

IMPACT CASE STUDY





Seeding change: Using seed funding competitions to shift power dynamics in PPI relationships

Who was involved?

- 1 Lead Site
- 1 National Partner
- 1 International Patient Foundation
- 8 Local Partners
- 7 Charity/community based organisations partners

Summary

How do we address power imbalance in PPI: researcher relationships? And how can we promote more inclusive PPI practices supportive of people with specific needs and marginalised groups in society?

PPI Ignite Network @ UCD used their PPI Seed Funding scheme (2022) to test ways to address these issues. A relatively small investment of €16,000 has resulted in expansion and positive changes in procedure towards PPI beyond academia. This was enabled by communicating beyond the typical research community, explicitly promoting PPI leadership without prescribing it, and developing local procedures that facilitated awarding of funding directly to PPI partners.

Our work

Seed funding applications had to be joint applications between UCD staff/ research students and PPI contributors. The specific theme was equality of opportunity for PPI in research. The project had to fit the theme, it did not have to be a research project, but did need to have an achievable deliverable.

We stated up front that (VAT-registered) PPI contributors could be the budget holder. We specifically stated that PPI contributors could lead the project. Criteria included all members of the collaboration having a specific remit, and this was one of the five scored categories.

We advertised the competition internally at UCD, but also via the Wheel, the representative network for the community and voluntary sector in Ireland. The intent was to encourage the community and voluntary sector to get in contact with UCD researchers, in addition to the usual vice-versa contact initiated by researchers.

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To help with the initial relationship building and introductions between interested parties from research and the community, we held an "Eat & Greet". This was designed to be a space to develop relationships with potential collaborators. To give time to develop the relationships, we had the competition open for 8 weeks post-launch.

To review the applications, we had two external assessors, one from an umbrella organisation for health research charities and one international patient expert partner (from EUPATI). From UCD, the assessors were the programme manager for PPI Ignite Network @ UCD, a research impact expert and the senior manager of research programmes at UCD. These were specifically asked to be assessors in order to use the process for knowledge translation; for example, the PPI Ignite Network @ UCD team learned more about proposal review and the research programmes team learned more about PPI.

Our impact

"Using experts with experience adds more weight behind the findings that will come out of the report. Perhaps one of the main advantages is it gives them [experts by experience experiencing homelessness] an opportunity to develop a number of skills throughout the duration of the project."

Trina Harpur, Dundalk Simon Community

The projects were funded for 12 months and will not reach completion until September 2023. Many impacts are to be realised, however, even in the short term there is already evidence of impact from the approach taken.

Of the sixteen applications, 25% had a PPI contributor lead. However, of the four successful awardees, 75% had a PPI contributor lead. Thus, three of the four awardees had the funding awarded directly to the PPI partner. As budget holder the ultimate decision making as to the allocation of that budget and the direction of the research is in the hands of the PPI partner.

This has led to development of PPI processes at some of the awardee sites. For example, one of the projects focuses on co-production of PPI resources for the involvement of people with intellectual disability. The remuneration of the co-designers, who have intellectual disabilities, needed a process implemented first as many did not have an existing bank account or perhaps hadn't experienced payment. This process, and the lessons learned from the experience of doing it, will be part of the recommendations produced by this project. This was unforeseen, but the PPI contributor leading the project had the expertise and support to overcome this challenge and develop a sharable process that others in the research community can learn from.

Another example of an impact is a change in approach to PPI within a charity. Previously, although their community had been involved in research this was typically on an ad hoc basis. The seed funding has aligned the charity closer with the PPI Ignite Network. They are using the seed funding opportunity to pilot a formal reporting and assessment channel to their Board on the involvement practices in their research. If the pilot is successful, they plan on expanding this to all involvement practices in research and beyond.

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"Between attending the PPI symposium [in UCD as part of the PPI Festival] and being awarded the seed funding we actually stopped for a moment to consider that question about what we want in our research long term. We don't necessarily capture or highlight the impact of involving our service users in research to our Board. But this has really given us the impetus to start to change that."

PPI contributor (seed funding awardee)

The UCD led- project collaborators were first introduced at the Eat and Greet session. These collaborators have clear mutual benefits from this new relationship. Acquired Brain Injury Ireland have extensive experience with this patient cohort and their needs, the UCD Irish Critical Care-Clinical Trials Network team have expertise in establishing and developing PPI relationships for research. Less than 12 months into the project, the collaboration has exceeded its intended reach for the PPI group and expanded to include people from all across Ireland.

These early impacts on procedural change and community reach demonstrate how small changes in our research processes like seed funding competitions can have positive impacts on partnership building.





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