PPI IGNITE NETWORK

IMPACT CASE STUDY 2

Capacity for change: Co-creating tools to strengthen PPI in charities and communities

Who was involved?

- **One lead site**
- **One national partner charity**
- **Six local partner charities**
- **Five charities (neither local nor national partners)**

Summary

Requests for charities and community-based organisations from researchers to collaborate on projects are growing. How can we tackle this issue and create solutions to reduce associated burden to make PPI collaboration more sustainable in practice? Working together we identified key operational bottlenecks that charities experience in relation to PPI and research. We then co-created two tools to address these issues. These tools have been implemented across a range of charities to help streamline their PPI processes and alleviate the added burden they experienced due to the increase in demand related to PPI in research.
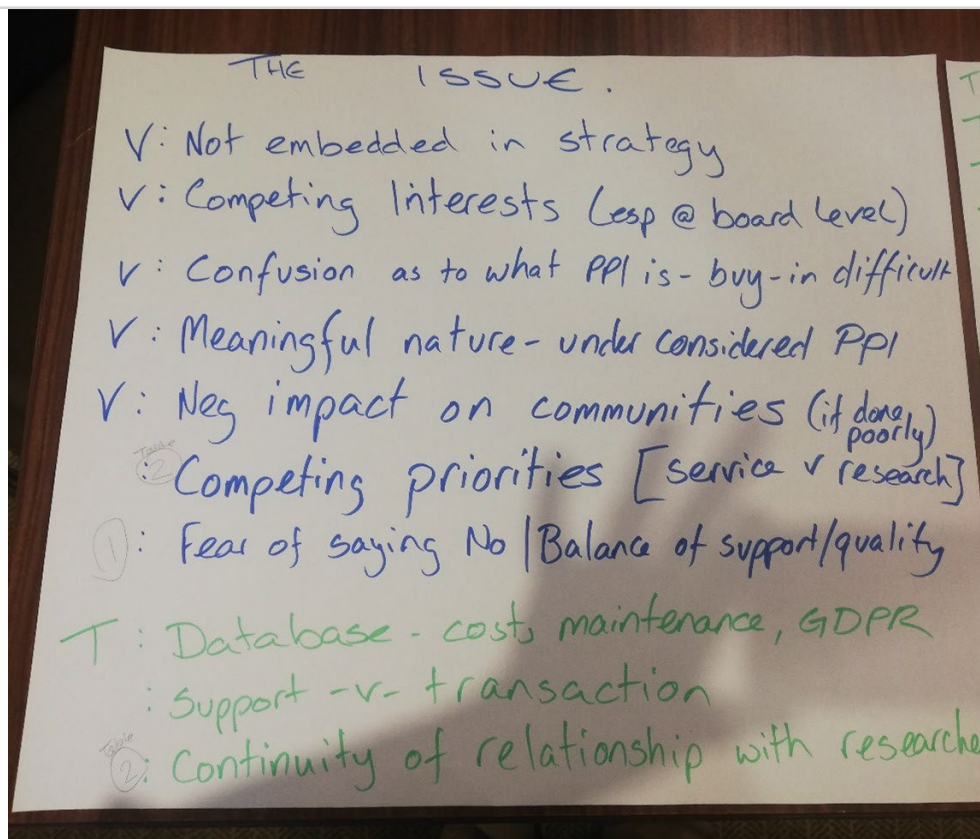
Our work

In 2022, the PPI Ignite Network @ UCD ran a seed funding scheme that prioritized applications made in collaboration with our local charity partners. Intended to assist our local partners in advancing in their research needs; in actuality, it resulted in researchers contacting our local partners, where their respective priorities did not align. This led to unintended burden on the charities and began the discussion of how to address some of the issues they face.

We held a workshop specifically for charities or community-based organisations active with PPI in research. Academics and other sectors were excluded from this phase. At the workshop, we teased out what issues arise, how universal they are, what actors are best placed to create solutions, and how feasible it was to address the identified issues within our current timeframe and budget.

After the workshop, we reflected on the priorities identified and considered potential solutions. These were presented to the charity partners and short life working groups were developed to co-create the solutions to ensure the tools were as usable and adaptable as possible for the diverse Community-Based Organisations (CBO) and charity sector.

Some of the value–based (v) and technical (t) issues in relation to PPI identified by charities at the workshop

Our impact

This case study demonstrates the benefits of the Network. Trying innovative approaches can highlight unintended consequences. The Network format allows flexibility and multi–sector collaboration to address issues experienced outside of academia for the betterment of the PPI ecosystem as a whole. We targeted the charities active in PPI as the primary audience for dissemination of this work. The tools were launched during the National PPI Festival 2023. They were also presented to the Irish PPI Shared Learning Group hosted by Health Research Charities Ireland, and to the UK Charities Research Involvement Group in 2024, reaching more than 100 charities with an interest in PPI.

Reducing operational burden for more sustained partnerships

The PPI Connect Decision tool was designed to help voluntary organisations and community–based organisations handle PPI–related requests from researchers for connections or introductions to their communities. The Decision Tool was developed to aid organisations to prioritise which approaches from researchers are most likely to be mutually beneficial. The Decision Tool has more than 370 downloads and has been implemented across a variety of organisations.

Managing mismatched expectations

The Expectations of Engagement template was developed in response to the identified challenge of mismatched expectations between researchers and voluntary and community–based organisations. This

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capacity for PPI within charities is crucial for ensuring that it becomes a sustainable and integrated approach to research. Investing in resources and long-term strategies with charities should ultimately lead to more impactful and sustainable PPI in research collaborations.

"I did use both [PPI Connect Decision Tool and Expectations of Engagement Template] and developed our own procedure around the decision making and we used the Expectations of Engagement template and amended accordingly for each project. Thank you so much for these as I found them invaluable, saved considerable amount of time, are very informative."

Christina Donnelly, Executive Director, Chronic Pain Ireland

template was codeveloped with charities and community-based organisations to clearly outline what can be expected from the organisation, and what the organisation expects from the researchers who approach them with requests related to PPI. The expectations of engagement for different voluntary and community-based organisations will differ. Each organisation can develop and adapt the format and content according to their needs and context. The template has been downloaded approximately 300 times and is actively being used by charities in a range of research projects.
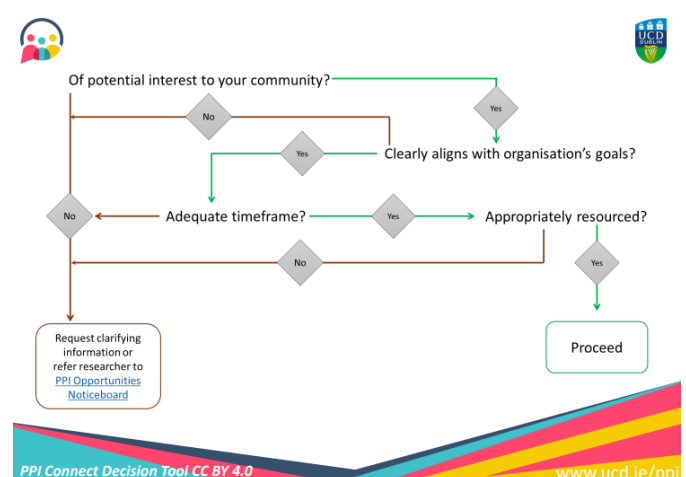
Knowledge Sharing

In addition to the new tools we developed, two organisations shared their application processes via the PPI Ignite Network @ UCD to allow other charities to see, amend and adapt those processes for their own needs.

In conclusion, charities face a risk of burnout as PPI in research grows. Building

Charity representatives from across the PPI Ignite Network and beyond working together to identify some of the capacity issues they face in relation to PPI in academic research

PPI Connect Decision Tool to help charities filter requests from researchers

www.ppinetwork.ie

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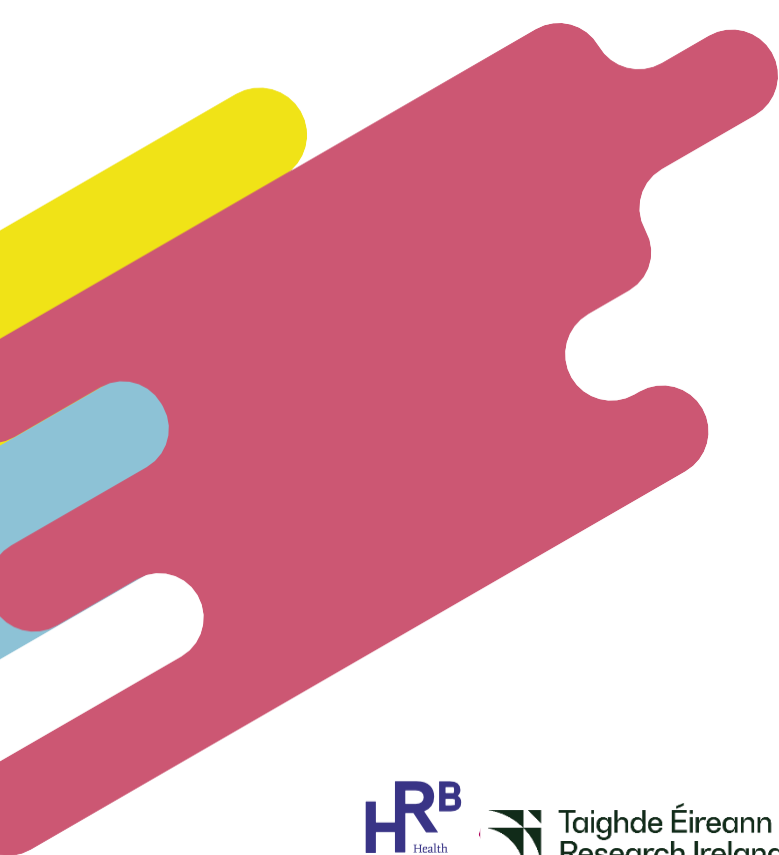"I believe this template provides them [researchers] with a clear understanding of our expectations when engaging with our community. If any issues arise during their engagement with members of our PPI group, I can refer to this document to ensure that the outlined expectations were considered appropriately."

Dympna Molloy, Muscular Dystrophy Ireland

"We use the PPI decision tree at TENI. Overall, the PPI Ignite Network @ UCD has been really useful to a) find out how other CSOs interact with researchers, b) build the skills to assess research projects, and c) be confident engaging with projects that benefit our community or align with our values and priorities."

Daire Dempsey, Transgender Equality Network of Ireland (TENI)

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