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VICTORIAN COMPREHENSIVE CANCER CENTRE

# Data-Driven Research Program

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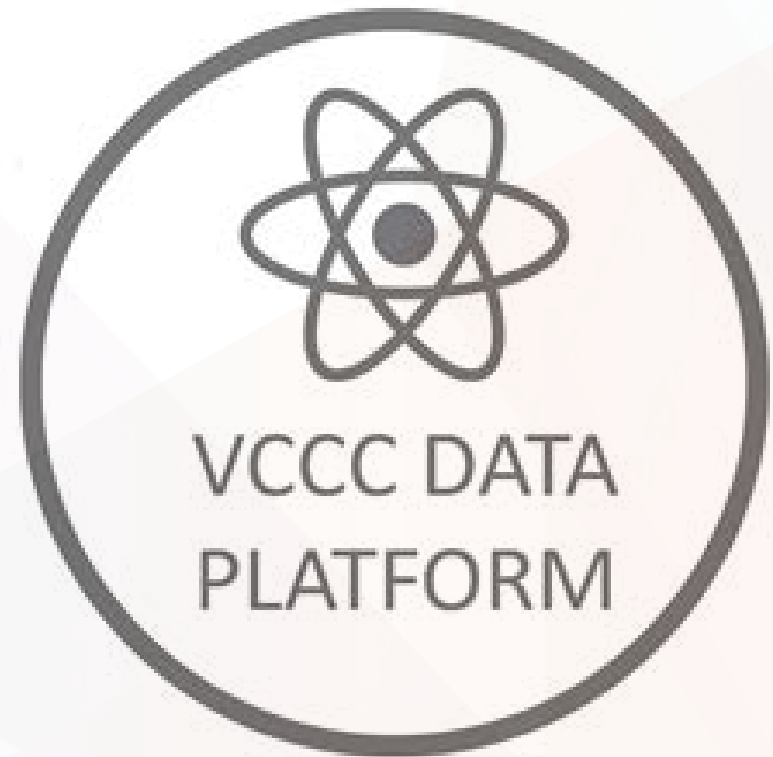


*Supported by*



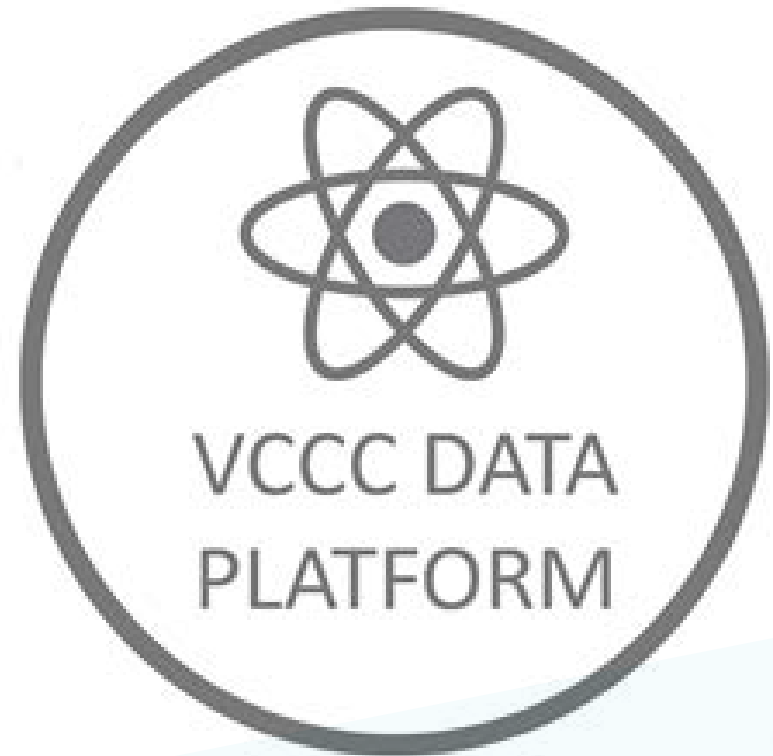
# Data-Driven Research Program

Linked  
Longitudinal  
Retrospective  
Health care continuum  
Secondary use  
Bottom-up

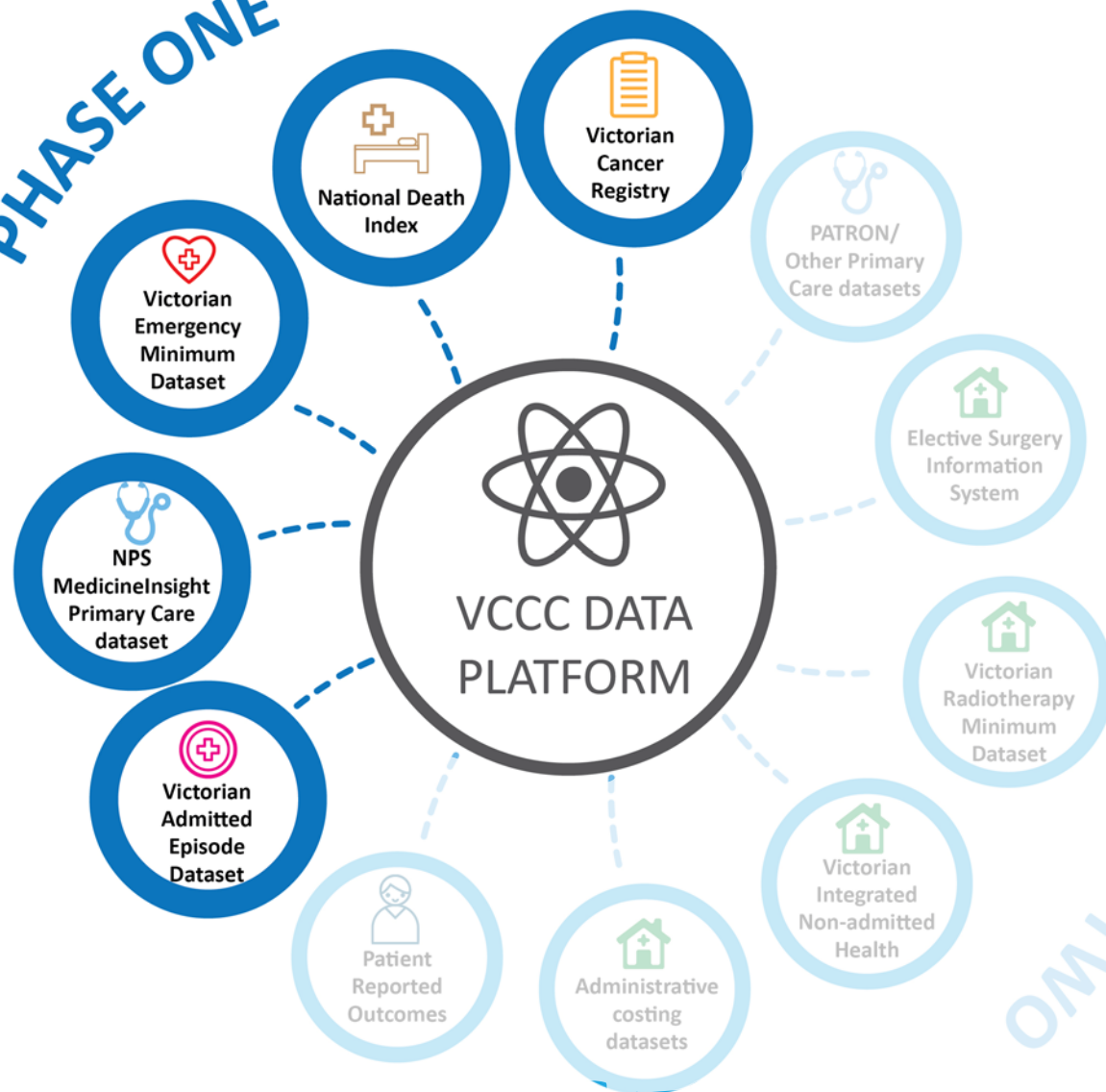


# Data-Driven Research Program

Patient  
Primary Care  
Population registries  
Clinical registries  
Community  
Hospital

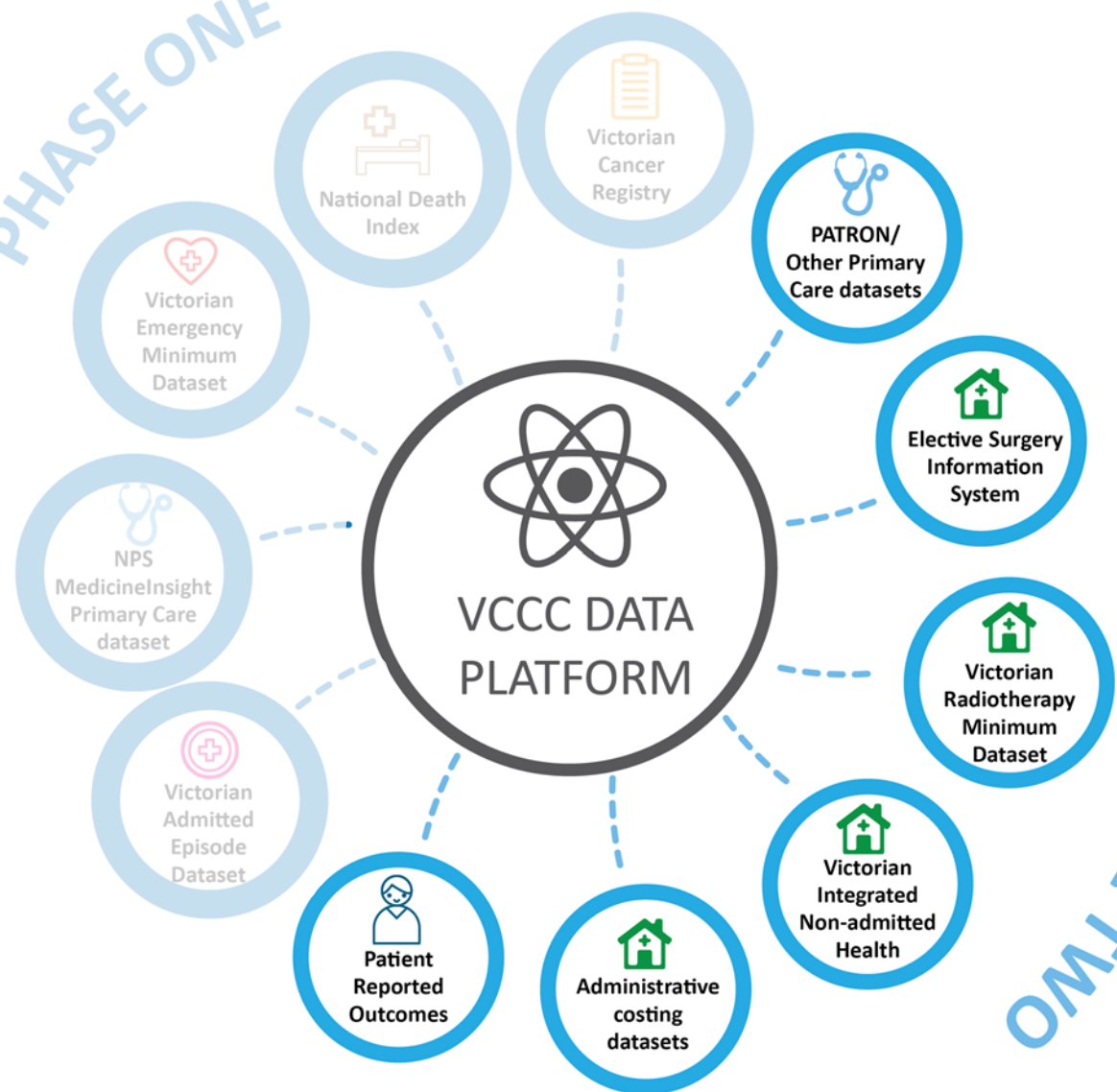


# PHASE ONE



# PHASE TWO

PHASE ONE



PHASE TWO





Data governance, privacy, security

Individual record-level matching

Data linkage, integration and interoperability

Data analysis and reporting

Data collection software for clinical and research



Project, analytical and technical support

Overarching linkage ethics/governance support

Full custodian control over data access

Project-specific non-member linkage

Secure access/data-distribution infrastructure





### Clinical

- Cardiology
- Dermatology
- Diabetes
- Oncology
- Clinical Trials

### Population Health

- Cancer Registries
- Diabetes Registries
- Rare Diseases
- Screening Registries
- Quality of Life

### Government

- Admitted Episodes
- Australian Cancer dB
- Bureau Statistics
- Death Dates/Cause
- MBS, PBS

### Primary Care

- Diagnosis
- Medications
- Prevention
- Referrals
- Test Results

### Administration

- Admissions
- Demographics
- Events
- Procedures
- Audit

### In-Hospital

- Imaging
- Pathology
- Pharmacy
- Radiology
- Scheduling

# BioGrid Members and Collaborators



ACT Health  
Canberra Hospital

AlfredHealth

Alfred Health  
The Alfred  
Cardiff Hospital  
Sunderling Hospital

Austin  
HEALTH

Austin Health  
Austin Hospital  
Heideberg Repatriation Hospital

Baker IDI  
HEALTH & DIABETES INSTITUTE

Baker IDI Heart and  
Diabetes Institute



Ballarat  
Health Services  
Ballarat Base Hospital  
Queen Elizabeth Centre



Barwon Health  
University Hospital Geelong



Bendigo Health  
Bendigo Hospital



Central Adelaide Local  
Health Network  
Royal Adelaide Hospital  
Queen Elizabeth Hospital

easternhealth

Eastern Health  
Angliss Hospital  
Box Hill Hospital  
Mooroodah Hospital  
Healesville Hospital



Gold Coast Hospital  
and Health Service  
Gold Coast University Hospital  
Robina Hospital



Goulburn Valley  
Health  
Goulburn Valley Hospital



Hudson Institute of  
Medical Research



Larrobe Regional  
Hospital  
Larrobe Regional Hospital



Mater Health  
Services Brisbane  
Queensland Diabetes  
and Endocrine Service  
Mater Hospital Brisbane



Melbourne Health  
The Royal Melbourne Hospital



Metro North Hospital  
and Health Service  
Royal Brisbane and Women's Hospital  
The Prince Charles Hospital



Metro South Hospital  
and Health Service  
Princess Alexandra Hospital

MonashHealth

Monash Health  
Monash Medical Centre, Clayton  
Monash Medical Centre, Moorabbin  
Dandenong Hospital  
Casey Hospital



Monash University



Murdoch Children's  
Research Institute



Northern Adelaide  
Local Health Network  
Lyell McEwin Hospital  
Modbury Hospital



Northern Health  
The Northern Hospital



Peninsula Health  
Frankston Hospital  
Rosebud Hospital



Peter MacCallum  
Cancer Centre  
Peter MacCallum Cancer Centre



Radiation Oncology  
Victoria Ltd



South Metropolitan  
Health Service trading  
as Fiona Stanley  
Hospital  
Fiona Stanley Hospital



South Western  
Sydney Local  
Health District  
Banksstown, Bowral, Camden,  
Campbelltown, Fairfield and  
Liverpool Hospitals



St John of God Health  
Care Incorporated  
Ballarat, Bendigo, Berwick, Bunbury,  
Burwood, Geelong, Geraldton, Midland,  
Murdoch, Mt Lawley, Richmond,  
Subiaco and Wannambool Hospitals



St Vincent's  
Hospital Melbourne  
St Vincent's Hospital Melbourne



St Vincent's  
Hospital Sydney  
St Vincent's Hospital Sydney



Sydney Local  
Health District  
Royal Prince Alfred, Concord  
Repatriation General, Balmain,  
Canterbury and Sydney Dental  
Hospitals



Department of Health  
& Human Services  
through the Royal  
Hobart Hospital  
The Royal Hobart Hospital  
Launceston General Hospital



The Royal Children's  
Hospital  
The Royal Children's Hospital  
Melbourne



The Royal Women's  
Hospital  
The Royal Women's Hospital



The University of  
Melbourne



The University of  
New South Wales



The University of  
Western Australia



The Walter & Eliza Hall  
Institute of Medical  
Research



Victorian  
Comprehensive  
Cancer Centre

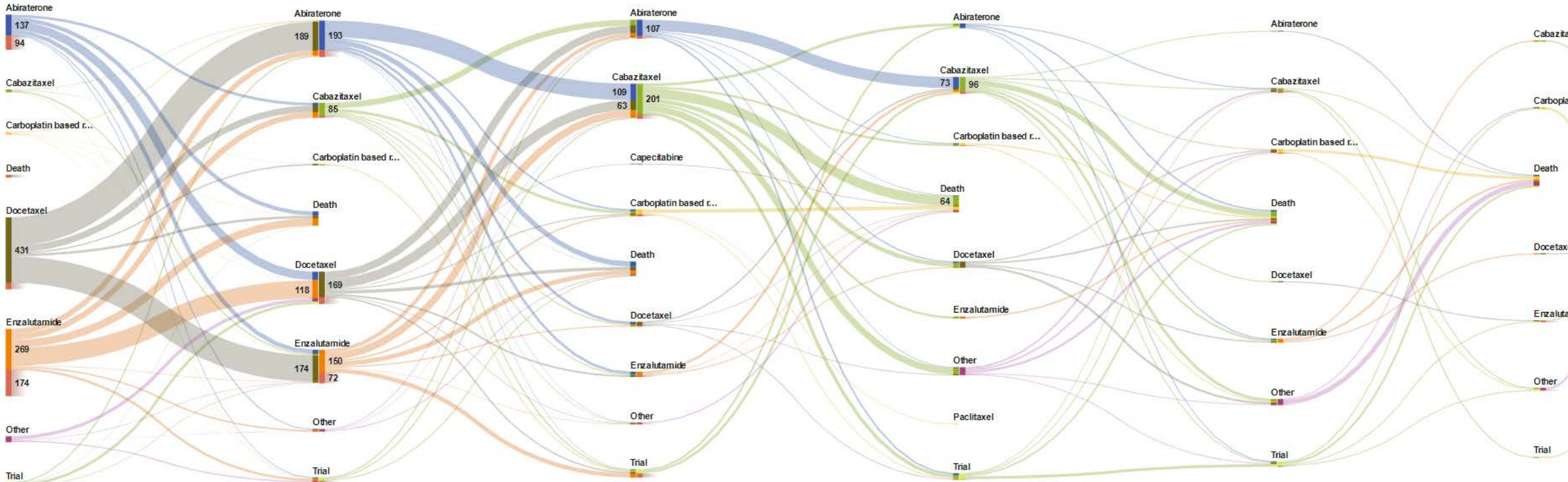


West Moreton  
Hospital and  
Health Service  
Ipswich Hospital



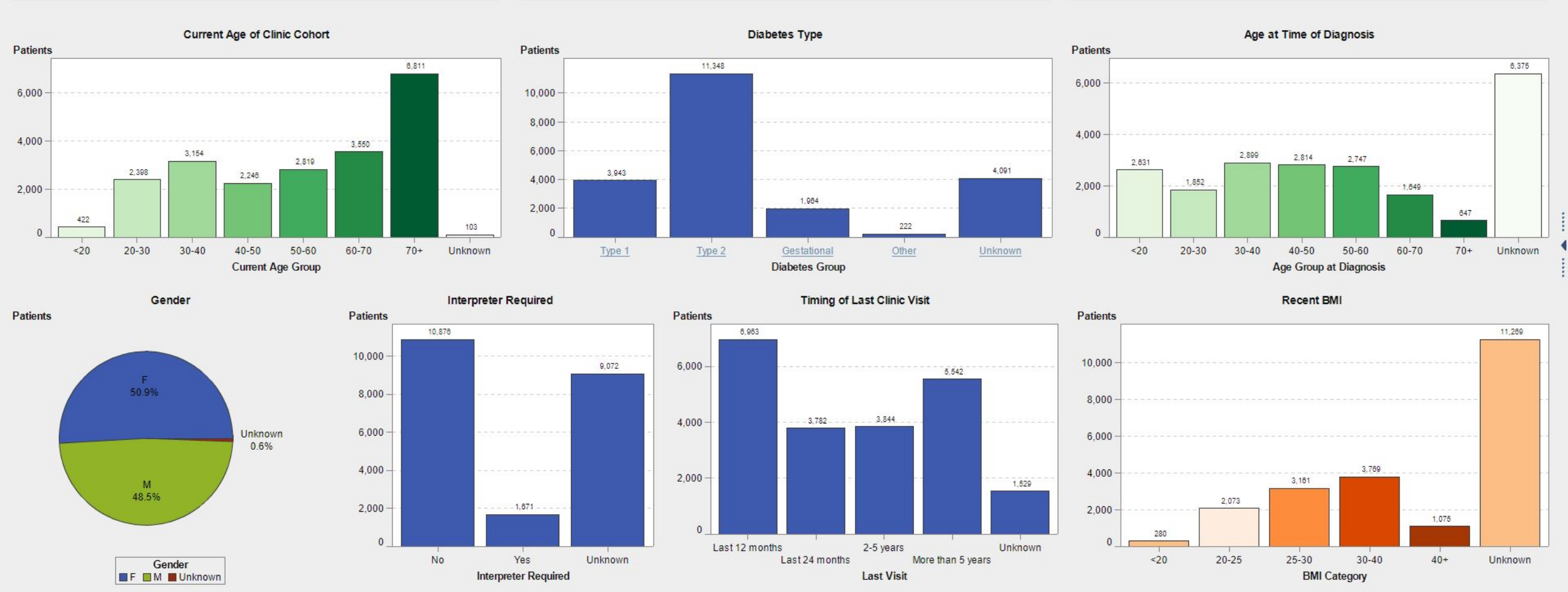
Western Health  
Footscray Hospital  
Sunshine Hospital  
Williamstown Hospital

ePAD Treatment Sankey Diagram



189  
2  
Path Weight by Link

Event  
■ Abiraterone ■ Cabazitaxel ■ Capecitabine ■ Carboplatin based regimen ■ Death ■ Docetaxel ■ Drop off ■ Enzalutamide ■ Other ■ Paclitaxel ■ Trial



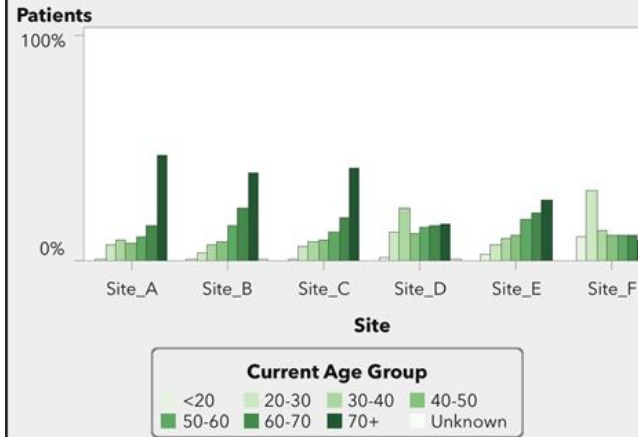




Site\_A Site\_B Site\_C Site\_D Site\_E Site\_F

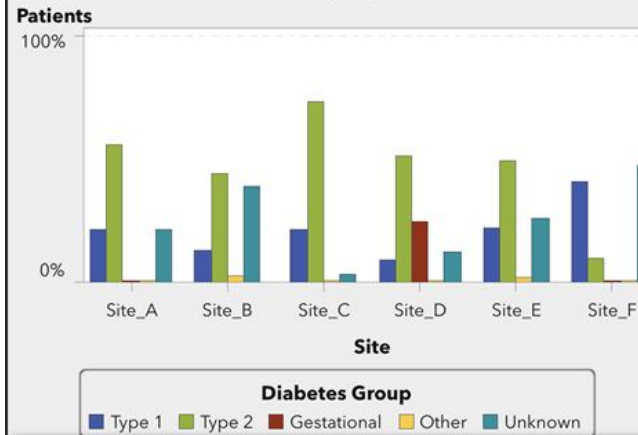
Current Age Group

### Current Age of Clinic Cohort



Gender

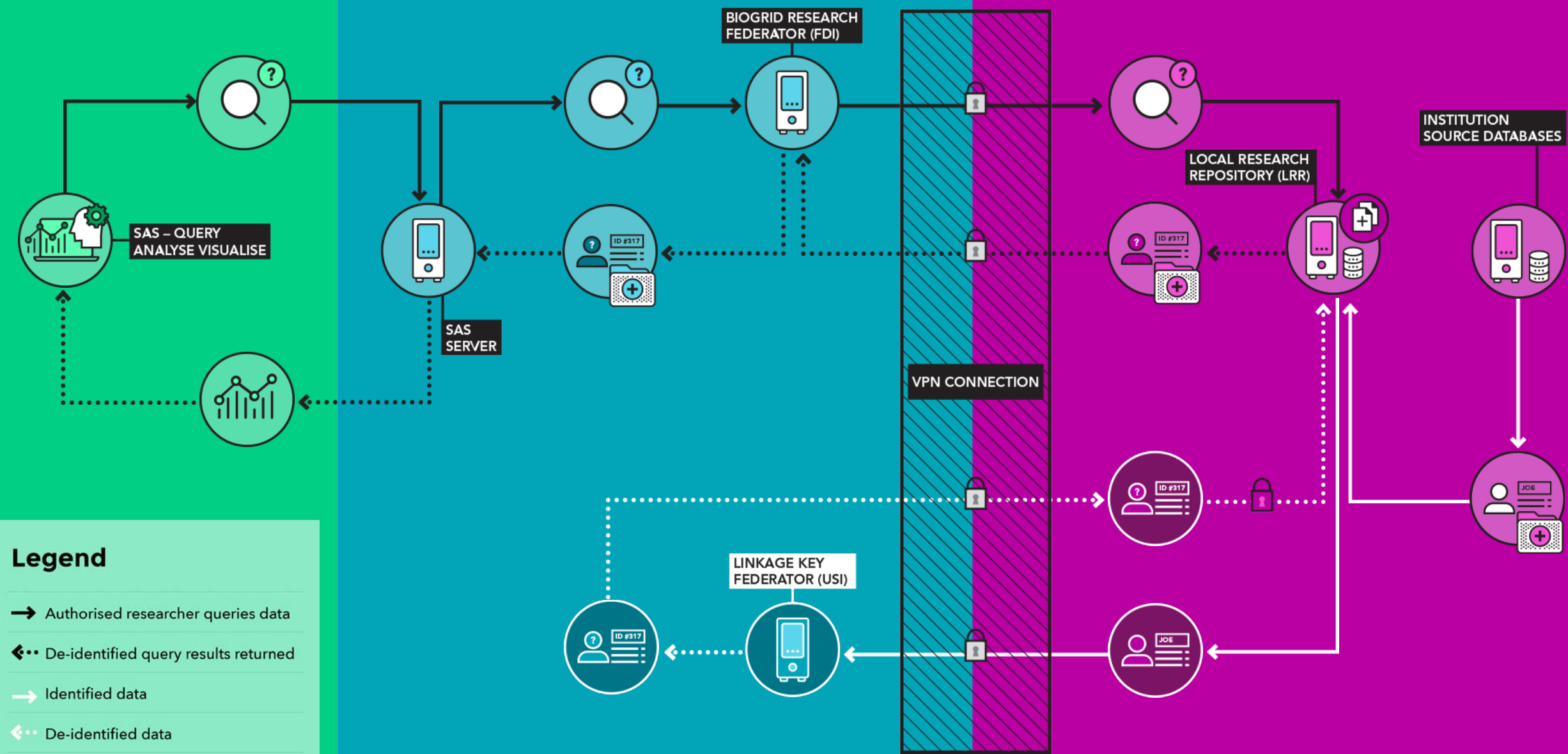
### Diabetes Type

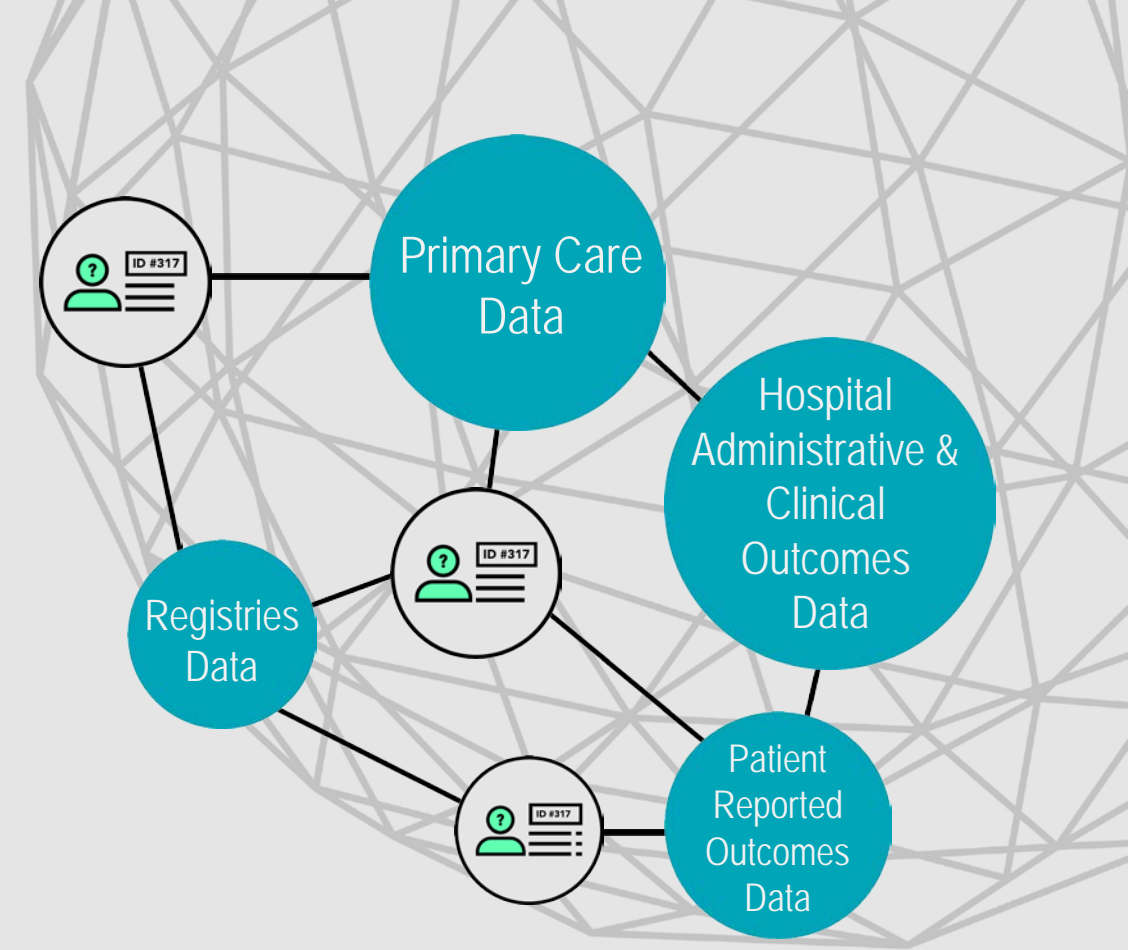
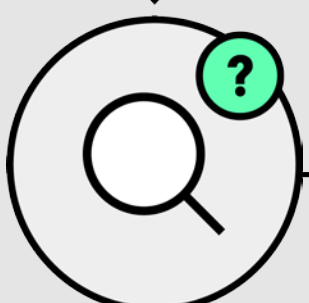


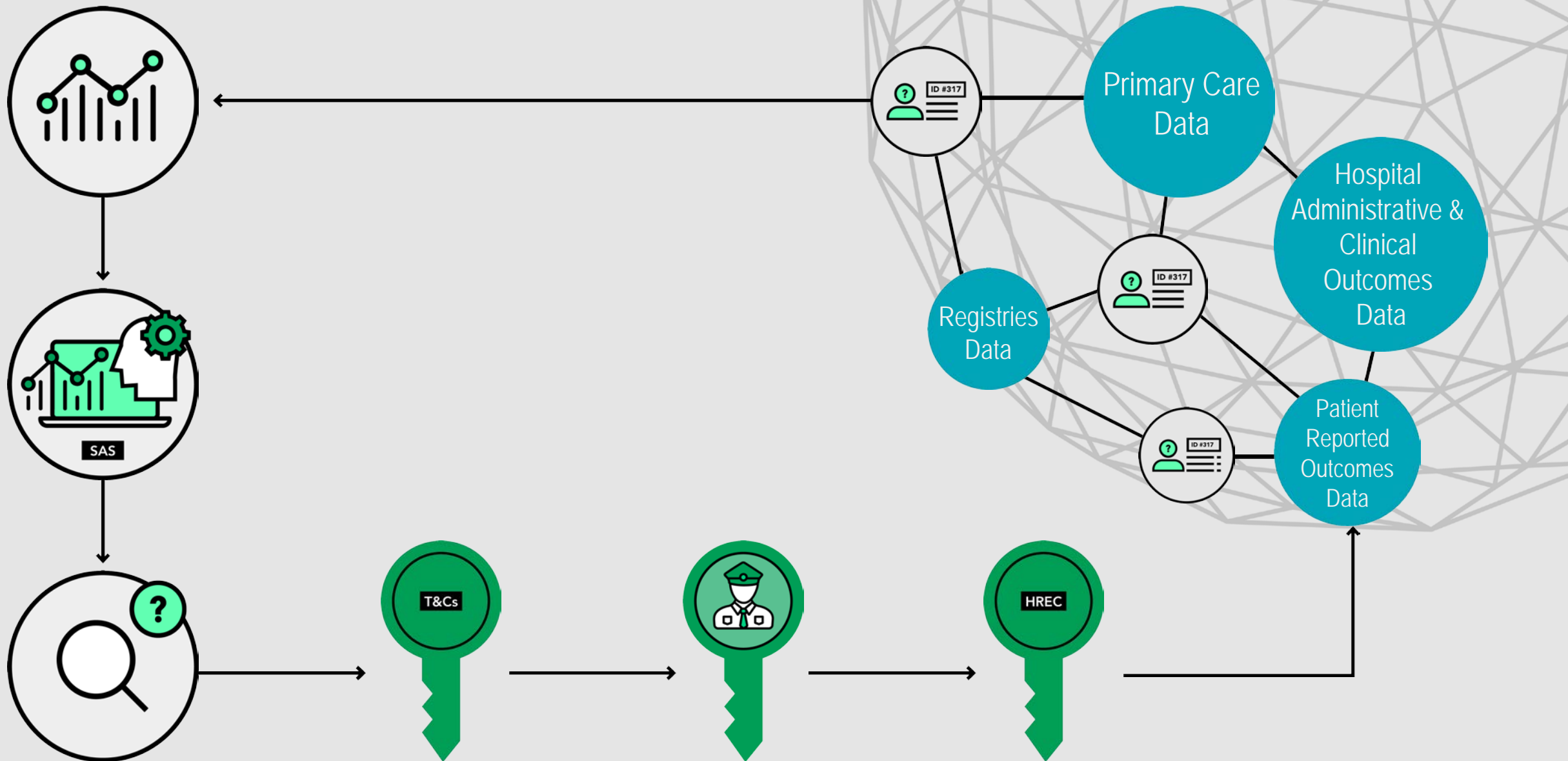
Researcher

BioGrid

Collaborating Institution Example











# Data for Decisions

A university-based program using general practice data for research

Department of General Practice, Melbourne Medical School

Jo-Anne Manski-Nankervis, Rachel Canaway, Jon Emery, Lena Sanci, Douglas Boyle, Jane Hocking, Jane Gunn, Anna Wood, Malcolm Clark, Phillippe Grimes, Jessica Bell, HaBIC R<sup>2</sup> team, Dr Timothy Monaghan, Sophea Ing, Silvia de Bono, members of the independent Data Governance Committee,

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[vicren-enquiries@unimelb.edu.au](mailto:vicren-enquiries@unimelb.edu.au)

[www.gp.unimelb.edu.au/datafordecisions](http://www.gp.unimelb.edu.au/datafordecisions)

**VicREN**

Victorian Primary Care  
Practice-Based Research  
& Education Network



# Data for Decisions and the Patron program

Underpinned by GRHANITE®

Part of VicREN: Practice-based research & education network

New / maturing program (pilot phase)

Not for profit

## Objectives

- To advance medical research and public health through creation and use of an enduring, curated repository of primary care data (Patron)
- Contribute to evidence-based development of healthcare-related policy, tools and practices
- Use Patron data to address research gaps and increase primary health care research capacity
- Provide leadership in good practice management and use of primary care data for research, teaching and policy development

[www.gp.unimelb.edu.au/vicren](http://www.gp.unimelb.edu.au/vicren)

## Data for Decisions

This practice is proud to be involved in the University of Melbourne's *Data for Decisions* program that collects anonymous (de-identified) information from patient health records in an ethical and secure way. All data collected is managed and stored by the University of Melbourne in accordance with Federal Privacy Law.

Data contributed from all general practices involved in *Data for Decisions* will only be used for research, teaching and policy purposes to improve the way medical care is delivered and inform the education of future health professionals.

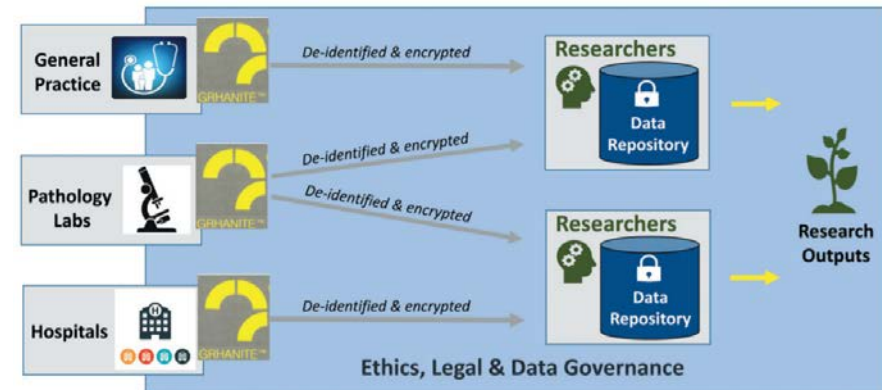
If you would like more information, please ask at reception for an information brochure or visit our website. If you do not want your data to be collected for the *Data for Decisions* program, please tell your doctor or the receptionist.

 For further information: [gp.unimelb.edu.au/datafordecisions](http://gp.unimelb.edu.au/datafordecisions)



## GRHANITE<sup>®</sup> software

- Developed by A/Prof Dougie Boyle Director of HaBIC R<sup>2</sup> Department of General Practice, The University of Melbourne
- Enables privacy protected data extraction & linkage
- Excludes person identifiable data fields
- Additional privacy filters in fields where user error is known
- Layers of encryption
- Enables opt-in, opt-out and waiver of patient consent
- Installation does not prevent use of other data sharing tools (Pen CS, POLAR, etc)
- Does not slow computer processing





## Example projects using Patron data

Defining the burden of antimicrobial prescribing attributable to sore throat

Doherty Institute

*Inform strategies to improve antibiotic prescribing practices*

*Provide feasibility evidence around developing a bacterium Group A Strep vaccine*

Meeting national targets to reduce mortality from chronic illness through general practice

Deakin University

*Evaluate changes to general practice performance for CVD risk screening before, during and after implementation of a patient-centred quality improvement initiative in a large general practice*

GP-NAPS: The feasibility of passive audit of antibiotic prescribing in general practice

University of Melbourne

*Determining the feasibility of passive audit of AB prescribing rather than onsite audit of patient files*

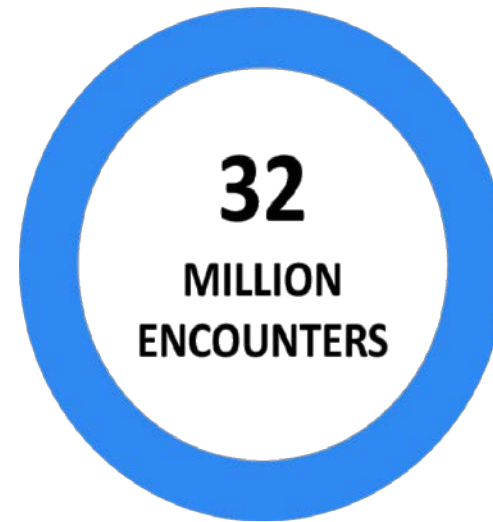
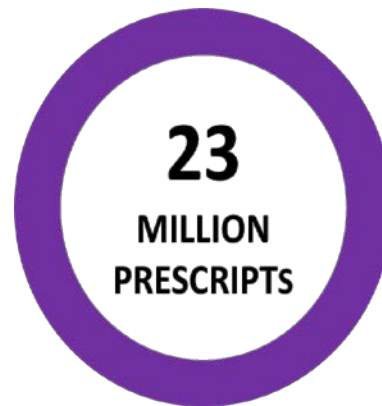
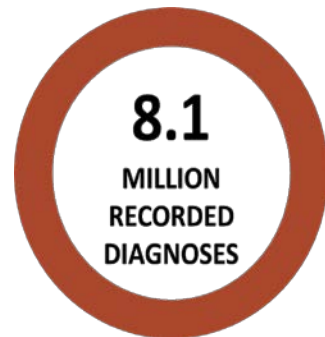
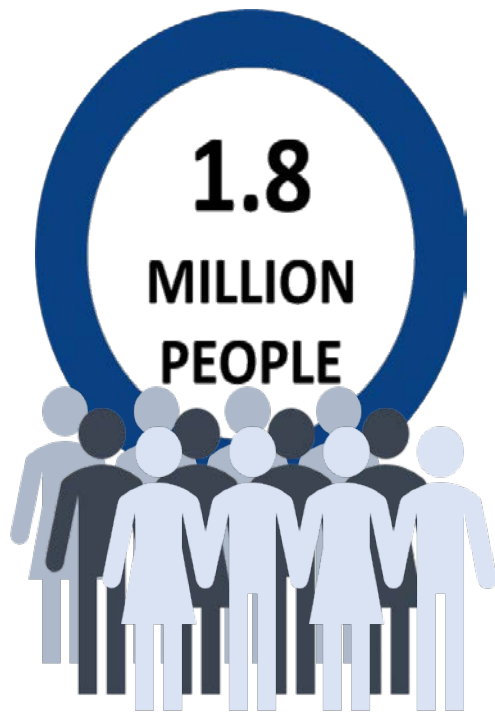
*Form a key component of a quality improvement activity*

Future Health Today: Creating a technological platform for detecting & managing people at risk of CKD

University of Melbourne

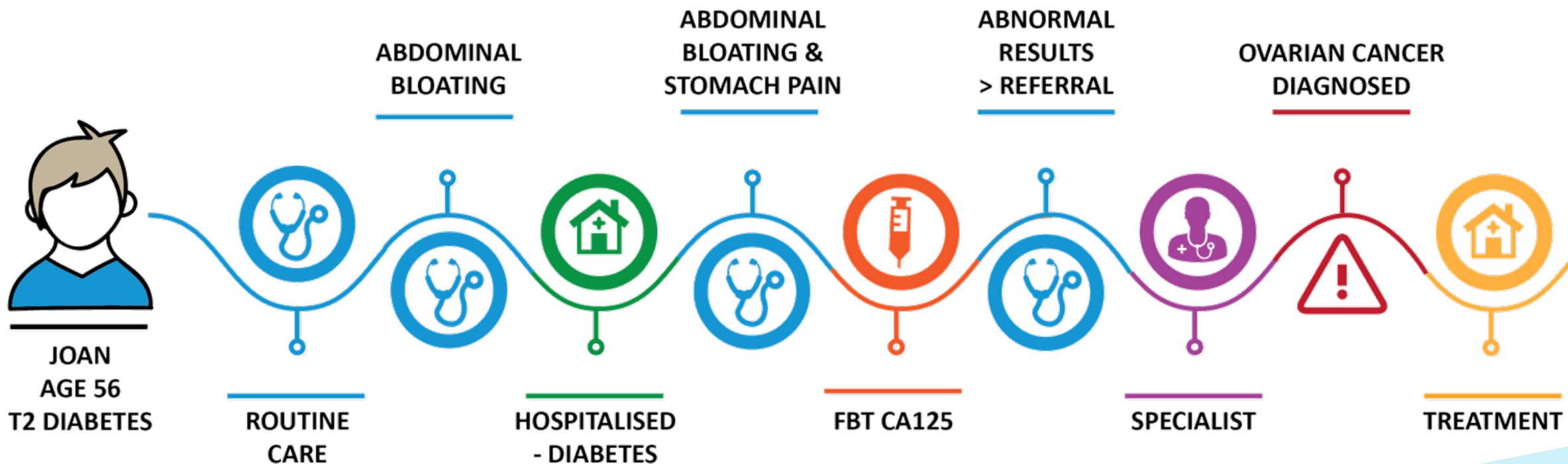
*Use of Patron data to develop & validate algorithms used in the CKD detection and management platform*

*Use Patron data to benchmark progress of practices using the CKD detection platform*









GENERAL PRACTICE

HOSPITALS & SPECIALIST CENTRES

GENERAL PRACTICE

HOSPITALS & SPECIALIST CENTRES

| Tumour Stream | Pts linked primary care | Avg # appts primary care 12m pre dx |
|---------------|-------------------------|-------------------------------------|
| Breast        | 197                     | 11.4                                |
| Haematology   | 178                     | 13.5                                |
| Lung          | 169                     | 15.7                                |
| Lower GI      | 133                     | 12.9                                |
| Head & Neck   | 117                     | 11.6                                |
| Urological    | 110                     | 12.8                                |
| Neurological  | 71                      | 10.1                                |
| Upper GI      | 67                      | 16.1                                |

| Hospital Diagnoses |
|--------------------|
| <b>1,984</b>       |
| <b>3,033</b>       |
| <b>2,711</b>       |
| <b>1,432</b>       |
| <b>1,378</b>       |
| <b>2,130</b>       |
| <b>900</b>         |
| <b>1,307</b>       |

| Pts linked primary care | Avg # appts primary care 12m post dx |
|-------------------------|--------------------------------------|
| 183                     | 11.8                                 |
| 172                     | 15.2                                 |
| 154                     | 15.1                                 |
| 128                     | 13.6                                 |
| 110                     | 12.1                                 |
| 99                      | 12.3                                 |
| 70                      | 13                                   |
| 67                      | 14.5                                 |

GENERAL PRACTICE

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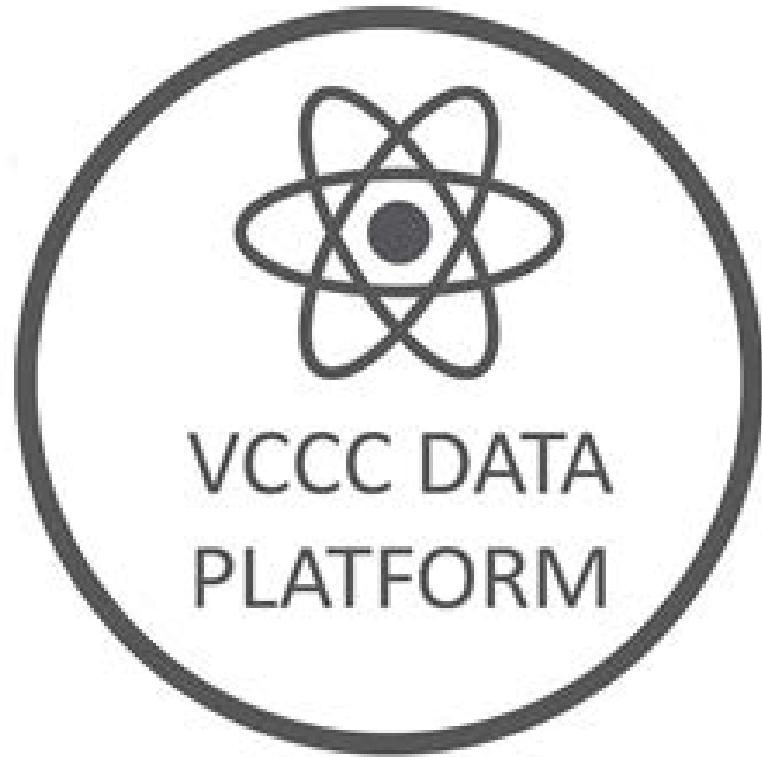
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GENERAL PRACTICE

HOSPITALS & SPECIALIST CENTRES

GENERAL PRACTICE



What next

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Supported by



Victorian Comprehensive Cancer Centre partners



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Victorian Comprehensive Cancer Centre Ltd

trading as Victorian Comprehensive Cancer Centre ABN 84 140 233 790

We acknowledge the Traditional Owners of the lands on which we work and pay our respects to their elders past and present.