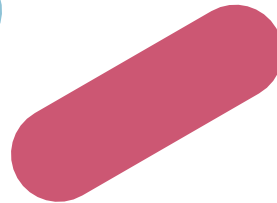




**PPI** IGNITE  
NETWORK

# IMPACT CASE STUDY



## Knowing me, knowing you: Collaborations within and beyond the Network influencing change

### Who was involved?

- Four national partners
- Two lead sites
- Two local partners
- PPI contributors on the Tusla REC
- Department of Children Equality Disability Integration and Youth (DCEDIY)

### Summary

Tusla is an active national partner in the PPI Ignite Network. Key impacts are:

- The development of a Policies Procedures Protocols and Guidances (PPPG) document to allow payment of public contributors on its Research Ethics Committee, offering a pathway for other public sector agencies to explore this challenging policy area.
- Co-development of a toolkit for working ethically with children and young people in research.
- Three national partners working together to co-develop and co-deliver an online research ethics course for

public and patients.

- Influenced by Tusla's guidance, a government department is embedding the voice of lived experience in a seminal piece of research.
- Tusla is a co-facilitator of the PPI Ignite Network Public Advisory Board, sharing expertise across the Network.

### Our work

Tusla developed *Guidance on Remuneration of Expert Committee Members*, building on previous work within the Network. This allows public contributors on Tusla's REC to be paid for time and expertise aligned with Tusla's financial regulations.

A toolkit to support researchers collaborating with children and young people (CYP) in research was co-developed by the PPI Ignite Network @ DCU, Tusla and Barretstown, a Network local partner. The toolkit drew on the insights of 55 people from within and beyond the Network, who gathered at a workshop in Barretstown Castle, Co Kildare.



Launch of Guide for Ethical Collaboration with Children and Young People at Barretstown Castle 30<sup>th</sup> Jan 2025. Left to right John Mitchell Barretstown, Prof Veronica Lambert DCU, Prof Suzanne Guerin UCD, Dr Harry Shier children's participation expert, Dr Roisin Farragher Policy analyst Tusla, Dr Edel Tierney and Marian Brattman Tusla National Research Office.

Led by national partner IPPOSI, two other national partners, Tusla and HSE R&D co-developed and co-delivered a new online course on research ethics for public and patients. The course included modules on research with CYP delivered by Dr Edel Tierney, and on PPI in RECs, delivered by Dr Virginia Minogue, Chair of the Tusla REC.

Deliberations and knowledge sharing is ongoing between Tusla and colleagues in DCEDIY on embedding the voice of those who are care experienced within the Care Experiences Programme ([Care Experiences: Journeys through the Irish care system](#)). In particular, guidance was provided on the development of the Programme's Care Experienced Expert Panel (CEEP).

Drawing on the process developed by Tusla to find public members for its Research Ethics Committee, the Network's PAB was set up in 2022 to bring the public voice to

the centre of the Network. Dr Edel Tierney from Tusla is co-facilitator of this Board.

## Our impact

Just as the work has been bi-directional and collaborative, so too have the impacts on the wider research eco-system.

### **A PPPG on payment of public contributors in a public sector agency**

Developing a *Guidance on Remuneration of Expert Committee Members* is significant. This is now operational across the Agency's approved committee structures. This is transformational in an area that has been contentious and difficult to solve but provides a way forward for other public sector organisations, Government departments as well as institutions and organisations to learn from and adapt for their own purposes. Within Tusla, we are sharing our knowledge about the process and



**“The workshop presenter on Children in research [Virginia] Minogue of Tusla whose presentation has truly remotivated my interest in child research and will be very much in my memory.”**

#### **Research Ethics Course participant**

aligning with HR and financial regulations. We are also sharing our knowledge within Network Universities, some of whom continue to refine their payment processes.

#### **Building capacity in PPI in research with children and young people**

The practical toolkit for researchers collaborating with children and young people in research projects will support and develop capacity for researchers wishing to engage children and young people as collaborators in research. The toolkit has been disseminated widely across the PPI Ignite Network and beyond including DCEDIY, Children’s Health Ireland, Empowering People in Care and will be presented at UL PPI summer school. Indeed, in the co-development of the toolkit the knowledge exchanged and expertise shared is influencing practice in organisations that were involved.

#### **Supporting PPI in Research Ethics Committees**

Led by IPPOSI, the delivery of a comprehensive, accessible research ethics online course was piloted in 2024. The online course was co-designed and co-developed with key stakeholders, including the National Office for Research Ethics Committees, patient partners and individual and educational contributors. The pilot course was a success, with high participant satisfaction and significant knowledge gains. 26 participants completed the course, from 12 counties. These individuals had varied patient and

public perspectives and included those with and without experience of PPI. The course empowered PPI representatives to contribute to ethical research practices in Ireland. The development of a sustainable partnership for future delivery is ongoing and plans are underway for future editions to be made publicly accessible via the HSE’s national online learning platform (HSeLanD) and incorporating feedback from participants to improve content, delivery and participant interaction. Furthermore, the Tusla REC uses its knowledge and lived experience of PPI in its reviews of applications and were able to recruit a public member to its REC as a result of the IPPOSI course.

#### **Spreading the word**

With DCEDIY colleagues, we have continued to support the Programme’s development of policies and procedures for the CEEP, in particular regarding the remuneration of its members, and their inclusion in the stakeholder advisory structure. The Care Experiences Programme also drew on the breadth of the Network for the recruitment of an independent coordinator to work with CEEP. We also highlighted the importance of a PPI approach for inclusion in the research specification for a cross-sectional research study.

Through the facilitation expertise we have shared our learning and skills set with PAB members learning from each other and building and enhancing trust around the table. This is mutual benefit as this PAB gives further visibility to Tusla’s work and promotes the voice of children and young people in the wider research ecosystem.



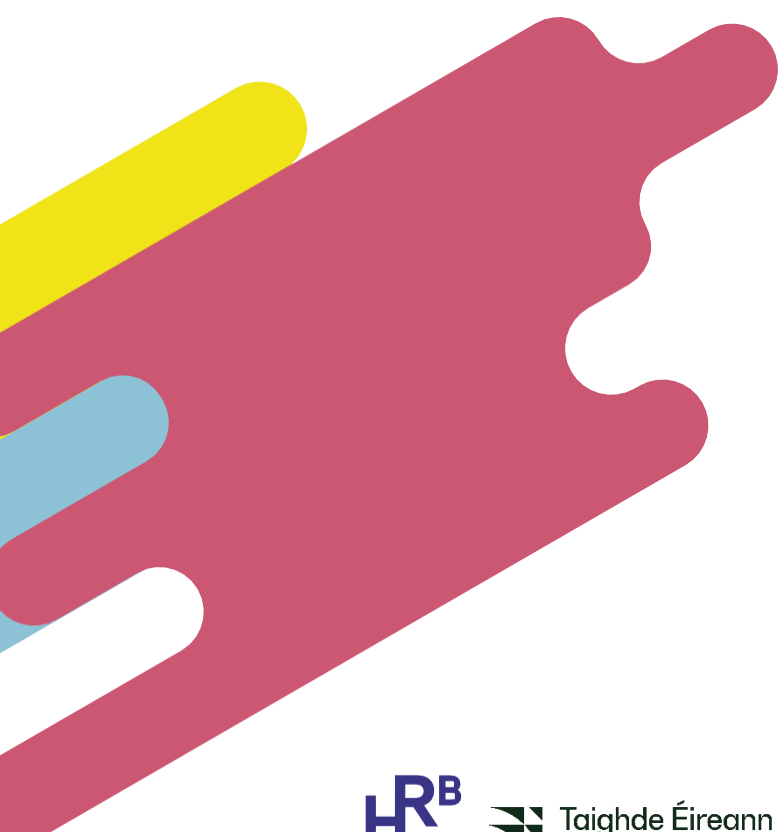
Having fun, trying out some icebreakers contained in the toolkit on the grounds of Barretstown Castle

# IMPACT CASE STUDY



“Working together with National Partners allows us to build Patient and Public Involvement (PPI) into every aspect of the research ecosystem. By collaborating we build capacity for PPI amongst researchers, patients and public members, and research ethics committees.”

**Dr Loes Knaapen, Research Ethics Training Coordinator at IPPOSI**



**Taighde Éireann  
Research Ireland**

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