
CONFERENCE ABSTRACT**From linked data to patient centred data: using health data to improve patient outcomes.**

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Healthcare is facing numerous challenges in an increasingly digital world. The availability of healthcare data is opening up opportunities to improve, or fundamentally change, methods of healthcare delivery. Artificial Intelligence, personalised medicine, big data are all offering outstanding potential (1). However all of these potentialities are underpinned by good data, and by comprehensive data. Both of these are currently lacking.

The path to good data relies in the efforts of clinicians to record data traditionally in only human readable form, into a form that is also machine readable (2). The next barrier is attempting to merge the various levels of data held in disparate systems, across primary, secondary care and across various institutions.

Outcome Health manages the POLAR program and its research arm, Aurora. Collecting data from over 600 practices across the eastern seaboard of Australia, it represents one of the largest GP data sources in the country. The program is designed around not just collecting data, but ensuring levels of data quality using a comprehensive strategy at all levels of data use (3).

But using primary care data alone is not sufficient to deliver care to patients. By using linked data we have developed a proof of concept of an emergency risk prediction tool using machine learning (4). By linking data between emergency departments and general practice, we were able to map the general practice journeys of those admitted to emergency over a 5 year period, and develop an electronic view of risk.

This has opened the door to an understanding that old concepts of data custodianship are outdated, and now to deliver care to patients also means having access to the relevant data about that patient, wherever it was created and is stored.

To do this we have embarked on a program of developing a framework for linked data between primary care, hospital settings and data held by the state. This raises significant challenges, both technical and social. Technical problems are the nature of ensuring adequate, verified linkage according to multiple needs, and quality measures of data. Social factors include the ethics and consent models, that are currently institution based, rather than patient based. Meeting these challenges is a priority and will be part of the presentation.

References:

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3- Pearce C, Mcleod A, Rinehart N, Ferriggi J, Shearer M. What does a comprehensive, integrated data strategy look like: The Population Level Analysis and Reporting (POLAR) program. *Stud Health Technol Inform*. 2019;In Press.

4- Pearce C, McLeod A, Rinehart N, Patrick J, Fragkoudi A, Ferrigi J, et al. POLAR Diversion: Using General Practice Data to Calculate Risk of Emergency Department Presentation at the Time of Consultation. *Appl Clin Inform*. 2019;10(1):151-7.