



PPI IGNITE
NETWORK

IMPACT CASE STUDY

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PPI Ignite Network Values and Principles Framework: a consensus on what matters

Who was involved?

- 6 lead sites
- 5 national partners
- 1 local partner
- 17 PPI contributors
- 20 researchers with PPI experience

Summary

While PPI and stakeholder involvement is increasingly becoming central to Irish research, there was little agreed guidance on what constituted good quality approaches. The [PPI Ignite Network Values and Principles Framework](#) provides a way in which people can discuss, plan, assess and celebrate what is meant by excellent PPI in an Irish context. It is striving for impact where these values and principles materially improve: the experience of PPI for PPI contributors and researchers working in partnership; the resulting research; and the translation of that research into societal gain. It also supports other stakeholders such as funders, NGOs and higher education institutions to assure the quality of PPI in projects, in partnerships and in the training of researchers.

Our work

Led by the Trinity College Dublin PPI Ignite Network Office, the [PPI Ignite Network Values and Principles Framework](#) was created in partnership with a number of the national PPI Ignite Network partners. The partners suggested or nominated PPI contributors and PPI-experienced researchers to co-create the framework. This co-creation happened in a number of online collective intelligence workshops led by the Trinity PPI Ignite Network Office on behalf of the Network.

With initial planning during Summer 2021, two primary workshops took place in October 2021, one with 17 PPI contributors and another with 20 PPI-experienced researchers. These workshops encouraged participants to speak about what were either good or bad experiences of PPI. Other participants, listening to these stories, then suggested what values were epitomised by the stories.

Then, in January 2022, the participants from both workshops came together online to devise statements of principle to contextualise the values chosen. In groups, they were asked to articulate what the values actually meant in the context of PPI so that there could be



Prof Mary McCarron, Trinity's PPI Ignite Network Site Lead, launching the Framework (photo: Fennell Photography)

clearer consensus on the meanings behind the values. The full set of values and principles were then shared with all participants for feedback. Once the final draft was ready, a workshop in September 2022 'road-tested' the values and principles; the participants were reconvened to consider how these values and principles would work in practice and whether any adjustments were needed.

The final [Values and Principles Framework](#) was then launched in October 2022 and has formed the basis for the building of a Quality Improvement Framework.

Our impact

The desired impact of this project is good quality PPI activity. A Values and Principles Framework provides the foundation for Quality Improvement with the intention of orienting the culture of PPI in Ireland towards good practice when building and sustaining PPI relationships.

A shared understanding of quality will help to set an expectation among all involved about what can be expected across the research cycle. It will also help to recognise and celebrate those who are doing excellent PPI

and provide a roadmap for those who wish to improve.

A shared Framework can also help higher education institutions in their training of researchers, or funders in advising applicants on what is expected in PPI relationships.

Launched in October 2022, it can already show positive indicators of change.

Guiding national and international approaches

Apart from the PPI Ignite Network Lead Sites, different partners have begun to adopt the Framework to guide their work:

- HSE Patient and Family Engagement, responsible for the [National Patient Forum](#), has decided to adopt the Framework to guide its future work (with 27 organisations across the Forum)
- [R2D2-MH, a Horizon Europe project](#) exploring mental health in neurodiversity, led by the Pasteur Institute in Paris, has adopted the values to drive its codesign (with 26 international partners)

Shaping the Conversation about Quality PPI

The Framework has already been downloaded from the PPI Ignite Network website by more than **300 visitors**. It has also been presented to over 100 people in a number of forums with PPI commitments and agendas:

- **November 2022:** [HSE Research & Development Share and Learn Seminar](#)
- **December 2022:** Health and Social Care Northern Ireland PIER public group presentation
- **December 2022:** [University of Galway Population Health and Health Services Research Joint Seminar Series](#)
- **February 2023:** R2D2-MH, a Horizon Europe project exploring mental health among neurodivergent populations
- **March 2023:** Trinity Advancing Your Research Career – Public Involvement
- **May 2023:** Maynooth University Public and Patient Involvement Training Day

Supporting the next generation of engaged researchers

Through becoming integrated into curricula, the Framework is helping to shape how researchers engage with external stakeholders:

- Campus Engage, within the Irish Universities Association, has integrated the Framework into its Train the Trainer Course '[Engaged Research and Innovation for Societal Impact](#)' (which has trained 31 facilitators so far in 2023 using the resource)
- PPI Ignite Network WP2 has incorporated the Framework into the development of a module for PhD candidates, which can have a significant reach across 8 universities

At the launch event, Prof Mary McCarron, leading the project, expressed the desire that the values would not just be 'on our walls but in our hearts'. To that end, these testimonials provide an indication of the impact of this Framework:

"As someone with a strong belief in the co-design and co-production of health research, I got involved in the Framework; I see it as an important step towards moving from tokenistic engagement to genuine involvement in how our health and social care services are designed and delivered."

Anne Lawlor, Chairperson, 22q11 Ireland Support Group



Dr Anne Cody, Health Research Board, Prof Mary McCarron, Trinity College Dublin and Prof Sean Dinneen, National Lead, PPI Ignite Network 'signing up' to the Framework (photo: Fennell Photography)

PPI Ignite Network Values and Principles

<p>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.</p>	<p>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.</p> 
<p>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.</p> 	<p>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.</p> 
<p>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.</p> 	<p>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.</p> 
<p>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.</p> 	<p>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.</p> 

“Being part of the development of the Framework was such a positive experience. Coming from the stance of a researcher within a PPI partner organisation, it was great to see the various actors involved work together to reach an equal consensus on the ethical principles that underpin all our work with patients and academics.”

Zoe Hughes, Senior Policy and Research Officer, Care Alliance Ireland

“Involving stakeholders is core to engaged research and innovation for societal impact. The Framework provides learners on the Campus Engage course with a new, innovative and evidence informed guide on how to do it right. We are very grateful to the Network for sharing across the university network.”

Kate Morris, Head of Campus Engage, Irish Universities Association

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