PPI IGNITE NETWORK

IMPACT CASE STUDY

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Influencing international thinking & practice

Who was involved?

- **Seven lead sites**
- **National partners**
- **Local partners**
- **PPI contributors**
- **PhD students and researchers**

Summary

The PPI Ignite Network is now recognised as a trusted, collaborative and innovative organisation, fostering the bottom-up development of diverse approaches supporting meaningful involvement. The Network's impact internationally is greater than the sum of its collective parts, delivering impact through many different channels.

Our Network model is inspiring others to replicate the key elements contributing to our success. International observers are commenting positively on the distinctive bottom-up approach we are taking to embedding PPI across the ecosystem. We are championing PPI in specific domains internationally, while expanding the breadth and depth of involvement in other domains. **Through strategic appointments**, we are influencing international practice. Through our **academic outputs**, we are **adding to the PPI evidence base**.

Our work

The commitment to PPI outlined in the Health Research Board (HRB) strategy is brough to life with the establishment of a national Network, funded by two major national health research funders, the HRB and Taighde Éireann – Research Ireland, with co-funding from the seven Universities at the centre of the PPI Ignite Network.

The structure, governance, Values and Principles, and key activities of the PPI Ignite Network are well documented elsewhere. Our Network newsletter, online hub and other communication channels open up our events and resources to all audiences internationally. Our national and local partners, our PPI contributors and our patient advocates also share the PPI Ignite Network story with international contacts.

Our Shared Learning Groups (SLGs), our national PPI Festival events, our conferences and seminars welcome international attendees and invite international contributors. We have prioritised delivery of PPI education and training to postgraduate students, aiming to embed PPI approaches in the research leaders of the future. We welcome all approaches to PPI, we do not prescribe specific approaches and we encourage innovation and exploration in pursuit of meaningful partnerships.

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> “Through my involvement with the PPI Ignite Network, I have built my personal capacity to now influence and collaborate with projects internationally and to share, with confidence, my knowledge of good PPI practices, impacting how researchers communicate with PPI contributors. PPI is now being regarded as a fundamental element of the research process in these organisations.”

Carmel Geoghegan, PPI Ignite Network Public Advisory Board member

Many network team members are involved in research networks in specific domains, demonstrating by example meaningful involvement approaches, for example, in diabetes, aphasia, dementia and pre-clinical, lab-based research.

Core Network members are involved in the governance of over 25 international organisations, have presented at close to 100 international events since 2021 and have been appointed to several strategic roles internationally. These include sitting on international funding decision-making panels, leading PPI-related reviews of research infrastructures, and acting as editors of leading academic journals focused on involvement and as advisors to organisations of worldwide renowned.

Since 2021, Network members have over 100 publications in peer-reviewed journals, almost half of which involve international co-authors from 25 different countries and 15% of which are in the 10% most cited publications worldwide.

Our impact

Our Network model inspires others

Researchers, research funders, and patient co-researchers internationally are asking us to share the key ingredients for success with them, to help them to change their own research cultures, locally, regionally and nationally. The thought-leadership of the HRB and funding from the leading research funders in Ireland is sparking discussions in other countries.

We collaborated on a funding application *PPI Ignites Us*, initiated by a patient researcher in Sweden, to establish networks based on the PPI Ignite Network model, in both Sweden and Denmark. The Danish Diabetes and Endocrine Association (DDEA), the leading funder of diabetes research in Denmark, has established a Public Advisory group to help develop PPI across their research and a public reviewer process for their funding applications, drawing heavily on visits to Ireland and discussions with Network members.

The DDEA is organising a 2-day training course in PPI for PhD scholars in Denmark, with Network members travelling to deliver some of the sessions

Members of International Collaboration of Aphasia Triallists conducting a PPI workshop in Denmark

Encouraging diversity in PPI approaches

International leaders in patient involvement comment on the distinctive approach of the Network, nurturing and encouraging diverse PPI approaches, rather than prescribing a specific approach or developing strict protocols defining involvement. The Network does not seek to define one answer or national guidance on every issue that arises, and instead encourages working in partnership, learning from each other, and accepting diversity as a strength.

One area of particular interest is the challenge of building connections between public and patients and research groups. We have received several queries on how the PPI Opportunities Noticeboard operates, including from Research Wales and research groups in Sweden, Finland, Canada and South America. Having shared the processes, the strengths and the weaknesses of our Noticeboard, some of these groups are now developing their own system to help public, patients and researchers to connect with each other for mutual benefit.

Championing PPI in specific domains

The National Lead of the PPI Ignite Network, Prof Sean Dinneen, has presented at several international fora on the D1Now study, a PPI exemplar of international renown, with young adults with Type 1 diabetes as research partners. In addition to inspiring the DDEA (example above), these presentations led to an invitation to organise a PPI workshop at the Diabetes UK Annual Conference aimed at highlighting PPI opportunities within a £50M philanthropic research programme, the Type 1 Diabetes Grand Challenge.

Network member Dr Ruth McMenamin, through her work as a member of the International Collaboration of Aphasia Trialists (whose members are drawn from over 40 countries) has lit the involvement flame among aphasia researchers worldwide. Initial PPI awareness-raising in 2019 led to the delivery of PPI training by PPI Ignite Network members to members and ultimately to the development of an online repository of aphasia-specific PPI resources to support the many aphasia researchers now embedding PPI in their research.

Members of our Public Advisory Board bring learnings from our Network to European organisations, helping them address patient involvement challenges, for example, in diabetes, dementia, and broader patient organisations.

Influencing international practice through strategic appointments

Strategic appointments of senior Network members to UK and EU initiatives, drawing on Irish experiences, are influencing strategy and practice across these entities. For example, Network members have been appointed to lead the PPIE review of a significant UK clinical research infrastructure, and to sit on an advisory group reviewing public involvement within a lead national research funder.

Influencing academic thinking and practice

The growth in publications by Network authors is adding significantly to the PPI evidence base, with an increased sphere of influence due to the number of international co-authors.

The newest SLG, focused on working with migrants and refugees, already has 70% international membership. The SLGs have opened the door to further collaborations, for example, a visiting professor from Brazil who is a regular attendee at the Facilitation Skills SLG introduced PPI and the PPI Ignite Network model to São Paulo University, at an event timed to be part of our national PPI Festival, and other colleagues at the University are now planning to visit to Ireland for Festival 2025.

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"A great advantage of the PPI Ignite Network's approach in Ireland is that it works firmly in partnership. Instead of searching for one answer to questions or how to do certain things, they are working in collaboration and learning from each other. And they welcome diverse approaches to meaningful involvement. I believe this is a healthy way of making PPI a normal part of the research ecosystem and a good example for other countries."

Hon Prof Derek Steward OBE, Patient Advocate

"I heard Prof Dinneen present on the impact of the PPI Ignite Network. I was delighted when he agreed to chair a PPI session at our Diabetes UK Professional Conference in February 2025. Our conference attracts thousands of health care professionals and researchers from across the UK. I wanted to ensure that the diabetes clinical community see the importance and impact of high-quality PPI work in enhancing research impact and implementation into clinical practice, specifically in relation to our Type 1 Diabetes Grand Challenge. We very much benefitted from Sean's expert steer and chairing of our session bringing an international perspective on meaningful involvement in all aspects of research."

Dr Elizabeth Robinson, Director of Research at Diabetes UK

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