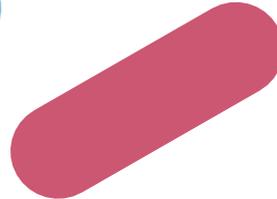




**PPI** IGNITE  
NETWORK

# IMPACT CASE STUDY



## Reaching beyond the Network to catalyse change

### Who was involved?

- PPI Ignite Network national office
- Seven PPI Ignite Network Lead Sites
- PPI Ignite Network national and local partners
- Patient and community organisations
- PPI contributors, patients and the public

### Summary

The PPI landscape in Ireland is changing rapidly. The PPI Ignite Network is at the core of a powerful network of networks that has developed across the research ecosystem and beyond. We are witnessing a changing culture, with lived experience increasingly valued, and the public and patients working in partnership with all other stakeholders more often, helping to improve research relevance and impact.

The labyrinth of connections and collaborations that have emerged from the PPI Ignite Network are driving culture change. Our training offerings, our events and Shared Learning Groups have welcomed attendees from all sectors and, as well as upskilling attendees, are mainstreaming the concept of PPI.

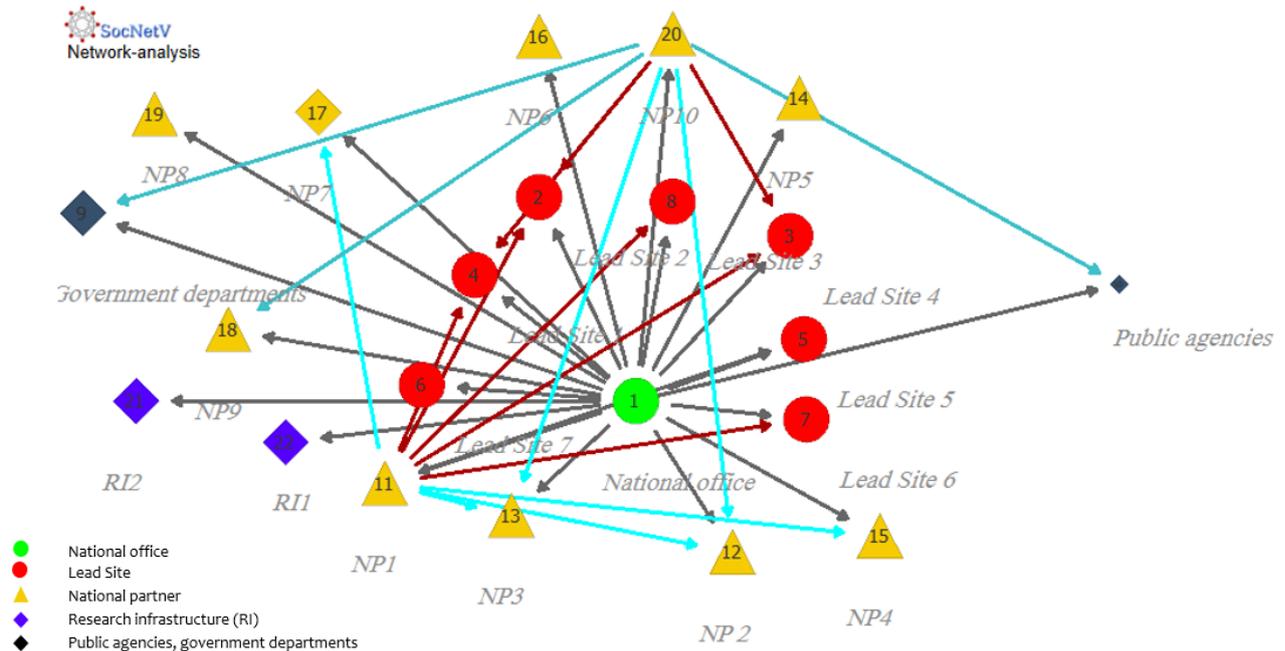
We delivered bespoke training to

organisations beyond the Network enabling them to develop their own PPI strategies; three of these organisations are set to join the next phase of the Network. Both our collaborative ethos and our conferences and events have provided networking opportunities. Cross-sector collaborations have developed innovative PPI resources and contributed in unanticipated ways to culture change. Our PhD and postdoc alumni, trained and experienced in working with people with lived experience, are affecting change in the organisations where they are now employed and linking back with the PPI Ignite Network, ensuring ongoing knowledge exchange.

### Our work

In addition to working with the PPI Ignite Network's 53 local and 10 national partners, we also work directly with public agencies, government departments, national research infrastructures, Higher Education Institutes (HEIs) beyond the Network, HSE staff and clinicians, charities, patient organisations, and patients and members of the public.

Network staff delivered bespoke PPI training to staff in public sector agencies, in start-up companies, in national research infrastructures and in HEIs that are not currently part of the PPI Ignite Network.



The network of networks emanating from the PPI Ignite Network is driving culture change in the national research ecosystem.

We provide ongoing advice and support to some organisations, as they introduce PPI approaches into their research and as they review and revise their own organizational policies and procedures to facilitate partnership working.

We promote a collaborative approach across the Network, with a focus on knowledge exchange and networking, for example, through our Shared Learning Groups and a myriad of online and in-person events, most of which are open to all and free of charge. The Network’s PPI Opportunities Noticeboard, the National PPI Festival, the resources shared on our online hub and our monthly newsletters all reach audiences far beyond the Network, influencing practice and igniting change.

Academics and postgraduate students from HEIs not involved in the Network attended our training events, joined our Shared Learning Groups and completed the Digital badge available from UCC. They sought advice through the Network’s general email [hello@ppinetwork.ie](mailto:hello@ppinetwork.ie) and used the PPI Opportunities Noticeboard as they began to embed PPI in their research.

Our national and local partners have opened doors that allow the Network to collaborate with other organisations in Ireland. Many new relationships have also emerged between various stakeholders who meet through the PPI Ignite Network.

## Our impact

We are impacting the research ecosystem in many different arenas across Ireland.

### Mainstreaming PPI in national discourse

Attendees at our training and events, particularly those from the public sector and patient and community organisations, are now contributing to sector-wide discussions on public and patient involvement and citizen engagement, influencing the national discourse. We have seen a similar impact within the academic research community.

### Influencing public sector agencies

We delivered bespoke PPI training to public sector agencies; these are now working to embed PPI approaches in their work. Two of these agencies are set to join the next phase of the PPI Ignite Network. For example, having delivered PPI training to the



*“We recognise the importance of working collaboratively with patients and members of the public, it is an integral part of our practices. The training provided by the PPI Ignite Network expanded our skills and knowledge in this space to further enhance the quality and depth of this involvement. We are grateful to the facilitators and the public representative [who co-delivered the training] for providing a very informative programme that was tailored to our needs.”*

**Dr Barbara Foley, Deputy Director, Health Information Quality & Assurance, HIQA**

HealthData@IE team at the Health Information and Quality Authority (HIQA), that team then established a PPI group and used the Network’s PPI Opportunities Noticeboard to help find public members.



**Attendees at one of HealthData@IE PPI workshops**

## **Impacting academic research beyond the Network**

Where we delivered bespoke training on embedding PPI across an organization, we have seen direct impact. For example, one HEI where we delivered this training will join the next phase of the Network and in the RCSI/Beaumont Clinical Research Facility, changes were made in staff recruitment, embedding PPI in a job description.

## **New collaborations making a difference**

Many of our local and national partners are now collaborating with each other and, equally importantly, are collaborating with other stakeholders in the broader research ecosystem, working to change the research culture ([read an example from one national partner here](#)).

One such wide-reaching collaboration led by national partner IPPOSI, involving the PPI Ignite Network, individual PPI contributors, and several patient organisations, resulted in [a significant change in social protection guidelines](#) removing a longstanding barrier to involvement in research for invalidity pension claimants.

## **Influencing health services**

Connections between Network Universities, clinical trial units, clinical research centres and teaching hospitals are strong, and clinical staff trained in PPI are introducing PPI on the ground within hospital settings. For example, there are PPI groups connected to intensive care units in two teaching hospitals.

Network staff have contributed to several HSE-lead partnership initiatives, are playing a leadership role in the development of PPI in national disease registries and have engaged in knowledge exchange with, for example, staff in the HSE Patient and Service User Engagement and some hospital-based Patient Councils. These activities are supporting a growth in patient partnership within the HSE organization.



*“Over the years, like-minded colleagues and I in the social sciences were trying to mainstream participatory research and build an understanding that participatory research meant active involvement in the research process and was distinct from qualitative research. The emergence of the PPI Ignite Network significantly accelerated this effort, generating a greater understanding of this work, building researchers capacity, and achieving greater.”*

**Dr. Danielle Kennan, UNESCO Child and Family Research Centre, University of Galway**

*“Having attended a PPI Ignite Network workshop on **Developing PPI in a Clinical Research Infrastructure**, I realised that developing PPI in our Clinical Research Centre (CRC) was not, at that point, the responsibility of any staff member. In our next recruitment campaign, for the senior role of Director of Research Nurse Education, senior management agreed that we would include responsibility for PPI in the job specification.*

*Since that time the CRC has developed its Governance Board to include two PPI representatives and we established the RCSI CRC PPI partnership committee. We aim to continue the development of PPI initiatives in the centre in the years ahead.”*

**Dr Fionnuala Keane, RCSI/Beaumont Clinical Research Facility**

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