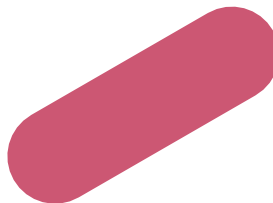




PPI IGNITE
NETWORK

IMPACT CASE STUDY



Embedding PPI into a Research Ethics Structure

Who was involved?

- **Tusla Child and Family Agency National Research Office**
- **PPI Ignite Network @ University of Galway (Formerly NUI Galway)**
- **PPI Ignite Network @ TCD**
- **PPI contributors from a Public Advisory Panel at University of Galway (HRB Primary Care Clinical Trials Network)**
- **Health Research Charities Ireland (HRCI)**
- **Other stake holders involved included the Chair of REC University of Galway, Community Knowledge Initiative, University of Galway, an academic from the Department of Social Work, University College Dublin**

Summary

Within Tusla's Research Strategy 2015–2017, an action was to develop an Independent Research Ethics Committee (REC) for the Agency. Working with the PPI Ignite Network, we consulted with PPI contributors to develop the best approach to recruit public members to our REC, successfully recruiting 16 members, five of which are Tusla staff and 11 of which are

Public contributors. These members influence the review and approval process for research conducted within Tusla, resulting in person-centred, ethical research and have influence how the REC operates. Other REC members have taken the learnings into their own environments, thus influencing the wider research landscape. Tusla has recently been central to developing the recruitment process for the Network's Public Advisory Board.

Our work

Tusla's founding legislation, the Child and Family Agency Act 2013, places a strong emphasis on partnership and co-operation with children and families in the delivery of services.

Tusla undertook to develop an independent Research Ethics Committee (REC) and involve members of the public and former service users as contributors on the Committee, to review and ethically approve research applications. A dedicated project team led by the National Research Office (NRO) was established with deliverables to consult and seek expertise in PPI to inform the best approach to the recruitment of public contributors on an independent REC. We worked with the PPI Ignite Network to shape



A 7 (e) Please provide details of where there has been patient and public involvement in the preparation and/or design of your application and/or provide details of proposed future public involvement in later stages of the programme. ⁷

The Irish Health Research Forum defines Public and patient involvement (PPI) in research as occurring when individuals meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge.

Provide information on the individuals/groups and the ways in which they will be involved in various stages of your study. If you feel that this is not applicable to your application, you must explain why.

[Click here to enter text.](#)

Definition of PPI in amended Tusla Standard Research Ethics Application.

this process, as well as expertise in the wider public and research community. Several distinct discussions took place initially and following this, a roundtable discussion was held at University of Galway in February 2020, facilitated by the NRO and the PPI Ignite Network Lead Sites. A guidance document was developed based on these discussions, reviewed by all roundtable attendees, and in 2021 a call for expressions of interest was issued.

The PPI contribution to the research ethics process has led to greater awareness of the importance of the lived experience in a research study: other REC members have brought this experience into their wider environments. The PPI contribution has also influenced the way in which the committee conducts its business.

The following testimonials from two TUSLA REC public contributors showcase the value of ethic review through a PPI lens:

“Involvement of the Public and Patient considerations in a REC will ensure that the many technical elements associated with research are aligned with the public needs and that the controls to ensure research is carried out in an ethical manner can be understood and explained to the public.”

Joe Murphy, REC Public Contributor



“In the context of the Tusla Independent REC, and, viewed through my lens as a PPI practitioner, I can see the strong growth in the understanding of what PPI is, why it is so important in health and social care research and why it has to be a key component that drives and supports the research question. There is a way to go yet, to ensure that all applicants and their supervisors understand why PPI is non-negotiable when it comes to health and social care research.”

Deirdre MacLoughlin, REC Public Contributor

The NRO and a public member of the REC joined a small Network working group and have strongly influenced the recruitment process for the Network’s Public Advisory Board.

Our impact

The consultation outlined above led to the following impacts:

- Development of a paper entitled ‘**Principles for involving PPI contributors on a Tusla Independent Research Ethics**’. The development of this paper allowed Tusla to develop its thinking and informed the approach to recruitment, selection and practices of the REC. This defined not only the Tusla REC

recruitment process, which concluded with the establishment of the REC in June 2021 but has already strongly influenced the process for the Network’s Public Advisory Board.

- **The induction training programme** for all REC members was informed by the consultation process.
- The consultation also resulted in the development of a **clear disclosure protocol** within the Standard Operating Procedure for any REC member to identify when an application may be problematic for them (e.g., conflict of interest, subject too personal) so that they can exclude themselves from review of that application.
- **A distress protocol** was also developed as a ‘safety net’ of support in place for all REC members. **Engagement with the Tusla Psychology Committee was conducted** to develop the protocol and ensure that appropriate structures are in place to support the REC.
- The recruitment approach also supported the **development of a culture of inclusion and respect in REC activity**. This culture means including people with lived experience of Tusla services, and members of the general public, in REC meetings.
- Following the establishment of the independent REC Tusla NRO were invited to present at a **DCU Seminar Series: PPI in research with children and young people in June 2021 to share their experiences**. The seminar was attended by 89 people, approximately one third were from patient and community organisations and NGOs and the remainder from academia.

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“Involvement of PPI as part of the REC is very valuable as it encourages the researcher to evaluate the relationship that the research study has with the public. It requires that the objective of the research is understandable to the general public and requires that the public have an involvement throughout the lifecycle of the project.”

Joe Murphy, REC Public Contributor

“We work collaboratively, reviewing applications in small groups before merging into one larger group for discussion. Working in this way gives everyone an opportunity to participate fully and to share our varied expertise and the public is well represented. I feel that this has influenced my own research and my approach to teaching research methods has been enhanced by what I have learned about PPI.”

Dr Patricia Kennedy, Independent REC Chair

- We have drawn on this experience to **embed and inform wider PPI opportunities in Tusla**, e.g., engagement with the Department of Children, Equality, Disability, Integration and Youth (DCEDIY), presentation to Tusla Research Advisory Group. We with this to be a springboard for wider engagement on PPI in Tusla Research.
- Public contributors on the REC now **have a guiding voice in shaping the research** in Tusla in the context of the ethical review of research applications. Effective involvement by public members on a REC supports ethically approved research which **reflects the needs of people availing of Tusla services**, thereby helping to ensure that our work has impact.
- Tusla is working with DCEDIY on the plan for the forthcoming **research and data project examining the lives of children in care and adults who were in care as children**, including advertising on research ethics processes for the study and

Evidence of the impact outlined above includes:

- **Amended Tusla Standard Research Ethics Application** form which specifically asks researchers to consider how they plan for PPI activity in their research project. If this is not applicable, they must explain why. This question is leading **researchers to reflect on whether PPI** is a possibility for them in their research design and methodology. The application which is subject to ongoing review by REC members, was amended to include a definition of PPI.
- Tusla’s NRO has delivered two **research ethics workshops** to university students and supervisors in this reporting period (November and December), including advising on this additional question, which was attended by approximately 14 people.



- The Standard Operating Procedures (SOP) of the REC were also amended following the involvement of PPI contributors on the REC. The SOPs were agreed in principle in 2019 and approved in full in 2021. Significant amendments included a new definition of Public Contributor and use of this term throughout; inclusion of a distress protocol for all REC members (arising out of the consultation noted above); and inclusion of at least one Public Contributor on the REC decision appeals committee.
- A REC transition group has been established between the NRO and the independent REC to support the move to an independent REC. NRO provide training and resources as appropriate. Shared learning was initiated within the REC when two Public contributors presented to the committee on PPI in research on October 6th 2021 (see figure 2). One action underway is to **develop a shared learning forum on PPI** and what this means in the context of the research programme of NRO and the work of the independent REC and the interdependencies between them.
- Tusla has partnered with the PPI Ignite Network to co-lead on the development of the call for expressions of interest for its Public Advisory Board and its approach to 'recruitment' drawing on its experience with the REC (see [call details here](#))

