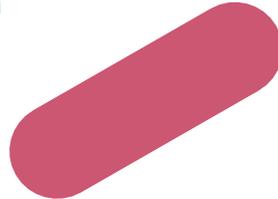
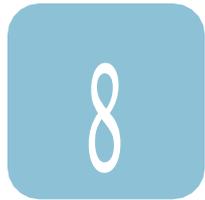




PPI IGNITE
NETWORK

IMPACT CASE STUDY



A global critical care PPIE programme

Who was involved?

- Irish Critical Care-Clinical Trials Network, UCD
- Global Critical Care PPI Group
- Irish Critical Care PPI Group
- PPIE partners and coordinators from Pakistan, Australia, Canada, UK and Japan
- PPIE working groups from three adaptive platform trials and the International Forum for Acute Care Trialists (InFACT)

Summary

A global federated Patient and Public Involvement and Engagement (PPIE) programme was established to ensure the patient voice of critical care informs our trials, particularly adaptive platform trials with complex designs. A supportive network was formed with PPIE groups in Ireland/UK, Pakistan, Australia, Canada and engagement activities in Japan.

The first ever global critical care patient and public advisory (PPI) group was established, federated across three of the largest adaptive platform trials; REMAP-CAP, PANTHER and PRACTICAL. 4 PPI partners now represent the patient voice on International Trial Steering Committees. PPI partners have informed trial design,

acceptability of conduct and interventions, processes including consent, patient-facing materials and outcomes. They have co-authored research understanding patient and public perspectives of critical care trials and are co-applicants on significant funding. PPI partners are shifting the mindset of critical care global leaders through open two-way partnership.

Our work

A global federated critical care PPIE programme was developed between 2020–2025, led by Leanne Hays and Alistair Nichol, on behalf of the Irish Critical Care–Clinical Trials Network, UCD. The Irish Critical Care–PPI Group (ICC–PPI) was established in 2019/2020 and with Australian and Canadian partners informed the REMAP–CAP platform trial testing treatments for pneumonia, particularly COVID–19 during the pandemic.

PPIE working groups for shared learning and support were established in REMAP–CAP (2021), PANTHER (a platform trial testing precision medicine in critical care, 2022) and PRACTICAL (tests treatments for respiratory failure) with four key objectives:



Attendees at the workshop in Barretstown share their knowledge and experience about the ethical involvement of children and young people.

- Involve patients and the public through establishment of national PPI groups and a global PPI group
- Inform trial design, conduct and governance
- Engage the broader public and improve dissemination
- Conduct empiric research to improve trials for future patients and families.

National PPI groups were established in Ireland/UK, Australia, Pakistan and Canada. Members of these groups joined the first Global Critical Care PPI group, federated across the 3 large platform trials. 10 members with lived experience of critical illness as patients, trial participants, their family who often provided consent to a trial and members of the public from Ireland, UK, Pakistan, Australia and Canada meet bi-monthly to inform trials. With national groups, they have impacted new platform design,

conduct and processes of ongoing platforms and primary and secondary outcomes; co-developed videos, reviewed patient-facing materials and results summaries; participated in media articles and funding applications and are co-authors on research. 4 partners are involved in a project developing consensus guidance on phase II respiratory critical care trials.

Our impact

PPI embedded globally in Critical Care trials

We have developed a global programme for PPI in Critical Care. It is an early example of federation where trials work together on a common goal. This includes developing supportive and shared learning working groups for coordinators and investigators interested in PPI with 4 national PPI groups. The bi-monthly meetings of the global PPI group ensure there is a PPI equivalent to the global committees that guide international trials. Almost all new treatments and funding proposals are now presented to the global PPI group prior to further development.



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RESPIRATORY HEALTH 2024

PPI, adaptive trials and precision therapeutics changing the face of lung failure management



Prof Alistair Nichol
Director, Irish Critical Care-Clinical Trials Network, University College Dublin

Dr Leanne Hays
Respiratory and PPI Programme Manager, Irish Critical Care-Clinical Trials Network

PPI partners are helping improve trial dissemination

Sharing PPI knowledge globally, impacting trial design and conduct

The PPI partnership ensures transparency between researchers and the public and has enabled input and impact. To date, PPI partners have reviewed 5 platform trials, informing the design of 2 precision medicine platforms, and 15 intervention domains to ensure they answer questions that are important and acceptable to patients, with appropriate processes.

They are informing how we approach consent, which is complex in the ICU as patients often lack capacity and there is a short timeframe to provide a treatment. A family member or friend is often initially approached during this stressful time. PPI members now sit on trial governance committees to represent the patient public voice in decision-making.

PPI partners have supported the development of patient-facing materials including consent forms and lay summaries, 4 co-developed videos including trial explainers and a consent training video for research staff.

Improving trial dissemination

PPI partners will guide dissemination of trial information globally. They have helped develop 9 trial results summaries, 2 strategies and 2 media articles. Members have attended and presented at conference/meetings and co-led working groups.

Shifting global Critical Care

PPI has huge value where only those with lived experience can fully understand a disease and its recovery, providing essential insights at every meeting. This programme has been presented at national and international conferences including the ANZICS-CTG meeting, Collaborative Clinical Trials Prato, InFACT ISARIC Capacity-Building meeting in Kigali, Rwanda and an invited session at the European Respiratory Society conference. Team members now provide support and advice to investigators establishing PPI in their research across disease areas and abroad.

Research with PPI partners

Research has included 3 co-authored projects including a statistical analysis plan, PPI and Equality, Diversity and Inclusion Strategies and a global public survey of >9,700 members of the public (Hays et al., under review). This survey assessed opinions of pandemic and non-pandemic ICU trials in 13 countries including 850 respondents in Ireland and included countries (Ghana, India, Japan and Pakistan) where public views had not been previously assessed.

Impacting new research

PPI partners have been co-applicants and collaborators on significant funding applications and have informed trial primary and secondary outcomes in three trials at the pre-funding stage. More than €15M platform trial funding has been awarded.

IMPACT CASE STUDY



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“Patient partner input and integration is now recognized as crucial in all aspects of clinical trial conduct in the ICU.

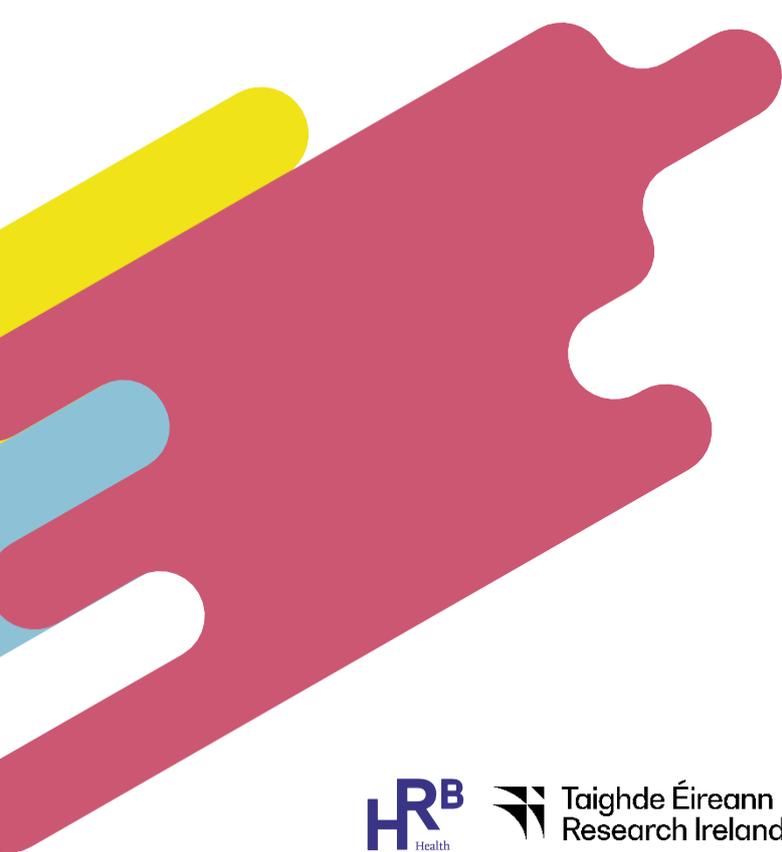
The Irish PPI group have established a world class PPI team that provides thoughtful, informative, engaged, and collaborative patient leadership to major ICU trial platforms around the world. They have elevated trials for everyone and through this have improved quality of care for patients around the world.”

Feedback from an international platform trial lead

“It was such a help to have a group of patients and public representatives who were motivated, enthusiastic, and keen to deliver research for the benefit of others, but who also understood how to contribute in a meaningful way and were not afraid to voice opinions.

It’s very obvious that the relationship is one of real partnership and that is invaluable”

A researcher setting up a new international Platform Trial



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