PPI IGNITE NETWORK

IMPACT CASE STUDY

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Growing PPI in the lab: International recognition of Irish expertise in PPI in preclinical and laboratory-based research

Who was involved?

- 1 Lead Site
- 1 European Infrastructure
- 3 European Patient Groups
- 1 European Patient Engagement Platform
- 1 International Funding Agency
- 1 Local Partner
- 1 Not-for-profit UK public involvement organisation

Summary

The PPI Ignite Network is raising the visibility of PPI expertise at a European level. Throughout the last 18 months there has been significant international collaboration in the space of PPI in preclinical research. This includes collaboration or consultation with researchers and organisations from the USA, UK, Belgium, Spain, Portugal, Netherlands, France, Germany, Latvia, Croatia, Malta, Greece and Luxembourg. This has led to resources such as the European Patient Engagement Resource Centre (patientengagement.eu). The European Patient Engagement Resource Centre is linked to the PPI Ignite Network members and resources and is the second largest driver of traffic to the <u>PPI</u><u>Ignite Network @ UCD</u> website.

Our work

There is a significant gap in the application of PPI in research that is not traditionally public facing. UCD has <u>a history of PPI in basic and</u> <u>translational laboratory-based research</u>. The establishment of the PPI Ignite Network has raised the profile and visibility of this expertise, building the profile of Ireland as a leader in this area. This has led to an extended network of PPI, academic and SME relationships across Europe and beyond.

The gap between laboratory-based preclinical research and clinical research is often called "The Valley of Death of Biomedical Research." The disconnect between discovery driven fundamental laboratory research and highly applied clinical research is one of the reasons behind this delay in the research and innovation pipeline. Public and patient involvement has been proposed as a mechanism to streamline the translation of preclinical research into clinically applied settings.

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Dr Emma Dorris, programme manager, PPI Ignite Network @ UCD, running a session on "Building the value case: patient engagement in early discovery and translational research" at PEOF, Barcelona 2022.

Considering the recognition of the potential role PPI may have in bridging the gap, there is increasing recognition of the expertise in PPI in preclinical and laboratory-based disciplines at UCD. SciVal analysis of UCD health research publications between 2019-2022 identified an 84% growth in PPI collaborations over that period. PPI Ignite Network @ UCD have had a noticeable increase in the requests for external guidance, advice and collaboration related to PPI from international, particularly European, organisations

Our impact

The Medical Research Council (UK) is a leading funding agency for pre-clinical and laboratory-based research in the UK. MRC commissioned VOCAL to inform their <u>public</u> <u>involvement strategy</u>. The PPI Ignite Network @ UCD programme manager, who specialises in PPI in laboratory-based research, was the only international representative of their external advisory group. She gave a keynote at the <u>MRCs first public involvement in practice</u> <u>webinar</u>.

PPI Ignite Network @ UCD is part of the European Infrastructure for Translational Research (EATRIS)/European Patient Forum Taskforce: Patient Engagement in Academic Research. This work included co-designing an EU-wide online resource designed specifically for patient engagement in translational research (<u>www.patient-engagement</u>. <u>eu</u>). The work and the resources of the PPI Ignite Network are heavily referenced in this resource centre, increasing the visibility and recognition of the Network.

The Patient Engagement Open Forum is led by EUPATI, Patient Focused Medicines Development (PFMD) and EPF focused on co-creation of solutions and transformation of the culture of medicines development. PPI Ignite Network @ UCD were involved as <u>guest</u> <u>speakers</u> and <u>session leaders</u> for the "Lost in translation: patient engagement in early discovery and preclinical research" series 2022.

The <u>new partnership</u> between the PPI Ignite Network @ UCD and the European Patients' Academy on Therapeutic Innovation (EUPATI) offers exciting opportunities. EUPATI's educational resources have served more than 6.5 million people globally. The formal partnership agreement includes an agreed schedule of collaborative work.

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"This partnership agreement will help us to enhance collaboration between researchers and people with lived experiences, and to improve access to knowledge on medicines' research and development for interested patients and other stakeholders. We look forward to working with EUPATI to build on the important PPI work taking place at UCD and across Europe."

Professor Orla Feely (UCD President)

PPI Ignite Network has been invited to the <u>European Society of Human Genetics</u> annual conference (June, 2023) and the <u>European</u> <u>Pain Federation (2022)</u> to deliver sessions on PPI in research. These are the largest European conferences in these fields, with more than 4,000 and 2,500 delegates respectively.

The Learning Planet Institute (LPI) is a research institute in Paris that focuses on collaboration in pursuit of a sustainable and inclusive society. In April 2023, PPI Ignite Network @ UCD were invited as the only Irish representative to the LPI European knowledge brokerage for HEI engagement with the public. It brought together academic and public involvement leaders from eight European countries. PPI/ PE is also emerging in the area of One Health through UCD's connection with the UNA Europa. "We are delighted to embark on this collaboration with University College Dublin as we believe that academic research and innovation are the key driving forces to improved health outcomes for all. Patients have an important role to play in the development of new medicines and treatments and together we can advance further awareness of this as well as the required skills and capabilities for meaningful involvement for both patients and researchers." Maria Dutarte (Executive Director of EUPATI)





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