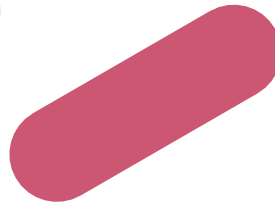




PPI IGNITE
NETWORK

IMPACT CASE STUDY



PPI Values and Principles: defining a strong foundation

Who was involved?

Seven Lead Sites

National and local partners

Public sector agencies

National and international researchers

PPI contributors, charities and patient organisations

Summary

After a comprehensive collaborative and co-designed process, the PPI Ignite Network Values and Principles Framework was published in October 2022, providing guidance agreed by all stakeholders on what constitutes good quality PPI approaches.

The Values & Principles Framework provides a way in which people can discuss, plan, and evaluate what is meant by excellent PPI. It can help to build meaningful, effective and sustainable relationships between PPI and research partners. It changes how research is approached, promoting an environment where all voices are equal, and the specific expertise and skills of each person are

valued and respected. The Network's seven Lead Sites have embedded the Values & Principles Framework throughout their work in PPI training and education, introducing attendees to the values and principles on which PPI partnerships should be built.

The Values & Principles Framework has been shared with researchers, PPI partners and research organisations to help assure the quality of PPI partnerships, of the resulting research, and the translation of that research into societal gain. Since its launch, the Values & Principles Framework has become a foundational reference point for PPI activity across Ireland. The Network's Framework for Quality Improvement, published in 2023, is based on the Values and Principles Framework.

Our work

Led by the Trinity PPI Ignite Office on behalf of the Network, the PPI Ignite Network Values and Principles Framework (V&P Framework) was co-created in collaboration with several PPI Ignite Network national partners, a local partner, PPI contributors and PPI-experienced researchers. Since its launch in October 2022, the VPF has been shared widely by the PPI Ignite Network team throughout their institutions and beyond, helping to shape PPI approaches in the many diverse audiences.



How to engage with Voices4Care members?

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How to engage with Voices4Care members?

The unique views and experience of service users, carers, former carers and interested citizens provide interesting and necessary perspective into research, education, practice, and policy within palliative care. AIHPC is adamant that engagement with Voices4Care is meaningful and not a check box exercise. We uphold the PPI Ignite Network Values and Principles and ask anyone who wishes to engage with Voices4Care to consider them|

The PPI Ignite Network believes that, in order to improve public and patient involvement (PPI) in health-related research, there must be a shared

Transparency

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

The All Ireland Institute of Hospice and Palliative Care (AIHPC), endorses the PPI Ignite Network's Values and Principles on its website

The Network team reaches these audiences in many ways, including by:

- Integration of V&P Framework into training workshops and undergraduate and postgraduate 'Introduction to PPI' lectures
- Ensuring that the V&P Framework underpinned the development of the Network's new postgraduate PPI module
- Revising existing postgraduate PPI modules to include the V&P Framework
- Listing the V&P Framework as a key reference for people new to PPI
- Drawing on V&P Framework (and the subsequent Framework for Quality Improvement) in PPI support clinics for research teams planning, implementing and evaluating PPI
- Guiding many specific projects within the Network, for example, the co-design of an evaluation form for PPI training and the review of the Network's EDI strategy
- Displaying V&P Framework posters and pull-up stands at in-person events and in permanent positions across Lead Sites
- Including the V&P Framework when presenting to strategic audiences new to PPI,

including senior university management, senior clinicians, industry leaders and attendees at international conferences

Our impact

Shaping quality PPI

The V&P Framework is becoming the cornerstone on which to build good quality PPI in Ireland, with meaningful, effective and sustainable PPI partnerships at the core.

As the first-of-its-kind Framework in Ireland, it provides our research community with a clear set of principles for carrying out excellent PPI and a first point of reference for those who wish to begin their PPI journey or improve their PPI practices. For PPI contributors and partners, the V&P Framework articulates how they should be engaged with. Additionally, it supports funders in advising applicants on what is expected in PPI relationships.

The V&P Framework is used to enhance PPI practices both nationally and internationally, to raise awareness and help shape the conversation around what high quality PPI looks like, and to support the next generation of researchers.



Pictured at the launch of the Framework for Quality Improvement in PPI (L-R): Anne Lawlor, Chairperson of the HSE Patient and Service User Forum and 22q11 Ireland Support Group; Iolo Eilian, Assistant National Director, HSE Patient and Service User Experience Office, HSE; Prof Mary McCarron, Professor of Ageing and Intellectual Disability, Trinity College Dublin; Dr Linda Doyle, Provost and President of Trinity College Dublin; Peter Brown, Director, Irish Research Council. Photo credit: Fennell Photography

Guiding national and international approaches

The V&P Framework has been adopted across a variety of research contexts, within and beyond academia, as a guide for how to conduct meaningful PPI. The V&P Framework has been adopted by the HSE Patient and Family Engagement, responsible for the National Patient Forum, to guide its future work, with 27 organisations involved across the Forum. The Irish Cancer Society is also planning to adopt the V&P Framework to guide its considerable PPI portfolio. The Chief Academic Officers, a prestigious group of academic clinicians with significant influence on the research culture at the boundary between hospitals and HEIs, has been influenced by V&P Framework as they consider how best to ensure a quality PPI environment is established in their sector.

At an international level, the R2D2-MH, a Horizon Europe project, with 26 international partners, exploring mental health in neurodiversity, led by the Pasteur Institute in Paris, has adopted the values to drive its co-design.

The greatest impact, perhaps, is the Network's Framework for Quality Improvement (QI) in Public and Patient Involvement, launched in October 2023. The QI Framework builds on the V&P Framework and contains a rubric for research teams to evaluate their quality journey and to promote meaningful PPI partnerships and improved PPI practice.

Raising Awareness and Shaping the Conversation about Quality PPI

The V&P Framework has been viewed via the PPI Ignite Network website more than 700 times since publication late in 2022.

The extensive promotion of and use of the V&P Framework by the PPI Ignite Network members is influencing PPI discussions with principal investigators during grant writing, with PhD scholars and postdoctoral researchers beginning their PPI journeys, with charities and patient organisations who are building PPI capacity and with a myriad of PPI researchers, working on specific research projects.

The PPI Ignite Network itself regularly revisits the V&P Framework when planning and reviewing its own governance meetings, PPI events and other activities. The Network's Shared Learning Groups draw on the V&P Framework to plan their sessions and attendees discussing PPI best practice and challenges repeatedly return to the V&P Framework as they seek to deepen their PPI knowledge and understanding.

Supporting the next generation of researchers

Integration of the V&P Framework in undergraduate and postgraduate education ensures that cohorts of PhD scholars are already embarking on PPI-driven research influenced by the V&P Framework. Furthermore, the Network's new postgraduate PPI module underpinned by the V&P Framework is being piloted in two Universities in 2024. This module will ultimately be available across all Lead Sites, having the potential to impact hundreds of PhD scholars in the coming years.



“Dementia Trials Ireland (DTI) aspires to work alongside its PPI panel in a manner reflecting best practice informed by PPI Ignite Network’s Values and Principles Framework. DTI is planning to conduct a PPI evaluation exercise in early 2024 to audit, using the V&P Framework, the quality of its PPI to date. The outcomes will inform the strategic development of its work programme and PPI processes going forward”

Dr Anne Marie Miller, Senior Network Manager, Dementia Trials Ireland

The V&P Framework has also been incorporated into the Campus Engage Train the Trainer programme ‘*Engaged Research and Innovation for Societal Change*’ with 31 trained facilitators, and the potential to reach hundreds more through the training these facilitators will offer within their own Universities. This has the potential to broaden the V&P Framework reach far beyond the Network’s remit of PPI health and social care.

As evidenced by the uptake of the V&P Framework over the past year and a half, it is clear that it is having an impact on PPI partnerships and practices across Ireland’s research ecosystem, at different stages of the research process, across a wide variety of disciplines, and a wide variety of audiences and collaborators.