

Public Patient Involvement – How NUI Galway is shaping the new normal in research

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The voice of the public and patients led the way at the sixth National Public and Patient Involvement in Research Conference at NUI Galway on April 28th, showing how the lived experience of patients and the public voice is increasingly helping to shape health research and ultimately, the healthcare delivered to patients.

Held online, members of the public, patients, carers, and the research community all attended the event.

Public and Patient Involvement (PPI) in research means that the people who are likely to be affected by the results of the research are directly involved in, and shape, the decisions made in planning and conducting the research and in interpreting and communicating the research results.

The theme for this year's conference was PPI: Creating the New Normal in Research. It allowed the patients and the researchers and others to celebrate the increasing integration of PPI into academic and clinical studies in recent years, showcasing examples of how it is carried out "with" and "by" patients and the public, rather than "to", or "for", or "about" them.

Carmel Geoghegan, opened the conference and drew on her own experiences as both a carer for her mother who had dementia, as well as being a patient.

"It makes perfect sense to have the real experts - the lived experience, those living with the diagnosis, those experiencing it first-hand - to be involved in the different aspects of research being at the table from the beginning, having input and an equal voice," Ms Geoghegan told the conference.

Embedded Patient Researcher Robert Joyce gave a powerful keynote address, sharing his experience of bringing 28 years of lived experience of secondary progressive Multiple Sclerosis to bear on a feasibility trial for people living with MS.

Mr Joyce is the first person to be employed in NUI Galway in a PPI role on the research team. His interviews on local and national radio stations had a direct impact on recruitment into the study and

his telephone contact with people living with MS encouraged participants to remain in the trial when intervention delivery moved online due to the Covid-19 pandemic.

"In our trial because the patient is involved all the time in a true collaborative sense it actually saves us time, it saves us effort, and it saves us cost because we don't do something that isn't appropriate," Mr Joyce explained.

Professor Martin O'Halloran, of the Translational Medical Device Lab, NUI Galway, and Aoife Lowery, Consultant Surgeon, Galway University Hospital and Associate Professor at NUI Galway, focused on embedding PPI in medical device development in Ireland, giving examples of the positive changes in medical device development and patient outcomes they have witnessed first-hand when drawing on patient experiences during the device design phase.

This included the Intellablate device for a non-surgical alternative for lung cancer patients and the Luminate Medical headset to prevent hair loss among patients undergoing chemotherapy.

Dr Nana Folmann Hempler, a researcher at the world-renowned Steno Diabetes Center in Copenhagen, described a study that aims to co-design and test an intervention aiming to improve access to and utilisation of healthcare and preventive services for people with multimorbidity living on the Danish Island of Bornholm.

The conference also heard from a member of the Bornholm community in the Baltic Sea, Carl Erik le Sage de Fontenay. He gave examples of the impact the community have had on designing the intervention, drawing on their knowledge of both living with multi-morbidity and of the logistics and geography of the local area.

The presentations and discussions also highlighted the work that remains to be done to ensure PPI is embedded meaningfully in all health and social care research.

This was conveyed in particular during the PPI panel discussion when individuals working with researchers discussed their experiences and emphasised the importance of a level playing field, remuneration, being part of the decision making and using language everyone can understand to enable meaningful engagement.

A shared voice for the further development and mainstreaming of PPI in research across Ireland is coming together under the newly-established PPI Ignite Network, funded by the Health Research Board and the Irish Research Council and led by Professor Sean Dinneen, Consultant Endocrinologist at Galway University Hospital.

Reflecting on the conference, Professor Dinneen said: "Meaningful involvement of the public and patients in health research, in co-designing our health services, is becoming a feature of the Irish and international research landscape.

"It is heartening to see how clinicians, health policy decision makers and those funding health research increasingly seek out evidence that the patient voice has impacted research findings, that those likely to be impacted by the

research outcomes are involved in shaping the research that generates these findings."

The increased focus on partnering with public and patients in research studies is also evident elsewhere, with patient representatives involved with the National Screening Service, others appointed to the recently established National Research Ethics Committees and public reviewers increasingly involved in the research funding decision-making process.

Broad representation in PPI partnerships is important, and the PPI Ignite Network has a particular focus on developing practices to create an ethos of diversity and inclusion that supports marginalised groups in society to be heard.

The HRB Primary Care Clinical Trials Network Ireland and PPI Ignite Network @ NUI Galway co-hosted the conference.

To learn more about PPI visit the www.nuigalway/ppi and a recording of the conference is available at https://www.youtube.com/watch?v=3jaDwGL_xvM

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