationships, enhancing dialogue and addressing conflict.
Everybody's opinion is fully heard.	The researchers remind PPI partners that they can voice their opinions.	PPI partners are confident that their opinions are being acted upon during a project.	There is evidence to show where PPI partner opinions have affected or influenced a project.
We negotiate and respect confidentiality.	PPI partners are offered an acknowledgment on outputs as they arise from a project.	Projects have a written record of how and whether people would like their involvement acknowledged.	There is written agreement on acknowledgement and confidentiality, co-created between each PPI partner and the researchers. This is revisited at appropriate intervals for revision.

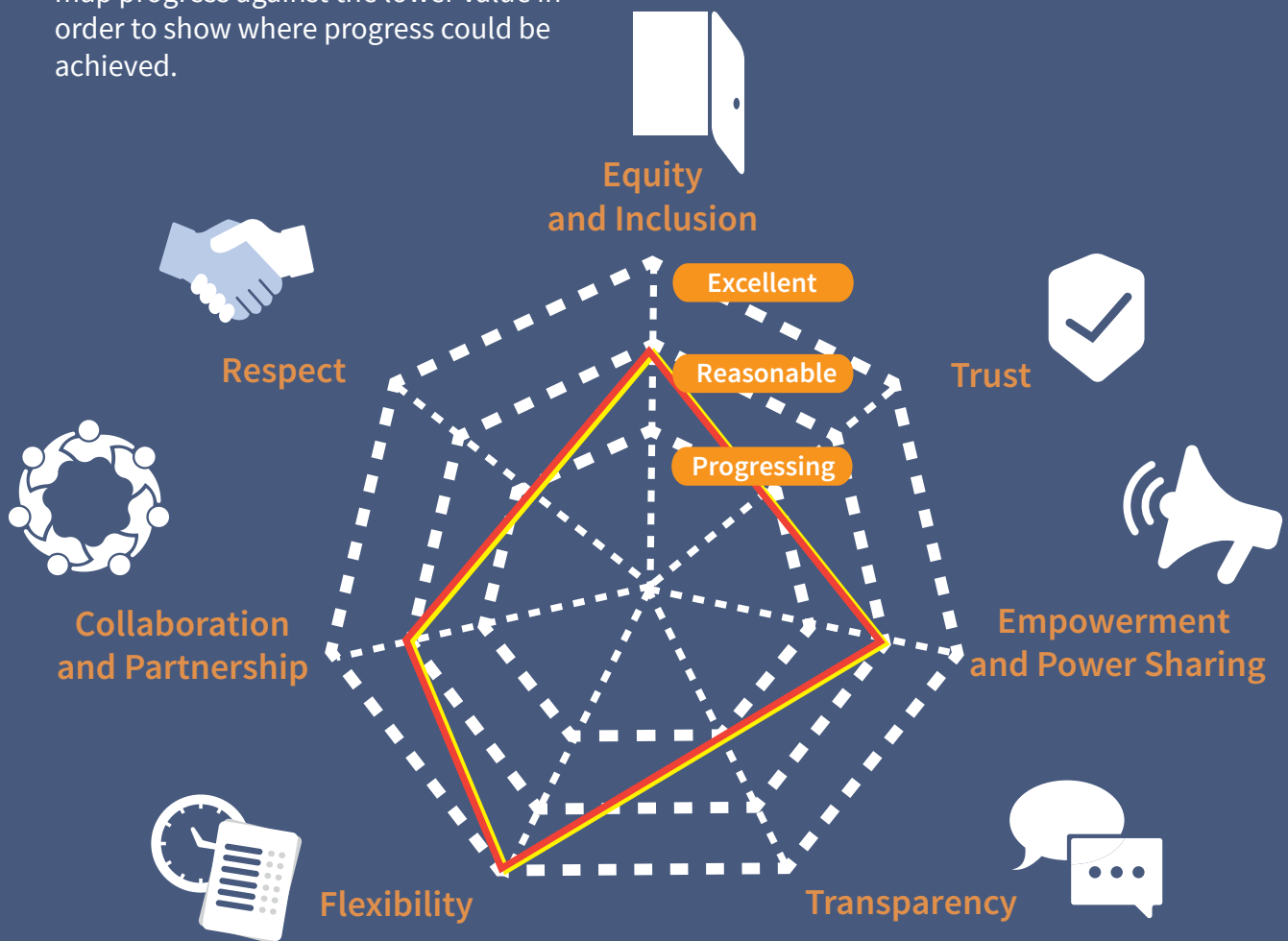
	Progressing	Reasonable	Excellent
FLEXIBILITY			
We recognise the time and other commitments involved in PPI and act upon this in our research plan.	The team holds meetings and activities at a time that suits most people.	The team holds meetings or plans PPI activities that suit the time constraints and commitments of PPI partners as a priority.	From the beginning, the team co-designs an agreement on the commitment required for the project, how each partner will be involved and how this will be reflected in plans and revisions of plans. This is revisited at appropriate intervals for revision.
We co-design appropriate changes and our responses to the experiences and to the views of PPI partners.	If PPI partners request a change, then it is considered by the researchers.	The team works together to plan changes to the research cycle due to PPI partner input.	There is a clear co-design process in place so that research plans can be adapted, based on PPI input.
TRANSPARENCY			
We have clear, open, mutual communication between the research team and PPI partners about research decisions and progress.	Researchers communicate with PPI partners if they are seeking PPI partner input.	Researchers and PPI partners meet regularly throughout the lifetime of the project.	An agreed communication protocol and schedule is in place so that the team can regularly discuss the project.
We have transparency in our development of a clear, shared understanding of aims, roles, processes and other terms of involvement.	PPI partners are supplied with details on the aims, roles, processes and other conditions of involvement.	The team works together to develop the aims, roles, processes and other conditions of involvement.	From the beginning, the team co-designs a Terms of Reference that covers aims, roles, processes and other conditions. This is revisited at appropriate intervals for revision.
EMPOWERMENT & POWER SHARING			
We include partners as early as possible in funding decisions, strategy and decision-making, the co-design and co-production of research.	PPI partners are kept informed from the beginning of the process.	PPI partners are included in decisions on all aspects of the research cycle and supported to play a role.	PPI partners feel empowered to play an active role in all relevant aspects of the research cycle.
We have a wide range of involvement strategies to ensure that partners are included as early as possible.	Researchers tell PPI partners that they can be involved across the research cycle.	From the beginning, researchers support PPI partners in understanding the research cycle and find different ways to share power with them.	From the beginning, there is an ongoing support for PPI partners so that they become empowered to play a full part across the research cycle.

	Progressing	Reasonable	Excellent
COLLABORATION & PARTNERSHIP			
We include PPI partners throughout the research lifecycle with commitments and expectations agreed from the outset, as much as possible.	Researchers tell PPI partners what they can expect as part of their involvement in a project.	PPI partners discuss and agree with the researchers how they can be involved.	From the beginning, the team co-designs an agreement on the expectations and commitments that they have about the project. This is revisited at appropriate intervals for revision.
We have a true partnership where all contributions are valued and respected equally.	The team verbally acknowledges everyone's contribution regularly.	PPI partners can articulate whether their contributions have affected or influenced a project.	There is evidence to show where and how PPI partner contributions have affected or influenced a project.
EQUITY & INCLUSION			
We identify and remove barriers and create entry points throughout the research lifecycle.	Researchers make efforts to remove particular barriers identified by PPI partners. They are also willing to consider re-entry into a process by a PPI partner who has withdrawn.	The team anticipates barriers to participation and acts upon them. It also clearly states ways in which PPI partners can re-enter the process if they have withdrawn.	The team co-designs barrier-free processes and activities and ensures that, with permission, anyone who withdraws is kept informed about the project and is invited to re-enter at appropriate points. The team also advises their organisation on any structural gaps identified.
We have real co-design and partnership that values equally people's diversity of opinions, experiences, abilities, backgrounds and expertise.	There is an effort to understand diverse opinions, experiences, skills and contexts.	The team keeps diversity and inclusion on the agenda in co-design and throughout the research lifecycle.	All team members are skilled in keeping equity and inclusion considerations as part of all co-design and other activities during the research cycle.



The rubric hopes to encourage progression along a continuum of improving approaches under each value. It may not be possible or reasonable to achieve excellence in every value, but this should be the direction of travel. As a useful visual to a team, it may prove helpful to map progress in relation to the rubric. The spider graph below (see Appendix 1) can quickly show a project or organisation how it is performing in relation to the values and principles.

Although there are two or three elements under each value, it may be best to map progress against the lower value in order to show where progress could be achieved.



Quality Improvement Outcomes for PPI

Five key outcomes have been identified through the implementation of the values and principles which can drive quality improvement in PPI in Ireland:

1. **Broadening Involvement:** PPI processes and activities are designed to involve a diverse range of appropriate PPI partners;
2. **Supporting PPI Partners:** PPI partners are supported in PPI processes and activities;
3. **Supporting Researchers:** Researchers and other staff are supported in PPI processes and activities;
4. **Establishing Relationships:** PPI processes and activities have proper agenda setting actions and other activities to establish productive PPI relationships;
5. **Aligning Organisation Culture:** Organisations have a culture and practices that support PPI processes and activities.

While each of these outcomes has an important role to play on its own, it is through the achievement of progress in the combined outcomes that there can be a substantial improvement in quality across PPI activity and a raising of that expectation among PPI partners and researchers.

Under each outcome discussed below, there are a set of considerations and a set of indicators that project teams or organisations can consider and adapt to suit their own context. These questions and indicators have emerged from the workshops with PPI partners and researchers as they envisaged a PPI sector that embodied the agreed values and principles.

Broadening Involvement

PPI processes and activities are designed to involve a diverse range of appropriate PPI partners

There is a need to ensure diverse routes into and through research for PPI partners, regardless of their status, class, illness, identity, long-term condition, ethnicity or level of ability or disability. This means that unintended or unnecessary barriers faced by diverse groups are removed from processes. It also means that these groups see signals which indicate that they are welcome and that their lived experience will be both useful to and respected by others within the process.

It is about creating opportunities that are attractive and appropriate to those who may become involved and to ensure that efforts are put into making people aware of opportunities.

Those who participate in PPI processes will often, due to their lived experience, have differing needs from the general public. This may mean they have issues with fatigue, with mobility, with literacy. They may also have a more sophisticated understanding of the health service than the general public. PPI activity needs to be built around the characteristics of those who it is likely to attract rather than a notion of the 'average' person.

There remains a need to build public understanding about PPI in health-related research, how it works and how people can become involved. It is important that many different types of researchers and PPI partners can build an understanding of PPI that is meaningful to them and one

where they have a reasonable level of agency and ownership.

By ensuring that any appropriate PPI partner can be involved, the intention is that those most impacted by the results of proposed research find their way to the research table to articulate what is useful and meaningful to them and that they can highlight unintended consequences or latent opportunities which are obvious to them through their lived experience.

The need to attract diverse groups may lead to a deeper understanding of how the social determinants of health can compound people's exclusion from better health and wellbeing. Co-designing research processes with those whose voices may have previously gone unheard opens up the prospect of creating findings which can better address complex issues.

It also provides ways in which PPI partners can find their way back into a process if they needed to drop out at any point. It ensures that the time which they and the team have invested continues to be of use throughout the research cycle. It also encourages the continuation of involvement by PPI partners in the longer term, beyond the life of a single project.

Reflective Questions

-----> **Are the materials created to introduce the project appropriate for the proposed PPI partners? Are they available and visible to those partners?**

Are the formats accessible to people with different abilities?

-----> **Have a variety of events and activities been created in order to attract a diverse group of appropriate PPI partners?**

-----> **Is there a plan in place to attract, support and involve PPI partners who are appropriate to the project but are, within the group, coming from diverse perspectives?**

-----> **More broadly, is the team communicating what PPI is and how it is contributing to research?**

Suggested Indicators of Quality

Depending on the context, these indicators have been suggested as ways in which to track or illustrate progress in this outcome.

Outcome indicators

- Showing the effects of diversity on the processes of and outcomes from a project or activity

Attitudinal indicators

- Conveying the research team's understanding about working with often-excluded communities or individuals

Process indicators

- Showing ways the organisation or research team articulate EDI (equality, diversity and inclusion) considerations in a funding application
- Showing how EDI is supported in the organisation's policy and strategy
- Demonstrating, within processes, diversity being encouraged, such as holding meetings off campus on territory more familiar to the PPI partners
- Capturing the debates in agendas and minutes of meetings which illustrate how inclusion is shaping the projects

Skills indicators

- Showing skills are being developed which support greater diversity such as training on disability accessibility or universal design, plain language or easy-read training or diverse communication training, training on EDI approaches

Other indicators

- Showing the diversity of the population as understood by the protected grounds of Irish equality legislation, with a recognition that gathering and processing such data can be complex and requires a knowledge of the appropriate processes and legislation
- Showing PPI as a role being mentioned in wider communications from the organisation
- Tracking new people coming into PPI processes but also showing that others are being retained, capturing how and why people enter a process and how and why they drop out

Supporting PPI Partners

PPI partners are supported in PPI processes and activities

It is important that PPI partners can contribute fully to a research project and be acknowledged for their input without being disadvantaged in any way. In order to do that, however, they need to have an understanding of the potential roles they could play and the possible ways that their lived experience could affect a project.

Although PPI has only relatively recently established itself as a concept in the Irish health-related research landscape, many research teams and universities are building the skills and structures needed to run effective PPI activities. It is important, however, that PPI partners are provided with ways in which they can understand the context in which they are operating. They also need to understand what they can expect and what both good and bad PPI practices look like. This helps to build reasonable expectations on all sides about many aspects of PPI work, lessening the likelihood of a mismatch in expectations about what is reasonable, or even possible, as a result of PPI activity.

It should also be noted that PPI partners may have a better understanding of certain aspects of the research cycle than the rest of the research team, such as achieving pathways to impact through advocacy.

It is useful for PPI partners to reach an understanding of how those skills can best be utilised in the research cycle so that they can help research teams to learn how to do this work effectively in their field of study.

Supporting PPI partners is also ensuring that those who might otherwise not be able to participate, due to a lack of resources or confidence, can play a role and can help research teams to understand and incorporate their lived experience. Bringing these often-excluded voices into the research cycle creates the prospect of ensuring that the wider determinants of health can be considered in all aspects of research.

If PPI partners feel valued and supported, they may invest more in a project and remain involved over the longer term, particularly in turning findings into societal impact. It would also be hoped that fostering skills and insights among PPI partners will also improve the overall research cycle by their knowing when and how to contribute. Over time, this may lead to novel approaches to PPI and a wider nexus of peer support among the burgeoning PPI partner community, motivating them to endorse and promote involvement in PPI activity.

Reflective Questions

- > **Have PPI partners received appropriate induction and supports to carry out their various roles? Where specialist training is needed, are PPI partners being offered this? Where work stimulates strong emotions, do PPI partners know how to access support?**

- > **Do PPI partners have access to resources within the organisation that are appropriate to their roles? For some PPI partners, this may go as far as being assigned an organisation email address, having library access, installing anti-virus software, or receiving a travel bursary to participate in dissemination activity.**

- > **Is there financial recognition for the roles PPI partners are playing by paying PPI partners or covering expenses? Are PPI partners fully aware of the tax/social welfare implications of payment?**

- > **Are PPI partners being properly recognised by the team and the organisation for the contribution they are making? Have they been given the opportunity to have their name appear on project outputs?**

Suggested Indicators of Quality

Depending on the context, these indicators have been suggested as ways in which to track or illustrate progress in this outcome.

Outcome indicators

- Showing the involvement of PPI partners in the dissemination of results to relevant patient populations or the public
- Capturing how PPI partners are acknowledged and recognised in outputs as co-authors, contributors or collaborators
- Demonstrating clear, co-created role profiles for PPI partners

Attitudinal indicators

- Conveying what is considered a meaningful role by PPI partners and by researchers
- Illustrating if and how PPI partners feel supported, which may need to be gathered by third parties or anonymously
- Showing the level of administrative burden PPI partners feel during their experiences

Process indicators

- Showing both formal and informal entry points into a process for PPI partners
- Conveying whether PPI partners are turning up for events and activities.
- Capturing the debates in agendas and minutes of meetings which illustrate how PPI partners are shaping the projects

- While the depth and type of role a PPI partner may play on a project may differ greatly, there can be indicators that show those partners getting appropriate access to organisational resources and protections. For example, if they are processing data, that they are not liable as a private individual for any data breach

Skills indicators

- Demonstrating skill development through proper induction processes, induction materials and training where that is necessary
- Showing the transfer of skills gathered by partners to other projects

Resource indicators

- Capturing the provision of supports and resources, including payment and the covering of incurred expenses. This would include complying with guidance on how to provide payment responsibly for PPI partners

Other indicators

- Tracking new people coming into PPI processes but also showing that others are being retained, which captures how and why do people enter a process and how and why they drop out

Supporting Researchers

Researchers and other staff are supported in PPI processes and activities

Researchers will experience many new challenges and opportunities as their PPI practice develops. It is important that they begin from a strong basic understanding, and they can develop skills that help them to work with a variety of stakeholders in a respectful way. As their practice matures, they will need to understand how to maintain vital relationships through changing circumstances and how to identify mutually beneficial opportunities for partnerships. It is also important that their organisation recognises their efforts and how their work can lead to greater societal benefit as well as benefitting perceptions of their organisation.

As researchers learn their profession, however, they may learn practices that are not coherent with PPI activity; in some ways, PPI can run counter to the processes researchers undertake in designing research protocols. Their relationship with and interaction with PPI partners can be very different to that which they have with their study participants. They can engage with them much earlier in the research cycle, can make efforts to create and to maintain a relationship, and can discuss many aspects of the study of which participants may not be aware.

At a deeper level, it is also important that researchers have a strong understanding of their own profession and why they do what they do so that they can maintain the kind of systematic rigour and ethical practice required to carry out good

research. A PPI partner will often not have research experience and will need the researcher to bring that lens to their 'lived experience' in order to understand how it can influence a project without compromising the research in some way.

Supporting researchers is also necessary when considering the need for time to build PPI relationships, which often require a mix of structured and unstructured activity. These relationships can yield far-reaching positive impacts but do require time in order to do so.

By supporting researchers, it is possible to create communities of PPI practice among researchers within particular fields or organisations. Providing this support also increases the likelihood that researchers' PPI practice will be of good quality, will be respectful of PPI partners and will ultimately lead to better health outcomes in their research field.

It also helps researchers to build skills and a confidence that can be used throughout their career around negotiation, problem solving and facilitation. Those researchers can also move the PPI agenda forward within their own field and in the research landscape more generally by supporting and mentoring future research teams and PPI partners.

Reflective Questions

- > **Are researchers provided with access to the training and support they need to be competent in all aspects of PPI activity? Does this training and support include activities such as co-creation, facilitation, supporting literacy needs, ways of building trust, relationship management and conflict intervention?**

- > **Are researchers provided with mentoring or peer support opportunities where they can learn from colleagues or PPI partners about how to improve their practice? Do researchers have access to some type of mediation or third-party support for PPI activity?**

- > **Are PPI activities recognised and rewarded in academic promotions, adjudications and awards?**

Suggested Indicators of Quality

Depending on the context, these indicators have been suggested as ways in which to track or illustrate progress in this outcome.

Outcome indicators

- Capturing PPI activity being considered for awards, inclusion in conference adjudication or counted in promotion considerations
- Illustrating that PPI is appearing in narrative academic CVs both within organisations and in funding applications, with perhaps a deeper exploration of whether the inclusion of PPI activity is making a positive difference in adjudications for funding or promotion
- Showing dissemination activities aimed at relevant patient populations, led or co-led by PPI partners
- Showing that elements such as lay summaries are being used in promotion of research projects and dissemination activities
- Capturing the acknowledgement or discussion of PPI within publications arising from a research project

Attitudinal indicators

- Capturing researchers' own feelings of being supported in their PPI endeavours in comparison with other research activities, including the administrative burden experienced by researchers and other staff in ensuring that PPI activities can happen
- Illustrating the kind of emotional payback vs emotional labour experienced by research and other staff in PPI activity

Process indicators

- Elucidating when and how issues or conflicts arise among research teams that include PPI partners and the ways in which these are escalated or resolved and what kinds of supports are available to all involved
- Capturing what PPI partners consider 'bad practice' from researchers

Skills indicators

- Showing training in place at all academic and appropriate support staff levels to improve PPI practice within an organisation, including specialist training regarding diversity and underrepresented communities
- Showing the extent to which PPI is featuring in academic curricula and in supports for PhD candidates and early-career researchers
- Capturing support available to articulate PPI plans and activities that can attract funder investment
- Capturing academic mentoring relationships to support PPI relationships, where mentors may be academic staff or PPI partners
- Illustrating what other activities are being taken up by researchers, external to their academic work, which help to build PPI insight or relationships

Resource indicators

- Illustrating the availability of seed funding for PPI relationship-building activities
- Capturing the use of organisational in-kind resources such as printing, catering, convening spaces or meeting rooms that can support PPI relationships

Establishing Relationships

PPI processes and activities have proper agenda setting actions and other activities to establish productive PPI relationships

It is important to reach some level of shared understanding between partners at the beginning of a process. There needs to be time and resources put in place to discuss objectives, tasks and budgets. There also needs to be a clarification on all sides about what obligations and expectations different partners have at the beginning of the process.

As PPI relationships begin, levels of trust and mutual understanding can be low. For there to be true collaboration and partnership, however, all aspects of a project cannot be fully set in advance of partner involvement. While it is true that expectations may be refined as a process develops, as circumstances change or as partners get a clearer understanding of one another's contexts, it is important that all partners dispel any misconceptions and negotiate conflicting objectives.

It is also true that research teams may not have a full picture of the PPI partners with whom they are working. They may be unaware of other skills, networks, identities or experiences that a PPI partner can bring to aspects of the project.

A useful establishing process can anticipate and calm future possible conflicts. It builds a richer picture of the project, helping to better inform a PPI partner's consent to become involved. It also allows those PPI partners who are not suited to a project a chance to exit.

By negotiating and establishing agreements at the beginning of a process, it helps to build a PPI relationship and gives all partners a shared understanding of the potential outcomes and impacts of a project. It also provides an opportunity for PPI partners to suggest how both their lived experience and other aspects of their lives can support a project.

This is also a time where PPI partners can gain a better understanding of the circumstances of research teams: their priorities, their expectations and their conditions. This should also highlight the kinds of restrictions that researchers may face around time pressure, competing deadlines and delays.

Reflective Questions

- > Do teams have the skills and capacity to co-create project plans and devise project budgets with PPI partners, plans that acknowledge the skills, networks, identities or experiences of all involved? Are reviews built into project plans?

- > Does the organisation provide 'seed' funding or in-kind support so that researchers can hold agenda setting and pre-project encounters?

- > Do teams run early-stage activities in order to develop terms of reference and partnership agreements?

- > Do teams have the skills and insights needed to build and maintain relationships with current and potential PPI partners? Where appropriate, are there both formal and informal relationship building activities included?

Suggested Indicators of Quality

Depending on the context, these indicators have been suggested as ways in which to track or illustrate progress in this outcome.

Outcome indicators

- Showing the outputs from project ideation and agenda setting activities
- Capturing the outputs from co-created protocols and agreements, such as Terms of Reference

Attitudinal indicators

- Illustrating that both Principal Investigators and PPI partners can articulate meaningful PPI roles
- Capturing agreed expectations between PPI partners and the wider research team
- Capturing whether Terms of Reference or other protocols were followed throughout a project
- Estimating levels of involvement and enthusiasm throughout a project
- Showing the level of clarity on the choice and control in place for PPI partners so that they can decide with what they wish to be involved

Process indicators

- Capturing of actual involvement in projects in comparison to initial plans
- Illustrating, in plans, whether reasonable amounts of time have been allocated to PPI activity
- Showing when and how PPI partners became involved with a project and where they were involved throughout the project, compared to the initial expectation

- Showing levels of PPI involvement in advance of funding application and how far in advance those activities occurred
- Illustrating the barriers and issues identified by PPI partners at the beginning of their involvement in a project

Skills indicators

- Showing whether the facilitation skills are in place to ensure that agenda setting activities are able to explore potential areas of involvement, uncover latent expectations and reach consensus on moving forward

Resource indicators

- Illustrating the availability of seed funding for PPI relationship-building activities
- Capturing the use of organisational in-kind resources such as printing, catering, convening spaces or meeting rooms that can support PPI relationships

Aligning Organisational Culture

Organisations have a culture and practices that supports PPI processes and activities

It is important that that organisations ensure that their systems and processes are designed to include and support excellent PPI activity and substantial relationship building between researchers and stakeholders. Consideration of PPI needs to be stitched into areas as diverse as ethical review, payroll, data protection, strategy development, human resources and evaluation. By orienting systems and processes in this way, unnecessary barriers or cumbersome internal procedures should not take up the time of either research teams or PPI partners, allowing for a greater focus on relationship building and partnership working.

While there have been research teams who have worked over many years with PPI partners, it has not been traditionally part of the research cycle for many. Trying to fully incorporate PPI partners into systems and processes that can have a legal or technical basis while still being respectful of their needs, context and potential limitations, can be challenging. Rather than planning PPI activity in good faith and then discovering that it is not possible under an organisation's policy, it is better that research teams receive explicit guidance in advance of making plans.

There is a need for organisations to grow and maintain in-house expertise that can continue to promote and celebrate good quality PPI and to encourage better practice. It provides opportunities for PPI practice to be considered and peer reviewed. It is also about ensuring that an institution builds a clear, long-term commitment to PPI practice for future generations of researchers.

The benefit of this is that it can give reassurance to PPI partners and to research teams that the organisation is supportive of their ongoing activities. It also ensures that a wealth of knowledge is built so that research communities can provide critical review on PPI activities, providing other perspectives and alerting the organisation of any inappropriate actions arising from misinterpretation of what is appropriate.

The organisational benefit is that, at a practical level, it can improve and streamline processes such as funding applications and contracting. At a deeper level, it may also build the reputation of the organisation as a partner in tackling societal issues and foster the skills needed to promote a culture of power sharing across the organisation, encouraging new ways in which those organisations can innovate through true collaborations with multiple stakeholders.

Reflective Questions

- > **Does the organisation provide support staff and resources that coordinate non-project-specific PPI activities?**

- > **Has the organisation made a public commitment to good quality in PPI through strategic documents or public declarations? Has the organisation created clear definitions and protocols around its PPI work in areas like HR, Finance, Communications?**

- > **Has the organisation created and supported ways to promote proper power-sharing with other partners on projects and activities?**

- > **Does the organisation have an ethical, legal or reputational oversight on PPI activity that takes place on its behalf?**

Suggested Indicators of Quality

Depending on the context, these indicators have been suggested as ways in which to track or illustrate progress in this outcome.

Outcome indicators

- Capturing PPI activity being considered for awards, inclusion in conference adjudication or counted in promotion considerations
- Illustrating that PPI is appearing in narrative academic CVs both within organisations and in funding applications, with perhaps a deeper exploration of whether the inclusion of PPI activity is making a positive difference in adjudications for funding or promotion
- Showing how PPI relates to the organisation's own strategy and metrics
- Illustrating the existence of staffing and champions that can support PPI as part of wider organisational development
- Capturing PPI activity as part of the development of applications to Research Ethics Committees and, where appropriate, involvement of PPI partners as members of Research Ethics Committees
- Capturing ways in which organisations can facilitate powersharing, such as pro-forma agreements, guidance on communications, financial arrangements
- Developing case studies that show different models of power sharing with other organisations
- Illustrating how an organisation recognises PPI partners in policies and processes, such as how it acknowledges or rewards them
- Capturing how PPI partners are 'visible' within the organisational culture, such as whether there is a critical dialogue with PPI partners, whether they appear within reports, whether they feature at events or in communications
- Showing the options available to PPI partners such as when they get paid
- Elucidating when and how issues or conflicts which are not or cannot be resolved at a team level are escalated or resolved and what kinds of supports are available to all involved

Attitudinal indicators

- Gauging the reputation of an organisation in its PPI activity among PPI partners rather than a particular research team and how this relates to the overall reputation of the organisation

Process indicators

- Illustrating how policies such as those on equality, diversity and inclusion relate to PPI activity and relationships
- Showing supports available for peer researchers who emerge from patient populations

Suggested Indicators of Quality

Skills indicators

- Showing how PPI-related skills are part of Professional Development activities
- Illustrating how PPI appears in Health Sciences curricula and how it is supported among PhD candidates

Resource indicators

- Illustrating the availability of seed funding for PPI relationship-building activities
- Capturing the use of organisational in-kind resources such as printing, catering, convening spaces or meeting rooms that can support PPI relationships and institutional protections around issues like being a data processor

Conclusion & Next Steps

This PPI Quality Improvement Framework is articulating a consensus on what constitutes good quality in PPI in Ireland. It provides a picture based on people's current experiences of PPI but with a focus on how those activities and relationships could be evaluated, enhanced and improved.

By considering the outcomes of quality improvement and the reflective questions they raise, it is hoped that research teams, organisations and groups will be able to develop activities and opportunities that help to build better-quality PPI approaches and relationships.

The Framework aims to develop an understanding and expectation among PPI partners of how their PPI relationship can and should develop within a project and the bedrock upon which productive and fulfilling PPI relationships can develop into the future. It is also hoped that this Framework will provide a perspective on how to remedy PPI approaches that are not productive or are not providing appropriate opportunities for PPI partners.

It is intended that the self-assessment rubric and the indicators will give stakeholders an opportunity to consider the level of quality within a project and its supporting organisation and whether it is acting coherently with the values and principles as stated in the Framework.

The Framework also provides wayfinding for the national PPI Ignite Network to encourage and promote better quality in PPI activity. The Network is already engaged in projects and actions that will address many key components of the outcomes such as developing training for researchers and induction for PPI partners. It also indicates, however, prospective resources and tools that are beyond the current PPI Ignite agenda, suggesting future directions for quality improvement in PPI.

Appendix 1 – Template for Rubric Mapping

