

**The promise and peril of big data for health research in Ireland:  
Acting on the results of Palliative and End of Life Care in Ireland (PELCI) study**

**Monday 5 December 2022, Wynn's Hotel, 35-39 Lower Abbey Street, Dublin 1, D01 C9F8**

**Programme**

**9:15-9:45 Registration and networking opportunity**

**Session 1 Taking a research perspective**

**9:45-9:50 Welcome**

Chair - Dr Teresa Maguire, Director of Research Strategy and Funding, Health Research Board

**9:50-10:20 The PELCI study: key findings for research, policy and data**

Dr Peter May, Research Assistant Professor in Health Economics, Centre for Health Policy and Management, and The Irish Longitudinal Study on Ageing (TILDA), Trinity College Dublin

**10:20-10:40 Big data for research in Palliative Care: Challenges and opportunities**

Joanna Davies, Cicely Saunders Institute, Kings College London

**10:40-11:00 Q&A**

**11:00-11:20 Coffee break and networking opportunity**

**Session 2 A system perspective and the European Health Data Space**

**11:20-11:40 Overview of the European Health Data Space**

Dr Sarah Craig, Head of National Health Information Systems, Health Research Board

**11:40-12:00 Trusted Research Environments; benefits and perspectives from Northern Ireland**

Dr Frances Burns, Northern Ireland Trusted Research Environment (NITRE)

**12:00-12:10 Q&A**

**12:10-12:15 Comfort break**

**Session 3 Taking action**

**12:15-12:35 Better, Broader, Safer: Using Health Data for Research and Analysis**

Jessica Morley, Director of Policy, Bennett Institute for Applied Data Science, University of Oxford

**12:35-12:55 Q&A, and discussion on how to take issues/ideas highlighted forward**

**12:55-13:00 Event close**

Chair, Dr Teresa Maguire

**13:00-13:30 Light lunch and networking opportunity**



**Dr Teresa Maguire** joined the Health Research Board in 2002. Prior to this she worked as a researcher at St Vincent's University Hospital Dublin and as Scientific Director with a biopharmaceutical company.

Teresa was appointed as Director of Research Strategy and Funding in 2020 where she oversees an annual investment of approximately €50M in clinical research, population health research and health services research. In addition, she leads the development of policies, strategies and priorities to maximise the impact of the HRB investment in health research and to demonstrate the value of that impact to all stakeholders.

Prior to taking up her current role in the HRB, Teresa spent time on secondment in the Department of Health to support the establishment of a new Research Services & Policy Unit tasked with supporting evidence-informed decision making in the Department and advancing a broad-based research strategy for the health and social care system.

Teresa has a BSc in Pharmacology from University College Dublin, a PhD from the University of Dundee and a Master's in Business Practice from the Irish Management Institute.



**Dr Peter May** is a health economist at the Centre for Health Policy and Management, Trinity College Dublin and The Irish Longitudinal Study on Ageing. He is the principal investigator on PELCCI and two other studies estimating future population health needs, costs and policy options in palliative and end of life care. He also collaborates on palliative care projects in England, the United States, the European Union and elsewhere.



**Joanna Davies** is a social scientist with a background in using administrative data to measure inequality. She has recently completed her PhD on socioeconomic inequality in palliative and end of life care at the Cicely Saunders Institute. Her research focuses on the use of routinely collected health and other large data to monitor inequality and investigate the causes of inequality in palliative and end of life care.



**Dr Sarah Craig** is currently Head of National Health Information Systems at the Health Research Board. This role includes the overall management of four

national service planning and surveillance databases in the areas of disability, mental health and alcohol and drugs. She currently chairs an in-house HRB working group on health data.



**Jessica Morley** is the Director of Policy for the Oxford Bennett Institute for Applied Data Science, directed by Professor Ben Goldacre and was

lead researcher for the recently published Goldacre Review *Better, Broader, Safer: Using Health Data for Research and Analysis*. Jess is also a graduate researcher at the Oxford Internet Institute working on her thesis *Designing an algorithmically-enhanced NHS*. Prior to working in academia full-time, Jess was a civil servant at the Department of Health and Social Care.



**Dr Frances Burns** is lead for the Northern Ireland Trusted Research Environment (NITRE) a strategic group from the Department of

Health, the Northern Ireland Public Health Agency and the Health and Social Care Honest Broker Service to enable connectivity, and data provisioning from within Health and Social Care Northern Ireland. She sits on the Health Data Research Northern Ireland Leadership Group working as part of Health Data Research UK (HDR UK) connecting Northern Ireland Health and Social Care data to support and accelerate research and enable streamlined data access and analysis. Within her role Frances is leading the introduction of regulations for secondary use of Health and Social Care Data in Northern Ireland. Frances was formerly programme lead for the Administrative Data Centre Northern Ireland (ADRC NI) and previously managed the establishment of the Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA). Frances holds a PhD in factors affecting impact of publicly funded research and innovation.