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.
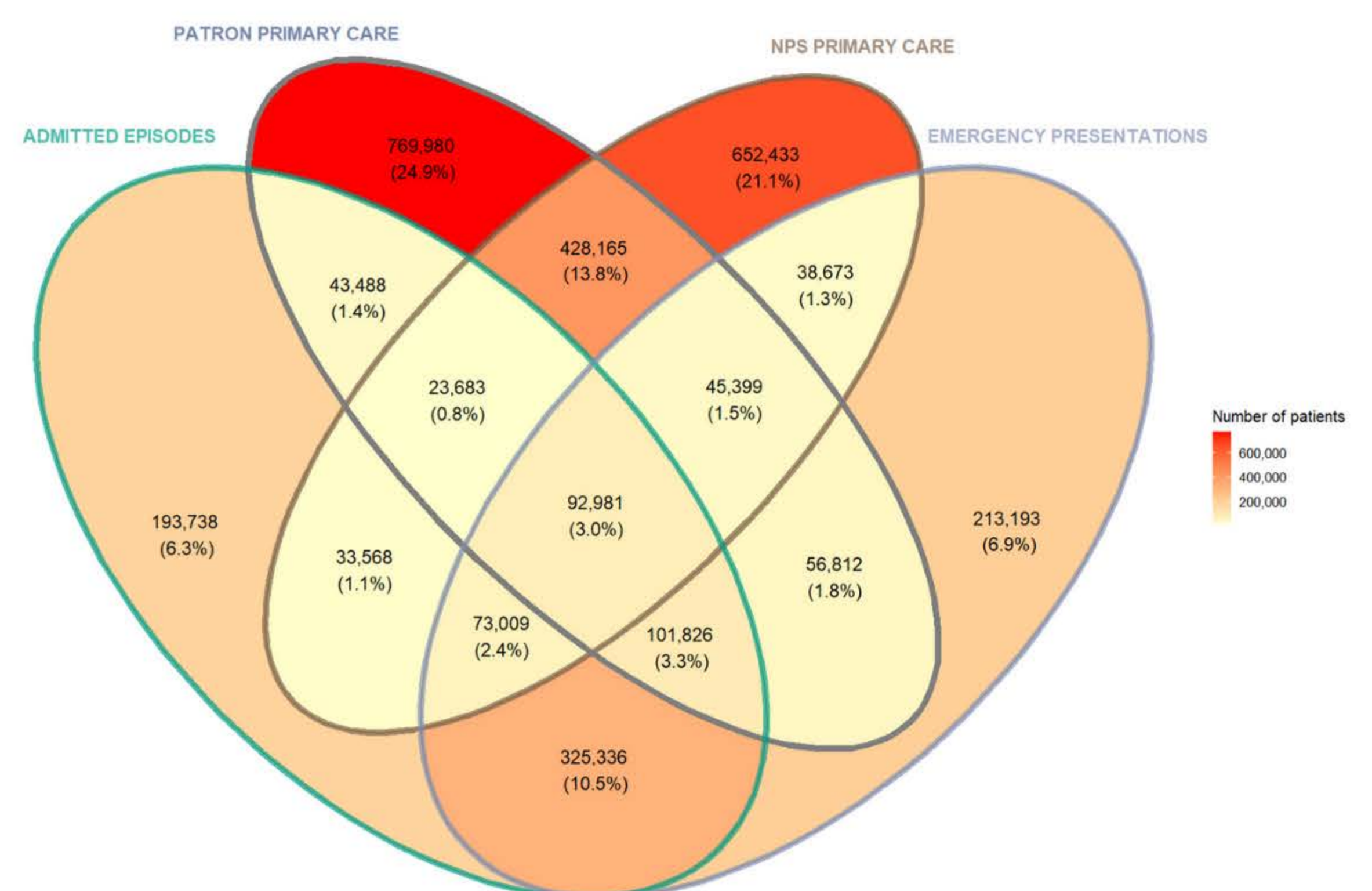
Patient linkage statistics

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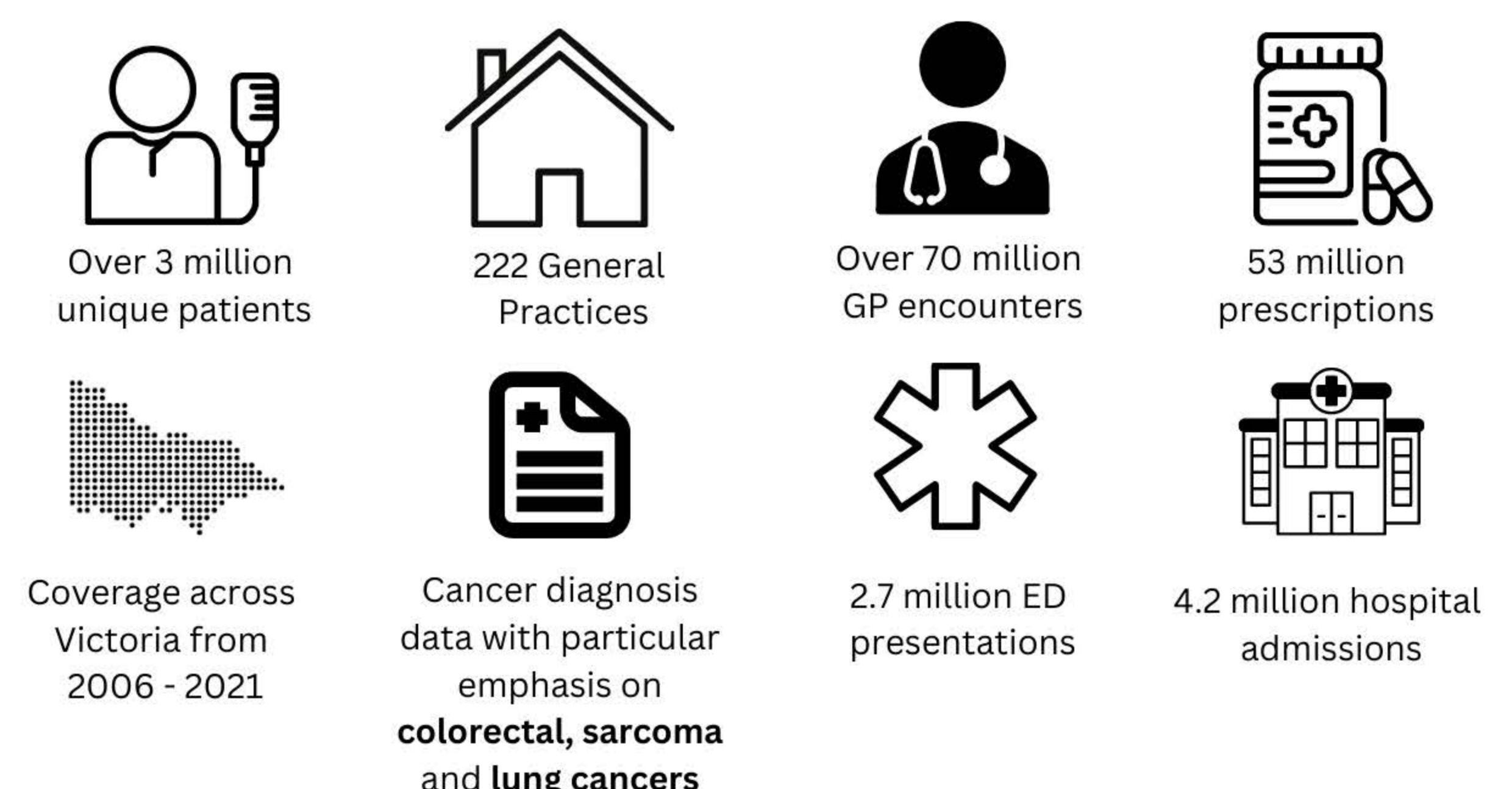
Importantly, Data Connect leverages BioGrid's **unified governance and ethics processes** to ensure requirements of data custodians are met while allowing users to access data through a single service.

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

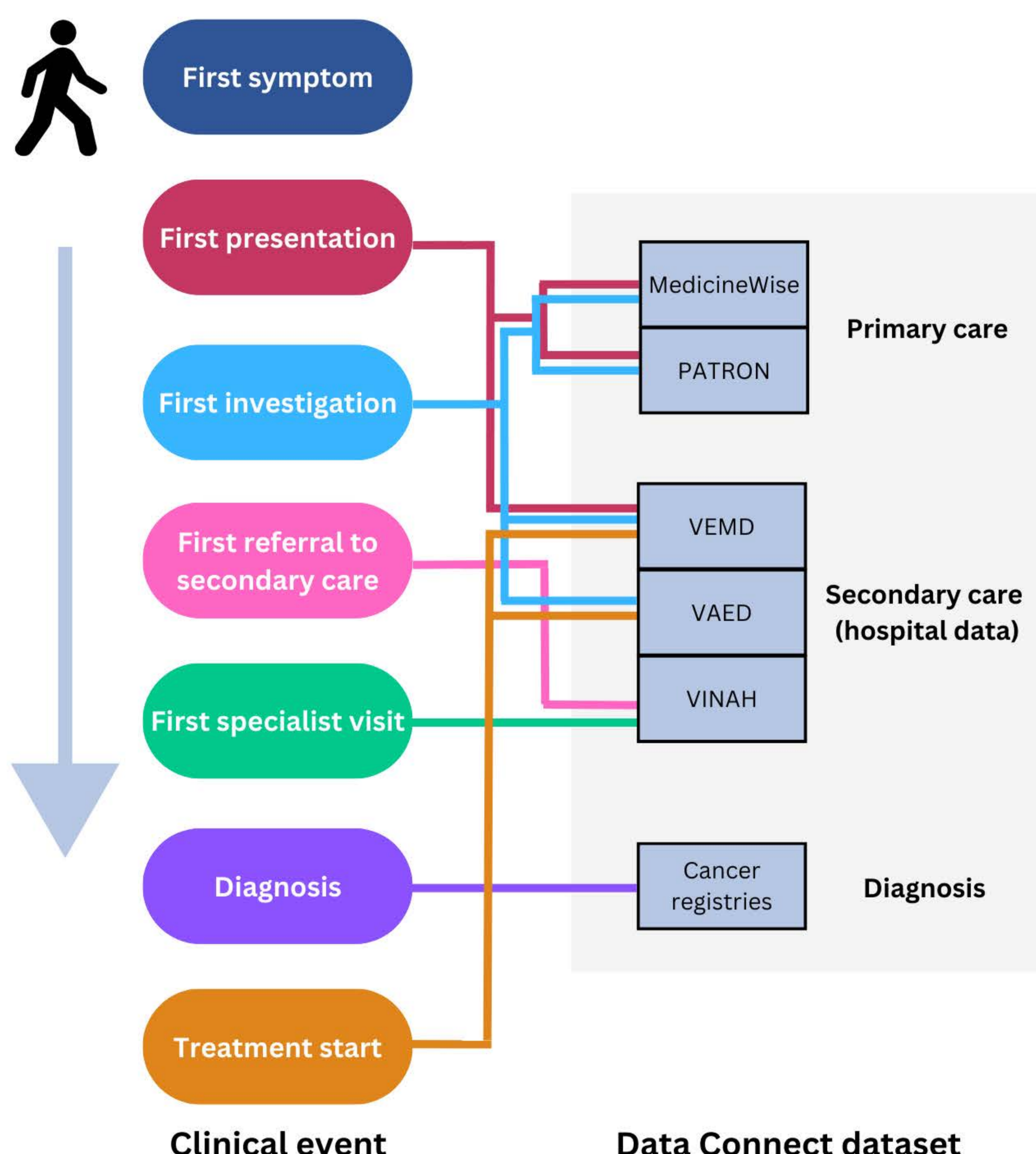## Some of the data available through Data Connect

Over 3 million unique patients

222 General Practices

Over 70 million GP encounters

53 million prescriptions

Coverage across Victoria from 2006 - 2021

Cancer diagnosis data with particular emphasis on **colorectal, sarcoma** and **lung cancers**

2.7 million ED presentations

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.

Clinical event | Data Connect dataset

First symptom	
First presentation	MedicineWise / PATRON — Primary care
First investigation	
First referral to secondary care	VEMD / VAED / VINAH — Secondary care (hospital data)
First specialist visit	
Diagnosis	Cancer registries — Diagnosis
Treatment start	

MedicineWise	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

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