Understanding cancer patients' journey of care through a newly-developed primary care focused linked data resource

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What is VCCC Alliance Data Connect?

Linking together patients' electronic health records allows for a better understanding of patient care across the entire journey of care, enabling data-driven research in order to improve patient outcomes.

The VCCC Alliance has created a de-identified, linked data resource for health research in the state of Victoria, Australia developed using BioGrid's federated data infrastructure. With over 3 million patients across the state, it is the first of its kind in Australia to bring together representative data from primary care, secondary care and clinical registry data sources in one platform.

Features of the linked data resource

Data Connect enables pre-trial feasibility assessment, as well as epidemiological and health services research to inform practice and policy decisions.

Importantly, Data Connect leverages BioGrid’s unified governance and ethics processes to ensure requirements of data custodians are met while allowing users to access data through a single service.

While the current focus is on primary care cancer research this resource has been developed to support health services research more broadly.

Some of the data available through Data Connect

- Over 3 million unique patients
- 222 General Practices
- Over 70 million GP encounters
- 2.7 million ED presentations
- 53 million prescriptions
- Coverage across Victoria from 2006 - 2021
- Cancer diagnosis data with particular emphasis on colorectal, sarcoma and lung cancers
- 4.2 million hospital admissions

Some current projects using Data Connect

- Time to diagnosis and treatment from first presentation in general practice, and factors associated with longer intervals.
- Associations between time to diagnosis and treatment on stage and survival.
- Patterns of abnormal test results in primary care preceding diagnosis, and potential opportunities to consider diagnosis sooner.
- Patterns of follow-up of abnormal test results before diagnosis to inform diagnostic decision support algorithms.
- Management of comorbidities in cancer survivors and comparison of quality indicators in those with and without cancer.
- Implementation of risk prediction algorithms into clinical practice through the Future Health Today program of work.

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Mediciswise: National Prescribing Service Primary Care Database
PATRON: University of Melbourne Data for Decisions Primary Care Database
VAED: Victorian Admitted Episodes Dataset
VEMD: Victorian Emergency Minimum Dataset
VINAH: Victorian Non-Admitted Episodes Dataset
AURORA: Australian Registry and Biobank of Thoracic Cancers
ACCORD: Australian Comprehensive Cancer Outcomes and Research Database