

Symposium Description (250 words max.)

Symposium Lead (name and affiliation):

Professor Louisa Jorm

Director, Centre for Big Data Research in Health, University of New South Wales

Co-convenor, RADiANT (Australian and New Zealand **Real-World Data Network**)

Rationale for Symposium:

Demonstrating the value of enduring integrated data assets in health services research

Topic description

RADiANT, the Australian and New Zealand Real-World Data Network, was established in June 2018 in response to the findings and recommendations of the Australian Government Productivity Commission into Data Availability and Use. It is a researcher-led and researcher-focused scientific network established to promote policy that supports good practice in the access to and use of real-world data for research. Multi-agency partnerships in Australia and New Zealand have designed and built integrated data assets to enable public good health research. But there is much more to be done, particularly in Australia. Researchers have a leadership role in the use of public data for public good research. They have a responsibility to help build and maintain the social license for these assets, to work in partnership with agencies to maximise the research utility of the assets, and to actively engage and contribute to the design and implementation of related legislation. This engagement is required to achieve equitable, efficient, innovative, sustainable and secure data access and use. In this Symposium, you will learn about three integrated data assets, and some of the pivotal discoveries generated from them. You will also learn about the current real-world data policy reforms, and related data initiatives, being contributed to by RADiANT members.

Presentation one

Associate Professor Rosemary Korda

Fellow, National Centre for Epidemiology and Population Health, Australian National University

Overview: The Multi-Agency Data Integration Project (MADIP) is a partnership among Australian Government agencies to combine information on health, education, government payments, personal income tax and the Census. We will demonstrate the utility of these data to inform policy on health care financing, by presenting methods and findings from our study on out-of-pocket costs. We used linked personal income tax, Census, Social Security, National Health Survey, mortality, MBS and PBS data to describe the distribution of out-of-pocket costs for medical services and prescriptions in relation to ability to pay and how this varies by sociodemographic characteristics and key health conditions.

Presentation two

Professor Rod Jackson

Professor of Epidemiology, Faculty of Medical and Health Sciences, The University of Auckland

Overview: We established three overlapping 'big-data' cohort studies in NZ, a primary care cohort (500,000 +), a hospital cohort (100,000 +) and a national cohort (2m +). These cohorts are electronically linked to routine national health datasets of laboratory investigations, drug treatment, hospitalisations and deaths. We use these linked data to: i. develop vascular and bleeding risk prediction algorithms to assist clinicians estimate vascular risk in different populations; ii. investigate under- and over-treatment of vascular risk; iii. develop a 'big-data' vascular health information platform to support initiatives to

increase appropriate treatment, reduce inequities and improve overall vascular health.

Presentation three

Dr Michael Falster

Biostatistician and Research Fellow, Centre for Big Data in Research and Health, University of New South Wales

Overview: The National Data Linkage Demonstration Project (NDLDP) was established to demonstrate the value of national linked data to inform health planning and policy, with the Australian Institute of Health and Welfare linking five years of hospital, emergency department, pharmaceutical, medical services and mortality data for NSW and Victoria. Using the NDLDP we identified significant underuse and variation in post-discharge pharmacological care for cardiac patients, demonstrating this novel linkage enabled evaluation of care pathways across hospital and community-based services. We also identified key gaps in the data, highlighting the value of embedding researchers in development of these enduring data assets.

Presentation four

Associate Professor Claire Vajdic

Co-convenor, RADiANT

Overview: Public data holdings have enabled internationally recognised research and vital policy and practice change. Australia is at a crossroads in terms of policy reforms for data governance and data infrastructure, with major ramifications for the future of real-world data science. We will give an overview of the current data access and use policy reforms and related data initiatives, being contributed to by RADiANT members. We will summarise how far we have come, and where we are heading. We will also reinforce the case for researchers shaping data use and access design principles, and achieving and maintaining a social license.