Advancing Health Research Through Data Sharing

Unlocking Data for Secondary Research: Impacts on Future Research and Health Outcomes

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HEALTH AND BIOMEDICAL RESEARCH INFORMATION TECHNOLOGY UNIT

PROFESSOR
DOUGIE BOYLE
DIRECTOR

- **HaBIC R²** brings technology expertise and **innovation** to research and health projects, delivering information and technical solutions to drive change and innovation that keep **people and privacy at the centre.**
- We collaborate with stakeholders across health, research, and government sectors to provide:
  - Software and app development
  - Trial recruit and evaluation tools
  - Health communication integration platforms.....

GRHANITE

GRHANITE™ software enables seamless data collection for audit, clinical research, and health surveillance. It overcomes legal, ethical, organizational, and technical barriers, making it applicable in any data collection environment within Australia.

PATRON

The Patron program utilises GRHANITE™ software to collect and de-identify information from patient records in consenting general practice settings. Patients have the option to withdraw their data, and participating practices.....

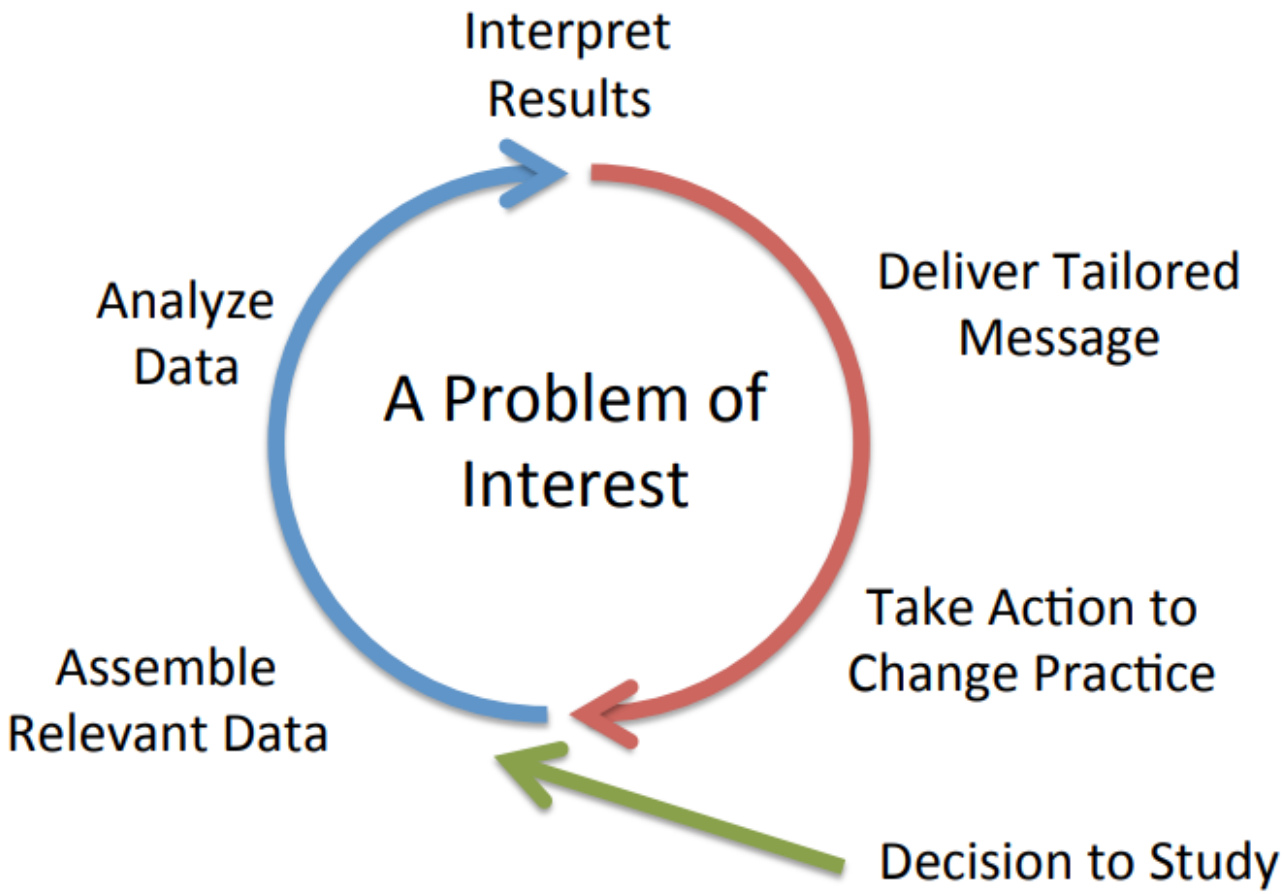
OMOP COMMON DATA MODEL

The standardized structure of the OMOP CDM promotes data interoperability and facilitates the development and validation of analytical methods and tools. It also supports the use of common vocabularies.....

FUTURE HEALTH TODAY

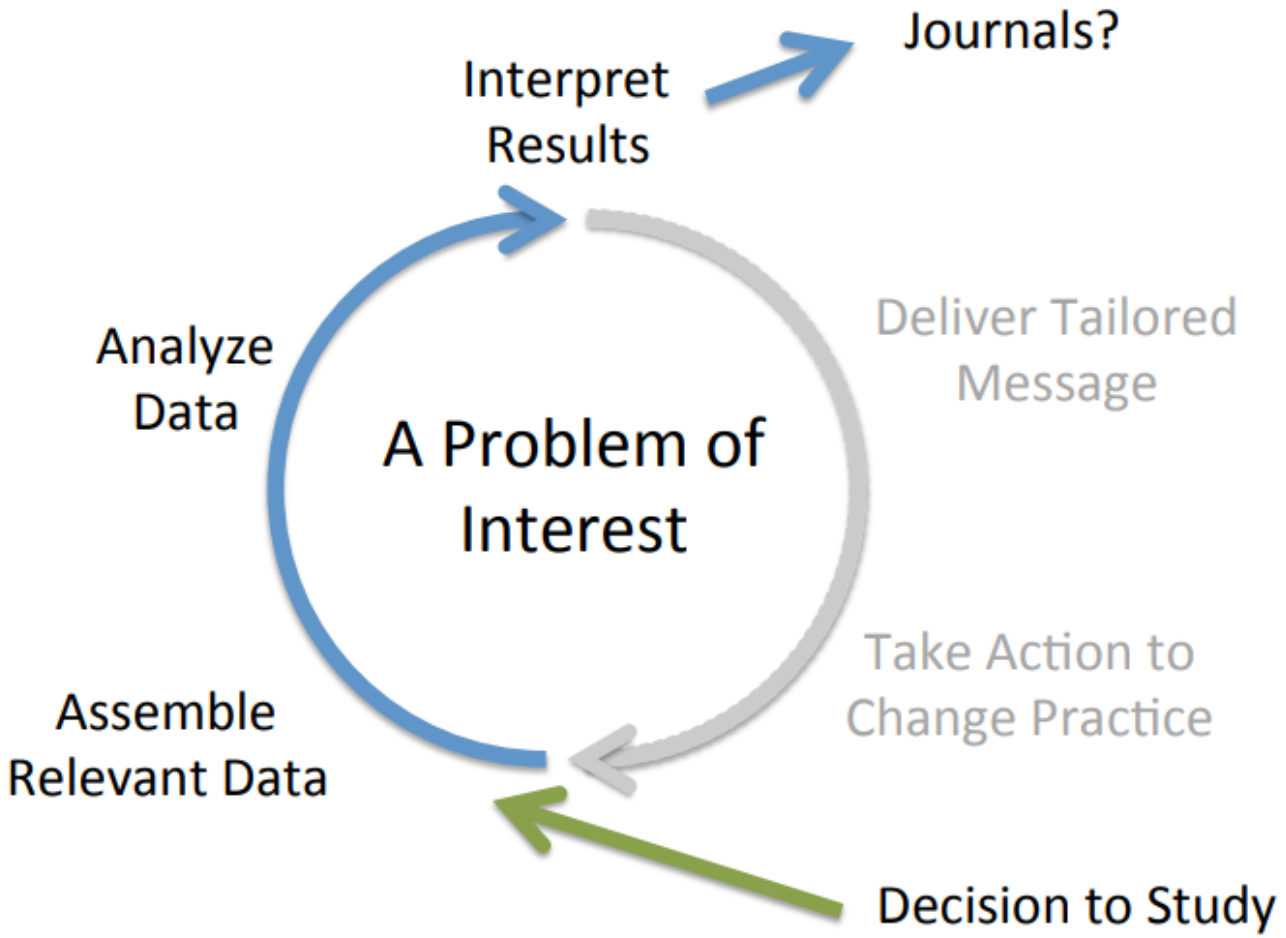
Future Health Today uses sophisticated algorithms to review patient records in general practice and automate the identification of patients who require further testing, diagnosis or management. Recommendations.....

Learning Health Systems



Charles Friedman 2014: https://medicine.umich.edu/sites/default/files/2014_12_08-Friedman-IOM%20LHS.pdf

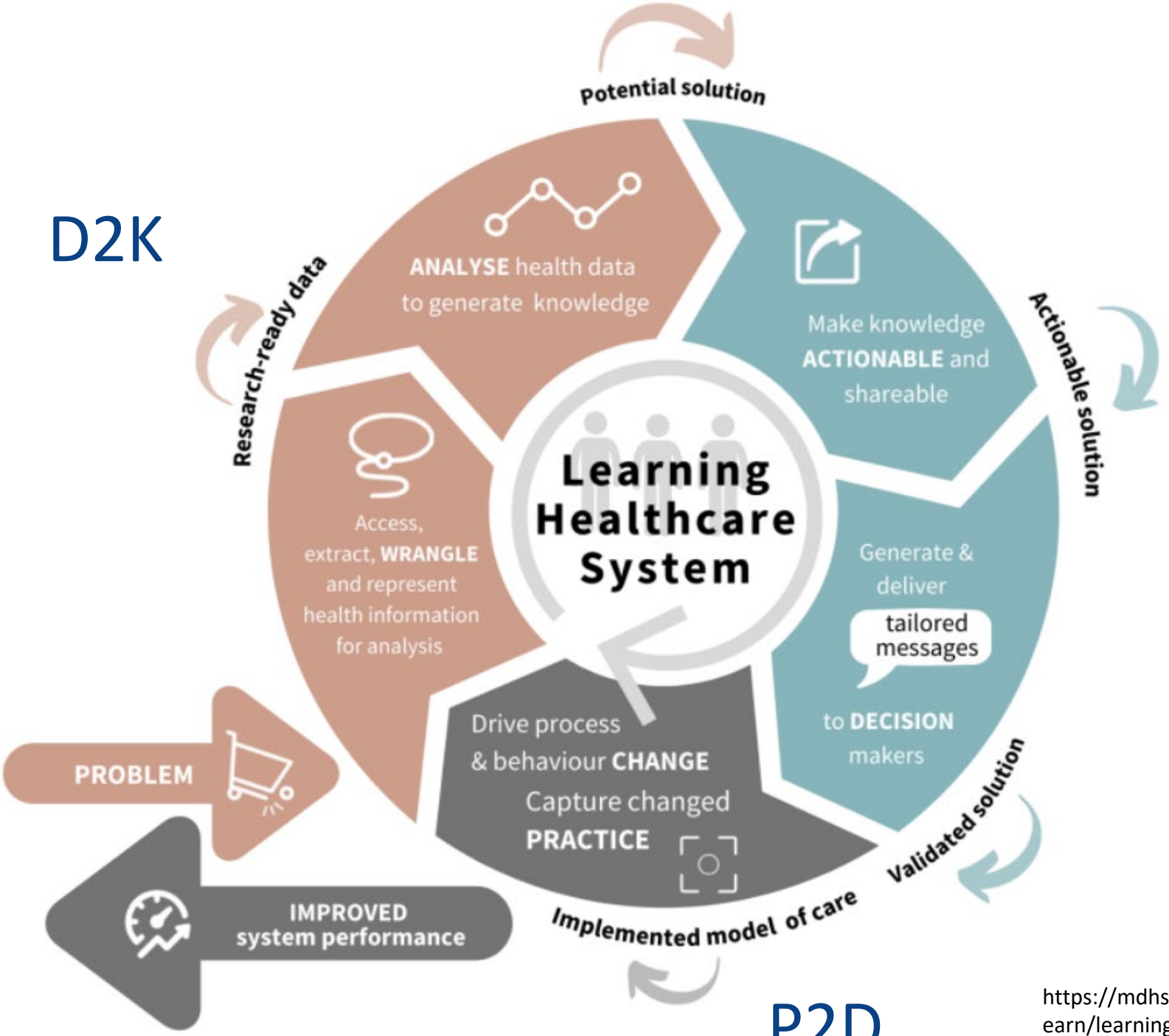
Learning Health Systems



Charles Friedman 2014: https://medicine.umich.edu/sites/default/files/2014_12_08-Friedman-IOM%20LHS.pdf

D2K

K2P



P2D

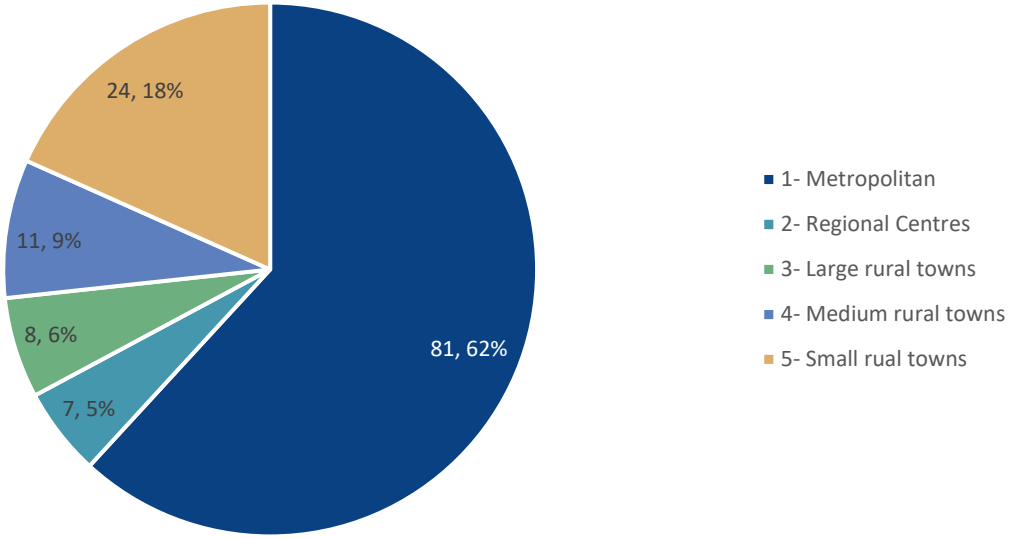
https://mdhs.unimelb.edu.au/digitalhealth/learn/learning-healthcare-system-academy

Patron dataset

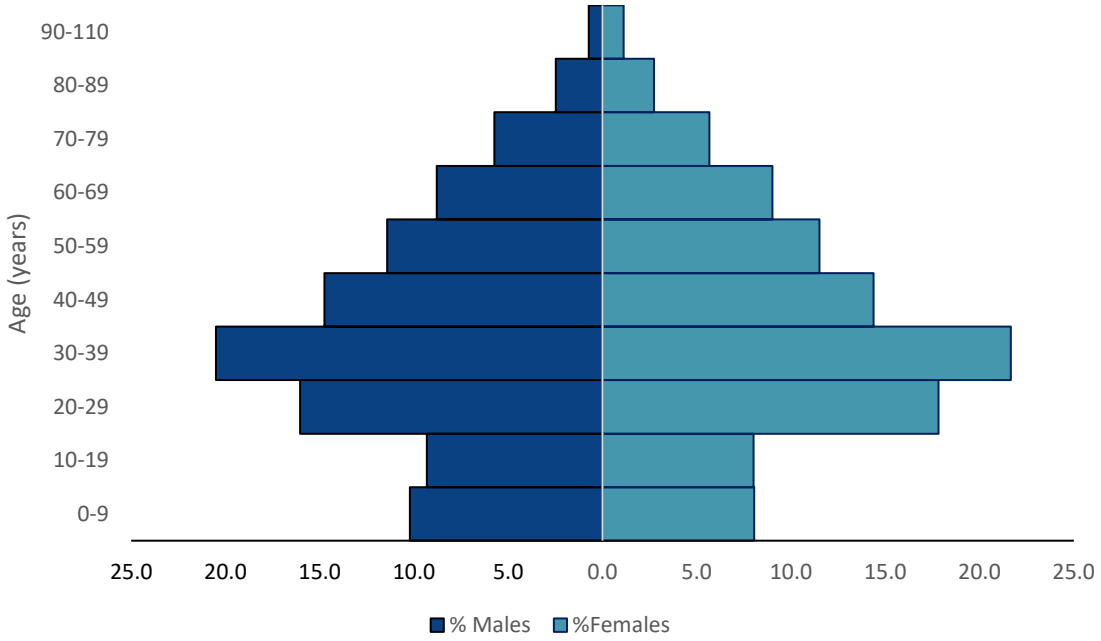
Total patient count: 5,042,008 Active patient count: 1,876,892

Adults with type 2 diabetes or pathology consistent with type 2 diabetes: 42,086

Number of practices in Patron by MMM



Sex and age distribution

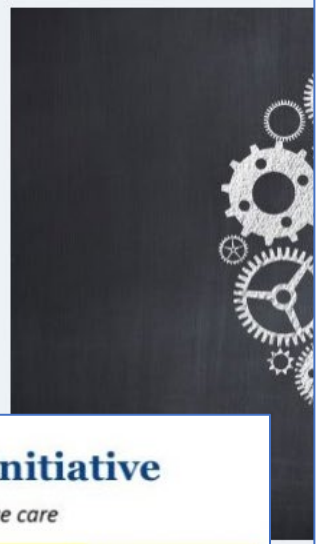


Data for Decisions and the Patron program of research

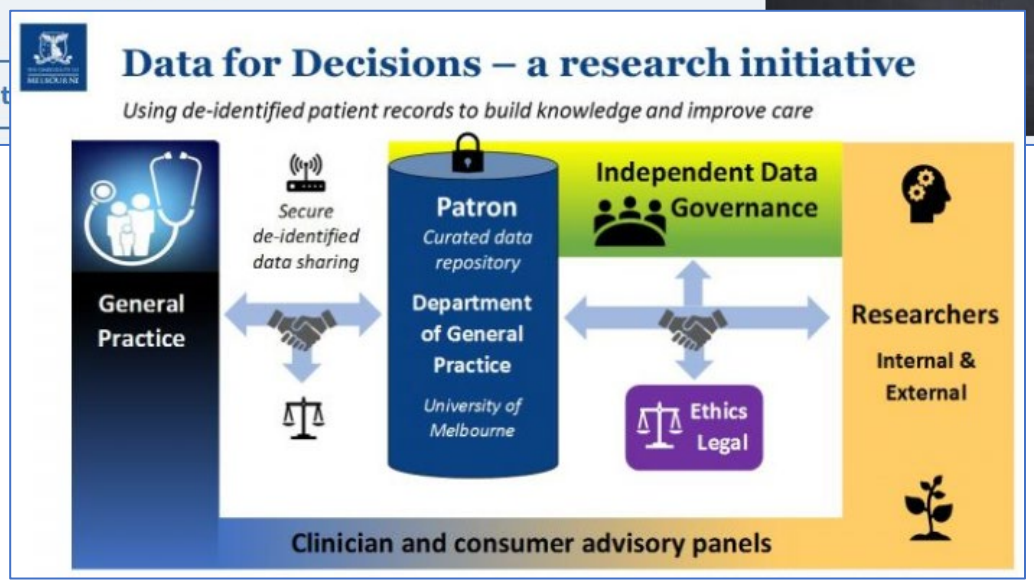
Creating knowledge from primary care data through research

Using data to expand knowledge

Data for Decisions focuses on the use of de-identified data from general practice medical records to expand knowledge and ultimately promote service and population health improvements. Every research project that accesses the data stored in the Patron primary care data repository does so only after meeting rigorous data governance and ethics requirements. Each project using Patron data is described below, and each research group will provide a reader-friendly summary of their findings, and list of resulting publications, when available.



Project Out



Projects Approved To Use Patron Data

1. Defining the burden of antimicrobial prescribing in primary care attributable to sore throat - PAT001
2. Meeting national targets and indicators to reduce mortality from chronic illness through general practice - PAT002
3. Trialing the implementation of a quality assurance framework in the Patron program - PAT004
4. GP-NAPS: The feasibility of passive audit of antibiotic prescribing in general practice - PAT005
5. Future Health Today: Detecting people at risk of chronic kidney disease - PAT009,010
6. Understanding and exploring adolescent health presentations in the Victorian primary care setting - PAT011
7. Studying the Continuum of Cancer Care through Linking Primary Data - PAT012
8. A descriptive study of the primary care use of people with a diagnosis of severe mental illness: A focus on cardiovascular and cardiometabolic health and risk factor screening - PAT013
9. Shared decision support for patients: An antimicrobial stewardship strategy to promote appropriate antibiotics use in primary care, pilot phase - PAT014

https://medicine.unimelb.edu.au/school-structure/general-practice/engagement/data-for-decisions#projects

Undercounts in standard reporting where coded GP database entries only are relied-on

	A	B	C	D	F
Disease	Patients with a coded diagnosis	Patients with a clinically validated free text diagnosis (with or without a code)	Patients with a clinically validated free text diagnosis but no coded diagnosis. (B-A = Undercount)	% undercount	P value
Asthma	46853	74038	27185	36.72	<0.001
Chronic Kidney Disease	8303	10721	2418	22.55	<0.001
Type 2 diabetes	23264	23877	613	2.57	0.004

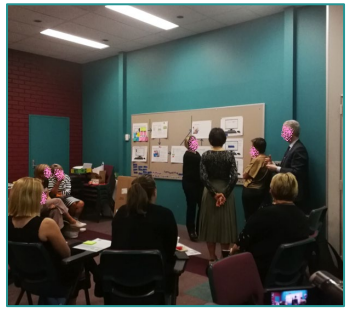
Source: https://www.researchsquare.com/article/rs-3287418/v1

Future Health Today: K2P

General practice

Majority of Australians visit general practice each year

There is a wealth of information stored in EMRs



Design by general practice

Co-design - GPs, practice nurses, practice managers, consumers

Advisory groups

Implementation study

Quality Improvement

Gap between guideline-based care and practice

Financial incentives (QIPIP)

Opportunities via digital technology

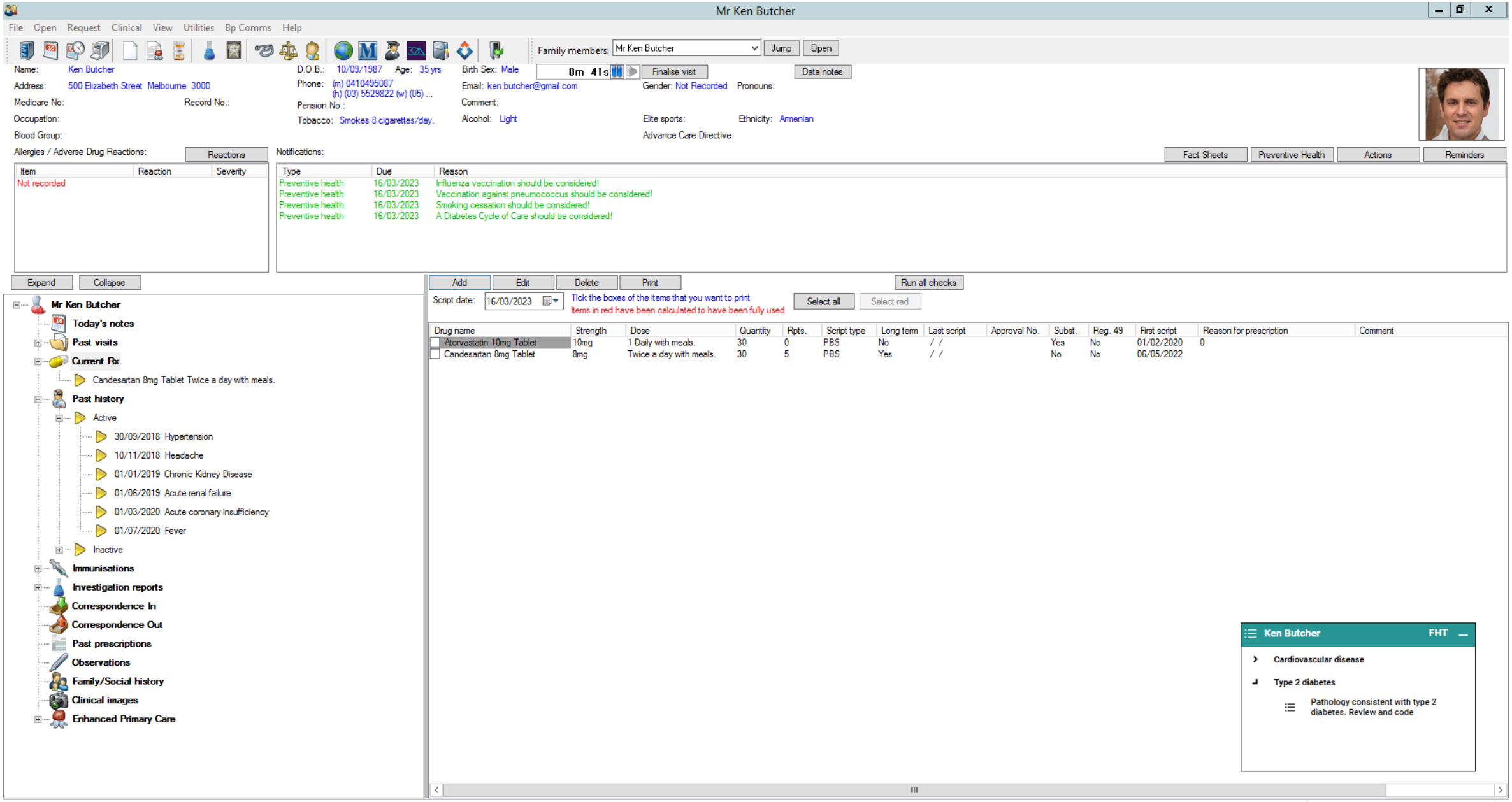
Future Health Today

Audit

Clinical decision support

Quality improvement

ECHO

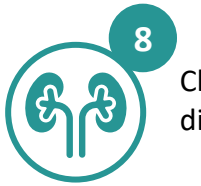

Mr Ken Butcher
File Open Request Clinical View Utilities Bp Comms Help
Family members: Mr Ken Butcher Jump Open
Name: Ken Butcher
Address: 500 Elizabeth Street Melbourne 3000
Medicare No: Record No.:
Occupation:
Blood Group:
D.O.B.: 10/09/1987 Age: 35 yrs
Phone: (m) 0410495087 (h) (03) 5529822 (w) (05) ...
Pension No.:
Tobacco: Smokes 8 cigarettes/day.
Birth Sex: Male
Email: ken.butcher@gmail.com
Comment:
Alcohol: Light
0m 41s
Finalise visit
Data notes
Gender: Not Recorded Pronouns:
Elite sports: Ethnicity: Armenian
Advance Care Directive:
Allergies / Adverse Drug Reactions:
Reactions
Item Reaction Severity
Not recorded
Notifications:
Fact Sheets Preventive Health Actions Reminders
Type Due Reason
Preventive health 16/03/2023 Influenza vaccination should be considered!
Preventive health 16/03/2023 Vaccination against pneumococcus should be considered!
Preventive health 16/03/2023 Smoking cessation should be considered!
Preventive health 16/03/2023 A Diabetes Cycle of Care should be considered!
Expand Collapse
Mr Ken Butcher
Today's notes
Past visits
Current Rx
Candesartan 8mg Tablet Twice a day with meals.
Past history
Active
30/09/2018 Hypertension
10/11/2018 Headache
01/01/2019 Chronic Kidney Disease
01/06/2019 Acute renal failure
01/03/2020 Acute coronary insufficiency
01/07/2020 Fever
Inactive
Immunisations
Investigation reports
Correspondence In
Correspondence Out
Past prescriptions
Observations
Family/Social history
Clinical images
Enhanced Primary Care
Add Edit Delete Print
Run all checks
Script date: 16/03/2023
Tick the boxes of the items that you want to print
Items in red have been calculated to have been fully used
Select all Select red
Drug name Strength Dose Quantity Rpts. Script type Long term Last script Approval No. Subst. Reg. 49 First script Reason for prescription Comment
Atorvastatin 10mg Tablet 10mg 1 Daily with meals. 30 0 PBS No / / Yes No 01/02/2020 0
Candesartan 8mg Tablet 8mg Twice a day with meals. 30 5 PBS Yes / / No No 06/05/2022
Ken Butcher FHT
Cardiovascular disease
Type 2 diabetes
Pathology consistent with type 2 diabetes. Review and code
Currently logged in: Dr Douglas Boyle (Main surgery) (7 messages)
Thursday 16/03/2023 03:25:40 PM

Conditions and recommendations

Current disease/condition areas

6 medical conditions | **54** recommendations for patient care

Cardiovascular disease



Chronic kidney disease

Risk of undiagnosed cancer

Type 2 diabetes

Sexually transmitted diseases (syphilis)

Asthma/COPD

Disease/condition areas in development for implementation studies (pilot or trial) = **7**

- Cardiovascular disease (revised recommendations)
- Chronic kidney disease (additional recommendations)
- Gestational diabetes and type 2 diabetes risk management
- Risk of undiagnosed cancer (unexpected weight loss, smoking)
- Hearing loss/hearing health (2 projects)
- Chronic respiratory disease
- Menopause

Disease/condition areas in development for simulation study only = **2**

- Type 1 diabetes (children)
- Low back pain

By end of 2025: **15** medical conditions | **68** recommendations for patient care

FUTURE HEALTH TODAY

Cohorts | Reporting | Resources | Quality Improvement | Education | Account | Disclaimer

Patients to be reviewed

Cohort name: Pathology Consistent with diabetes

ACTIONS | PRINT/EXPORT | RESET FILTERS

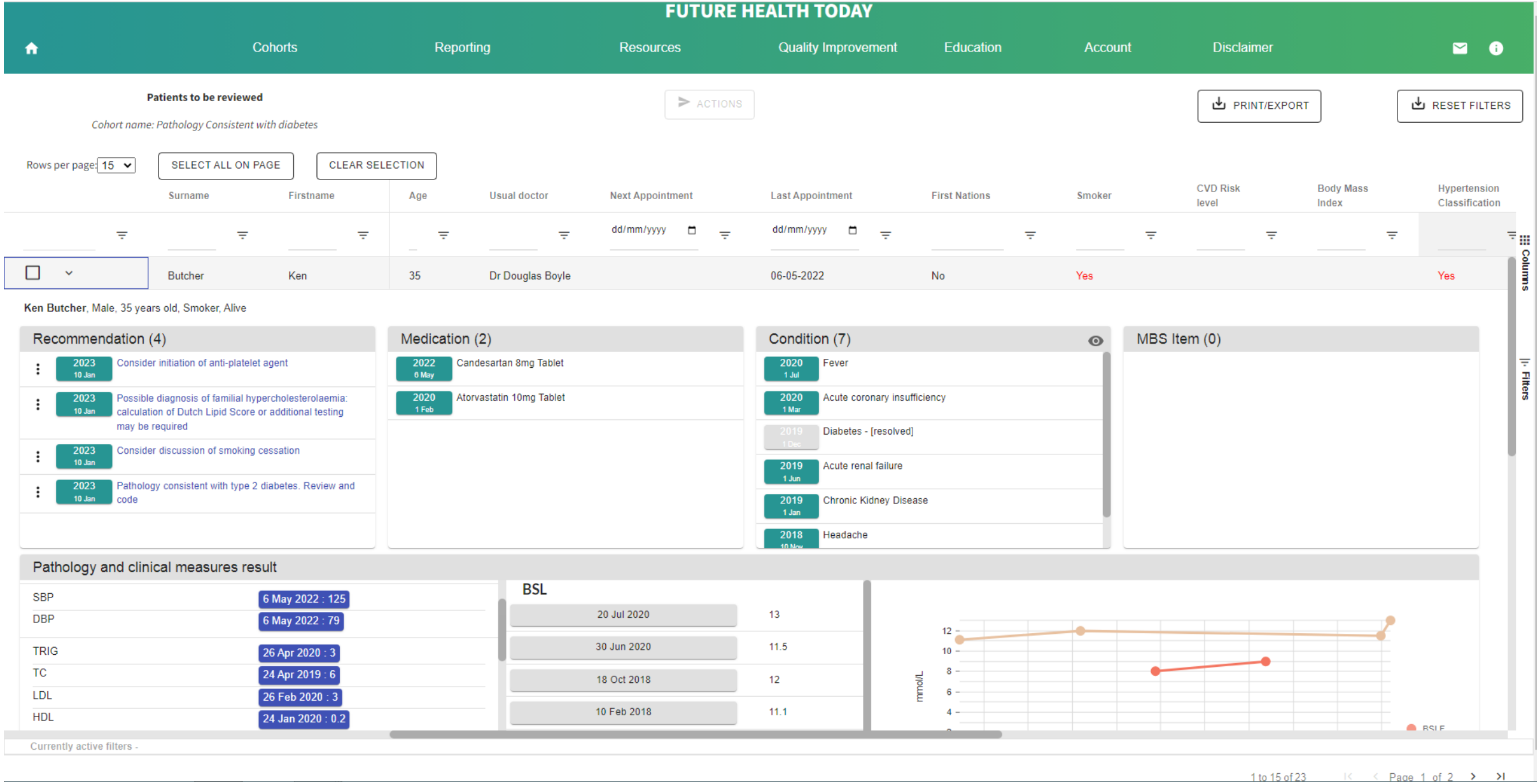
Rows per page: 15 | SELECT ALL ON PAGE | CLEAR SELECTION

Surname	Firstname	Age	Usual doctor	Next Appointment	Last Appointment	First Nations	Smoker	CVD Risk level	Body Mass Index	Hypertension Classification
				dd/mm/yyyy	dd/mm/yyyy					
Butcher	Ken	35	Dr Douglas Boyle		06-05-2022	No	Yes			Yes
Smith	Eason	42	Dr Douglas Boyle			No	No			No
Smith	Ethan	29	Dr Douglas Boyle			No	Yes			No
Smith	Sebastian	32				Yes	No			No
Wright	Andy	53	Dr Douglas Boyle		12-04-2021	Yes	No			Yes
Wright	Elian	53				No	No			No
Wright	Grady	53	Dr Douglas Boyle			No	No			No
Wright	Jonas	54	Dr Douglas Boyle		12-04-2021	No	No			No
Wright	Kasen	54	Dr Douglas Boyle			Yes	No			No
Wright	Nasir	54	Dr Douglas Boyle		12-04-2021	No	No	High		No
Wright	Remy	53	Dr Douglas Boyle			Yes	No			No
Wright	Ruben	54	Dr Douglas Boyle			Yes	No			No
Wright	Sage	67	Dr Douglas Boyle			Yes	No			No
Butcher	Hellen	43	Dr Douglas Boyle		10-06-2022	Yes	Yes			Yes
Kee	Heather	32	Dr Douglas Boyle		01-09-2021	Yes	Yes			No

Columns | Filters

Currently active filters -

1 to 15 of 23 | Page 1 of 2


FUTURE HEALTH TODAY
Cohorts
Reporting
Resources
Quality Improvement
Education
Account
Disclaimer
Patients to be reviewed
Cohort name: Pathology Consistent with diabetes
ACTIONS
PRINT/EXPORT
RESET FILTERS
Rows per page: 15
SELECT ALL ON PAGE
CLEAR SELECTION
Surname
Firstname
Age
Usual doctor
Next Appointment
Last Appointment
First Nations
Smoker
CVD Risk level
Body Mass Index
Hypertension Classification
Butcher
Ken
35
Dr Douglas Boyle
06-05-2022
No
Yes
Yes
Ken Butcher, Male, 35 years old, Smoker, Alive
Recommendation (4)
2023 10 Jan Consider initiation of anti-platelet agent
2023 10 Jan Possible diagnosis of familial hypercholesterolaemia: calculation of Dutch Lipid Score or additional testing may be required
2023 10 Jan Consider discussion of smoking cessation
2023 10 Jan Pathology consistent with type 2 diabetes. Review and code
Medication (2)
2022 6 May Candesartan 8mg Tablet
2020 1 Feb Atorvastatin 10mg Tablet
Condition (7)
2020 1 Jul Fever
2020 1 Mar Acute coronary insufficiency
2019 1 Dec Diabetes - [resolved]
2019 1 Jun Acute renal failure
2019 1 Jan Chronic Kidney Disease
2018 Headache
MBS Item (0)
Pathology and clinical measures result
SBP 6 May 2022 : 125
DBP 6 May 2022 : 79
TRIG 26 Apr 2020 : 3
TC 24 Apr 2019 : 6
LDL 26 Feb 2020 : 3
HDL 24 Jan 2020 : 0.2
BSL
20 Jul 2020 13
30 Jun 2020 11.5
18 Oct 2018 12
10 Feb 2018 11.1
mmol/L
12
10
8
6
4
BSLF
Columns
Filters
Currently active filters -
1 to 15 of 23
Page 1 of 2

Cohorts | Reporting | Resources | Quality Improvement | Education | Account | Disclaimer

Review Cohort

Cohort

Pathology Consistent with diabetes

Created on: 16-03-2023

Cohort disease: Type 2 diabetes

Cohort Criteria:

Pathology consistent with type 2 diabetes. Review and code

DELETE COHORT

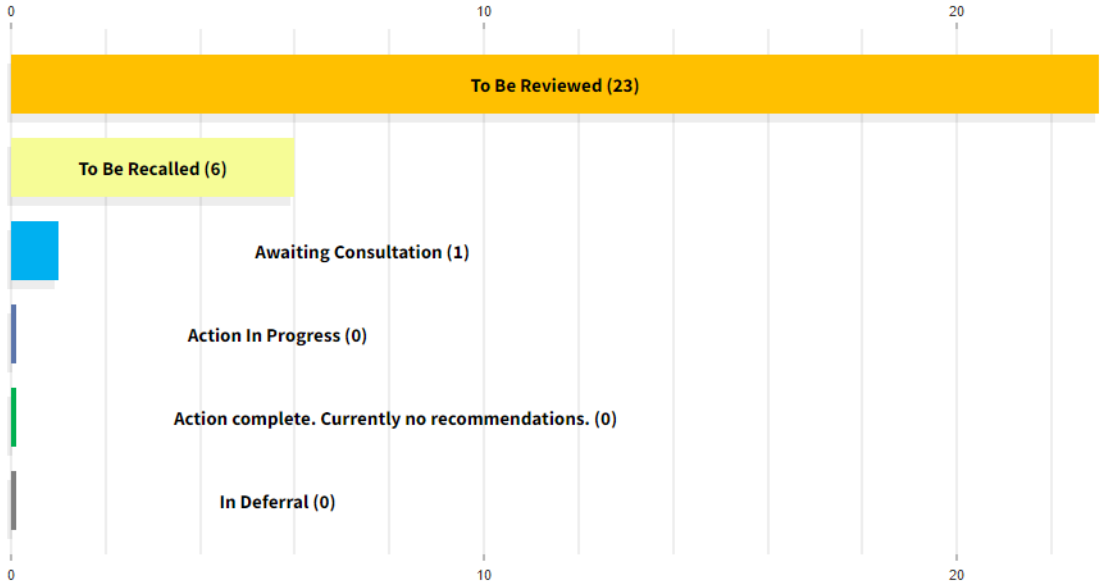
30 Patients still with active cohort recommendations

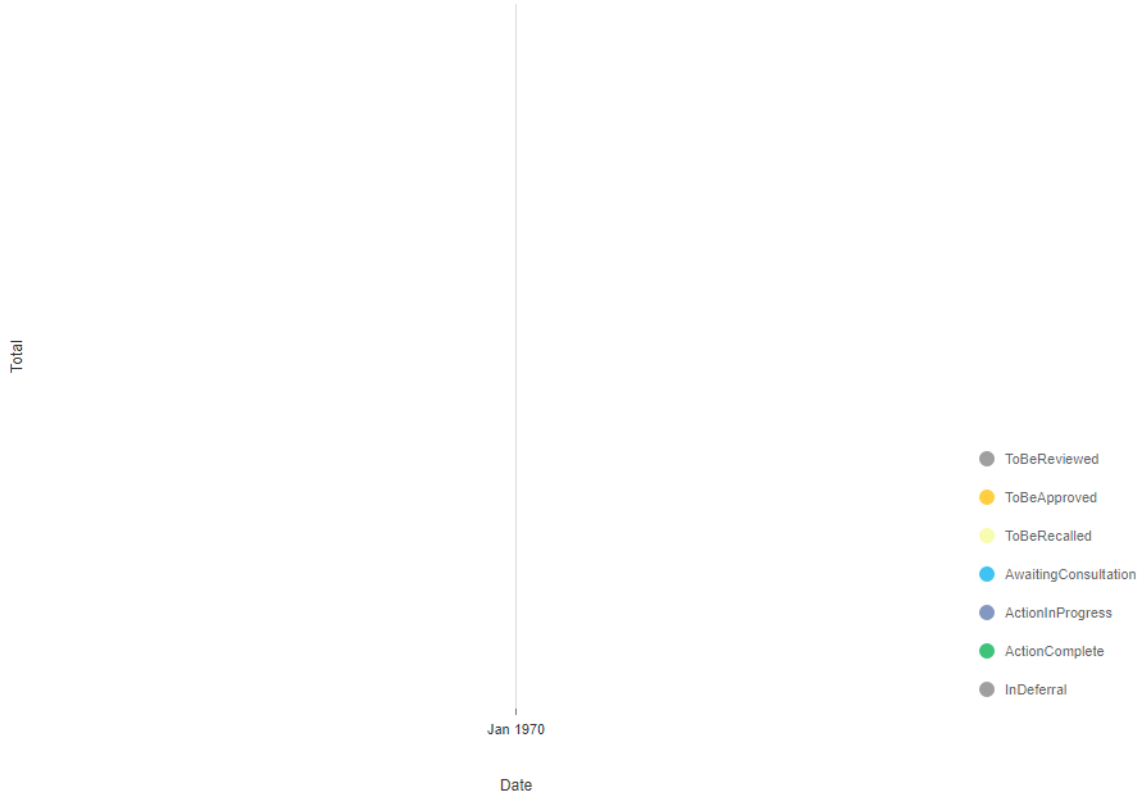
30 Patients in the entire cohort

0 REVIEW NEW POTENTIAL PATIENTS +

Patient Status

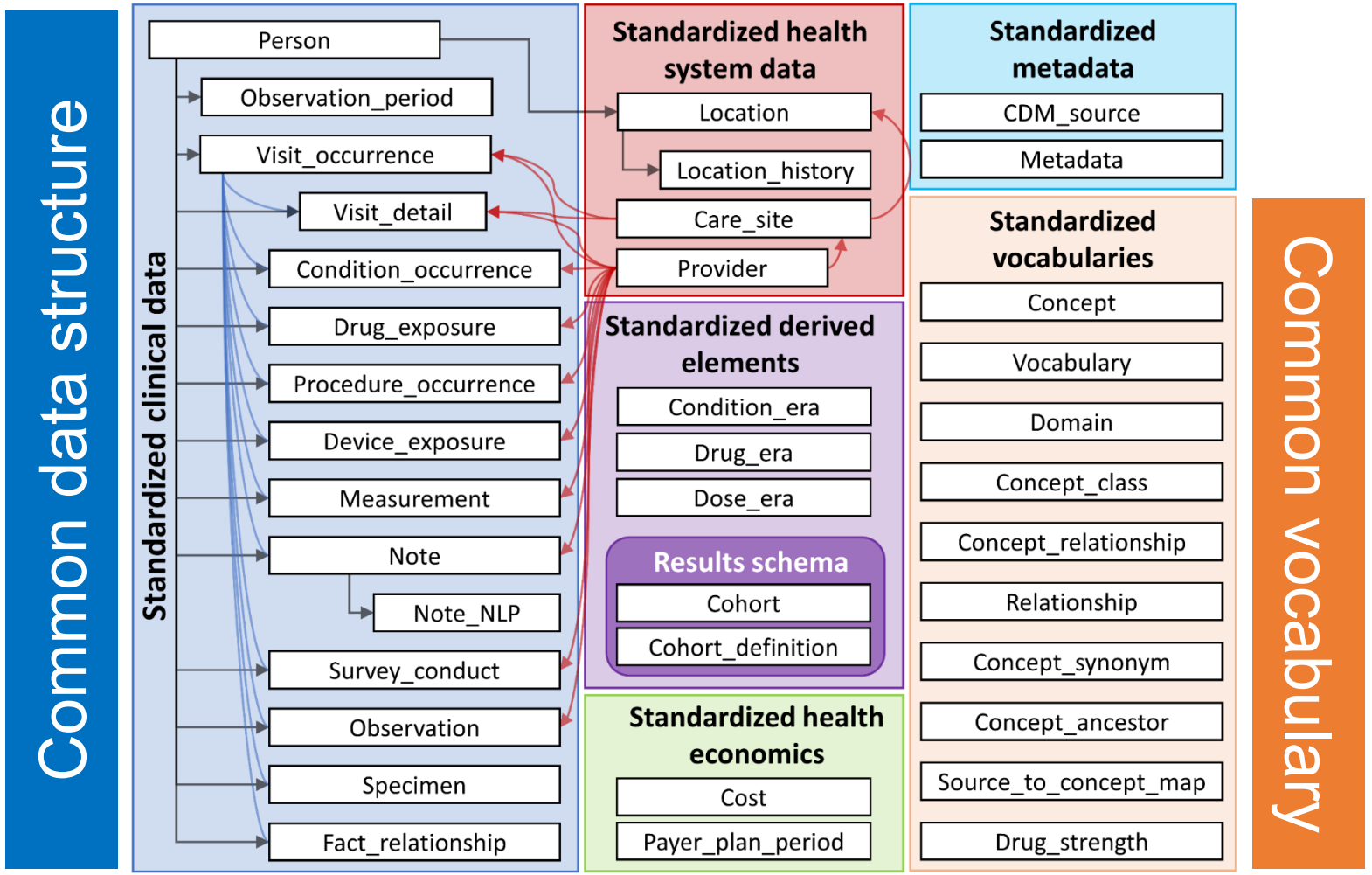
Click on the graph bars below to see the patients within the status, or click **here** to view all patients.

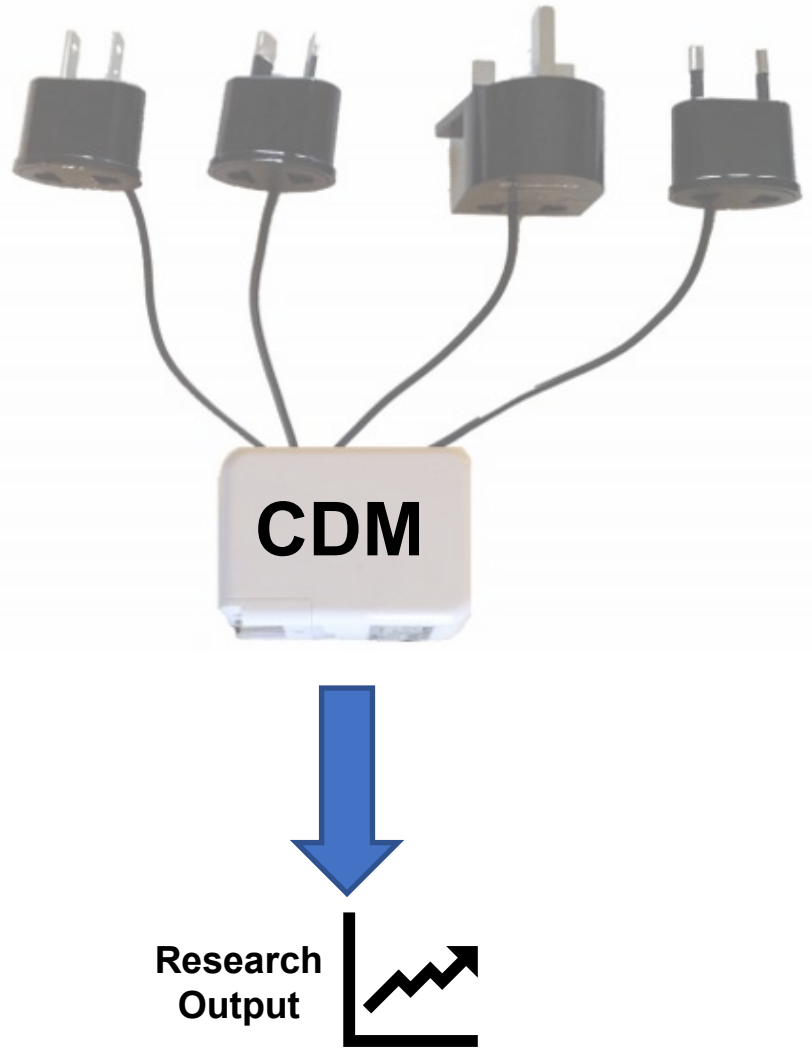




To create or modify a QI activity for this cohort, click **here.**

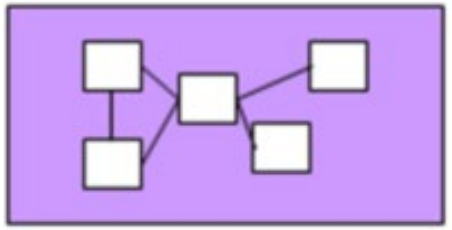
The OMOP Common Data Model





OMOP – Observational Medical Outcomes Partnership

GP Records



- Data Application
- Ethics
- Consent Mechanisms
- Data Management Plan
- Data cleansing
- $$$ + Time

Analysis

Research Output

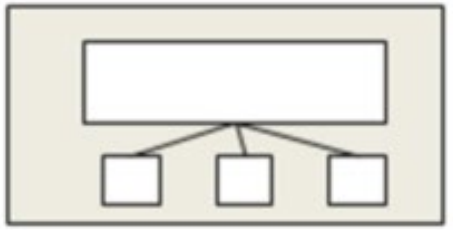
Hospital EMR

- Data Application
- Ethics
- Consent Mechanisms
- Data Management Plan
- Data cleansing
- $$$ + Time

Analysis

Research Output

Disease Registries



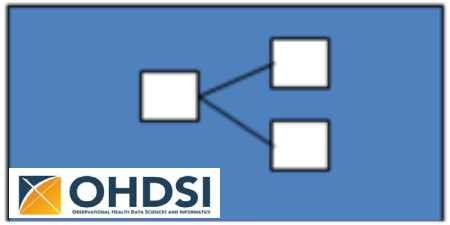
- Data Application
- Ethics
- Consent Mechanisms
- Data Management Plan
- Data cleansing
- $$$ + Time

Analysis

Research Output

THE UNIVERSITY OF MELBOURNE

GP Records

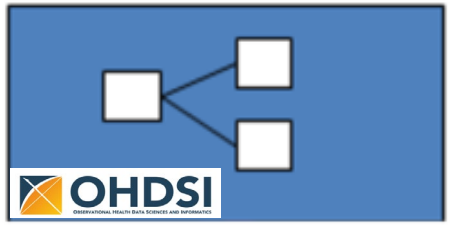


- Simplified ethics and governance
- Request study model run on repository
- No data cleansing
- $ + Fast

Results

Research Output

Hospital EMR



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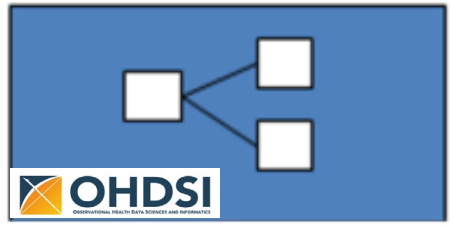
Results

Research Output

Disease Registries

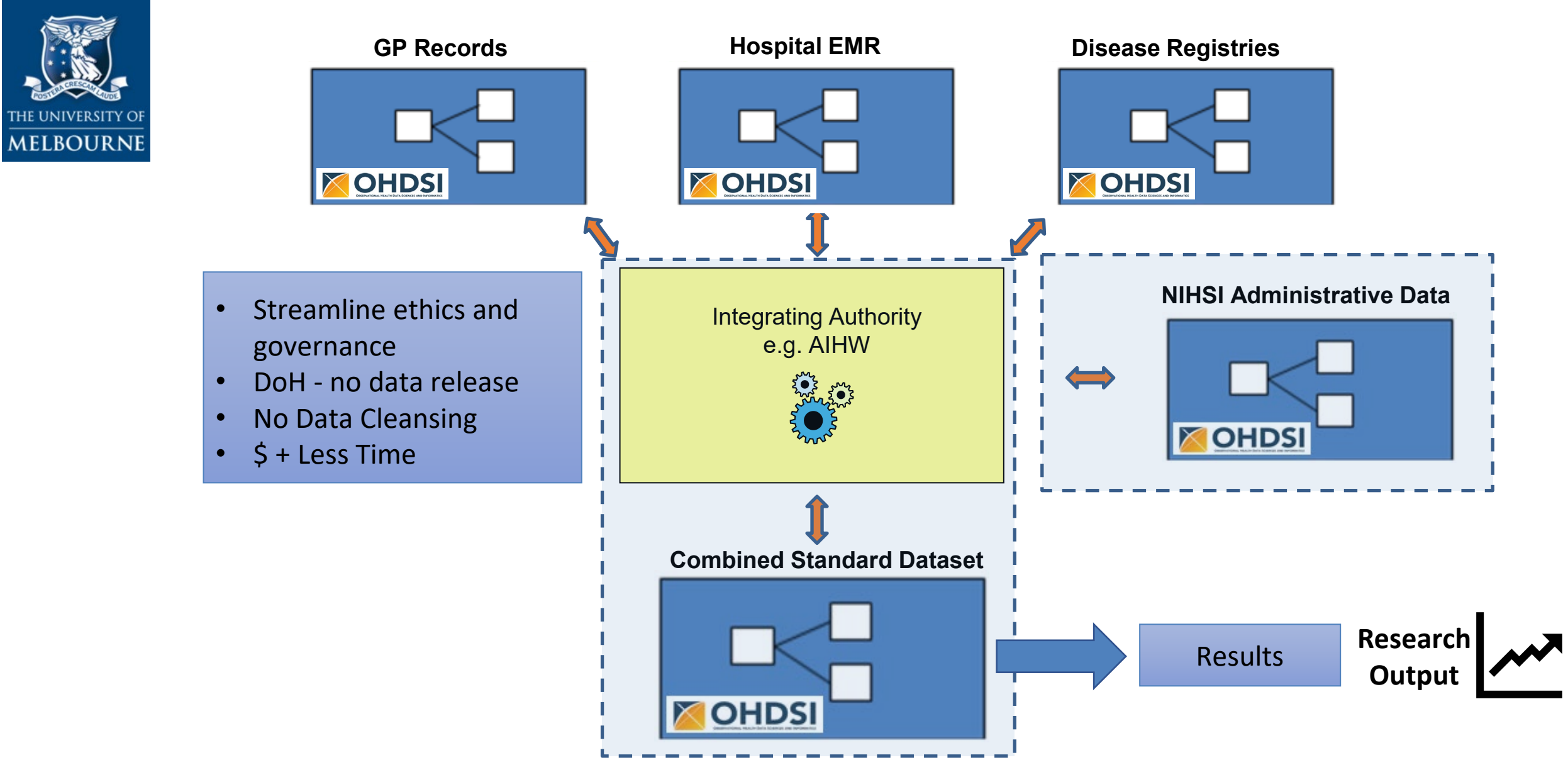


- Simplified ethics and governance
- Request study model run on repository
- No data cleansing
- $ + Fast

Results

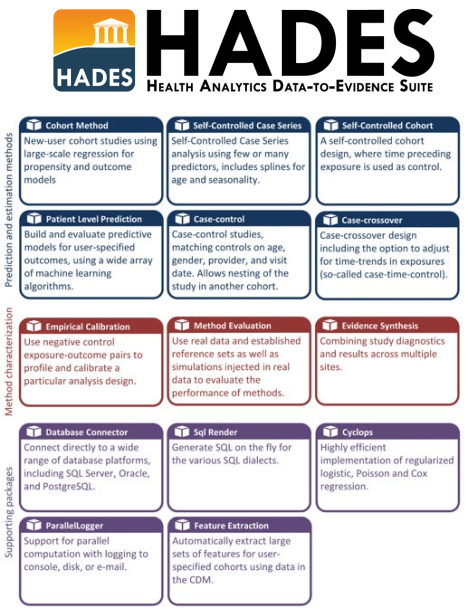
Research Output

Combine Output



Common data models - accelerating research

OHDSI
OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS



HADES

HEALTH ANALYTICS DATA-TO-EVIDENCE SUITE

HADES (formally known as the **OHDSI Methods Library**) is a set of open source R packages for large scale analytics, including population characterization, population-level causal effect estimation, and patient-level prediction.

The packages offer R functions that together can be used to perform an observation study from data to estimates and supporting statistics, figures, and tables. The packages interact directly with observational data in the Common Data Model (CDM), and are designed to support both large datasets and large numbers of analyses (e.g. for testing many hypotheses including control hypotheses, and testing many analyses design variations). For this purpose, each Method package includes functions for specifying and subsequently executing multiple analyses efficiently. HADES supports best practices for use of observational data as learned from previous and ongoing research, such as transparency, reproducibility, as well as measuring of the operating characteristics of methods in a particular context and subsequent empirical calibration of estimates produced by the methods.

HADES has already been used in many published clinical and methodological studies, as can be seen in the Publications section.

https://ohdsi.github.io/Hades/#Learn_How_to_Use_HADES

https://ohdsi.github.io/Hades/packages.html

OMOP via ATLAS – Snapshot of Patron Data – June 2022

ATLAS Data Source Patron
People 2.182 Million

Search
Search the OMOP standard vocabulary to navigate data

Concept Sets
Create reusable codes

Cohort Definitions
Construct a cohort based on inclusion and exclusion criteria

Characterisations
Summarise characteristics of cohort/s

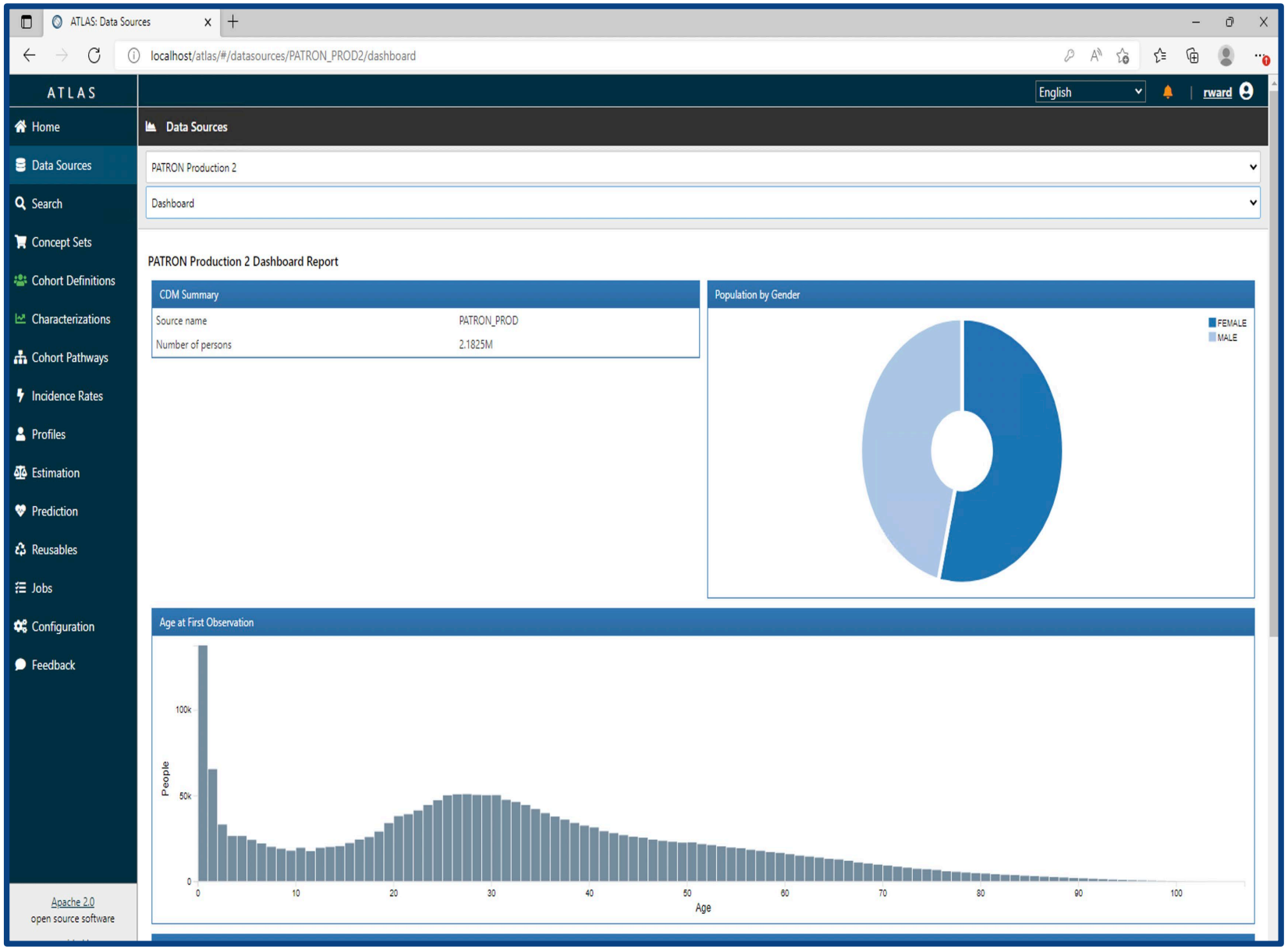
Cohort Pathways
Review sequence of clinical events within each cohort

Incidence Rates
Incidence of outcome of interest within cohort

Profiles
Exploration of longitudinal patient data

Estimation
Population-level estimation studies using comparative cohort designs

Prediction
Patient-level prediction machine-learning algorithms



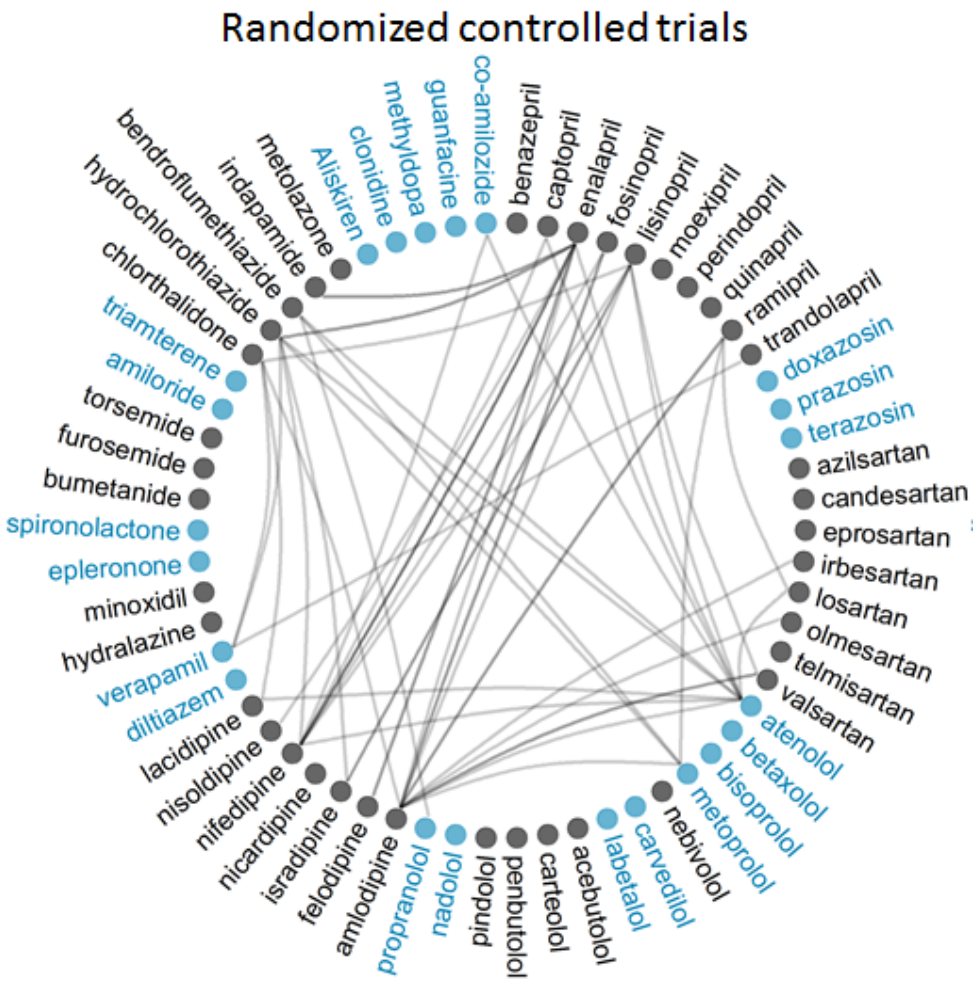
LEGEND

LARGE-SCALE EVIDENCE GENERATION AND EVALUATION IN A NETWORK OF DATABASES

Goal: To generate real world evidence on the effects of medical interventions using observational healthcare data to support clinical decision making

How: Developing a comprehensive framework for doing observational health-care science at scale

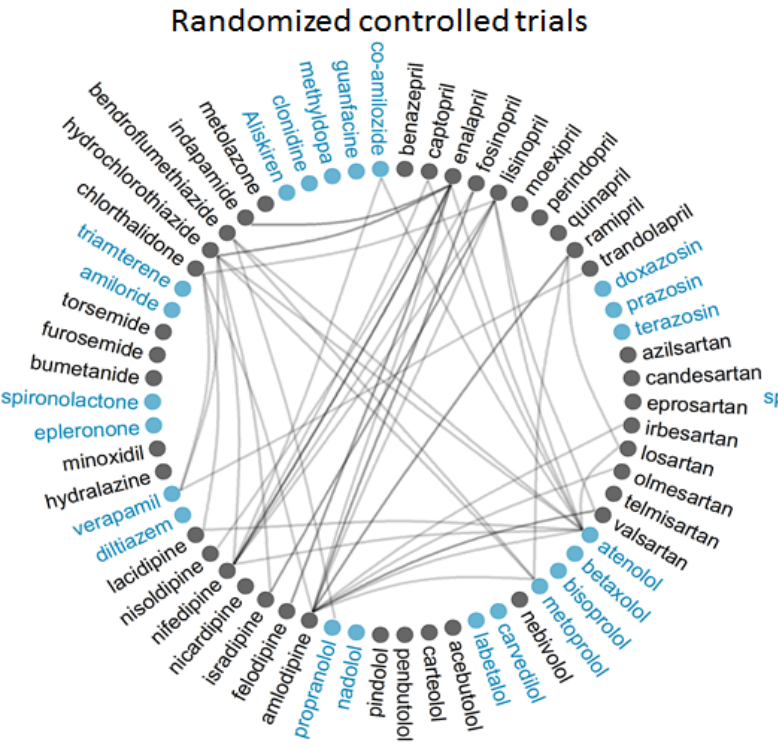
Clinical data to inform guidelines on first line treatments for Hypertension?



OHDSI in action……

LEGEND

Large-scale Evidence Generation and Evaluation in a Network of Databases



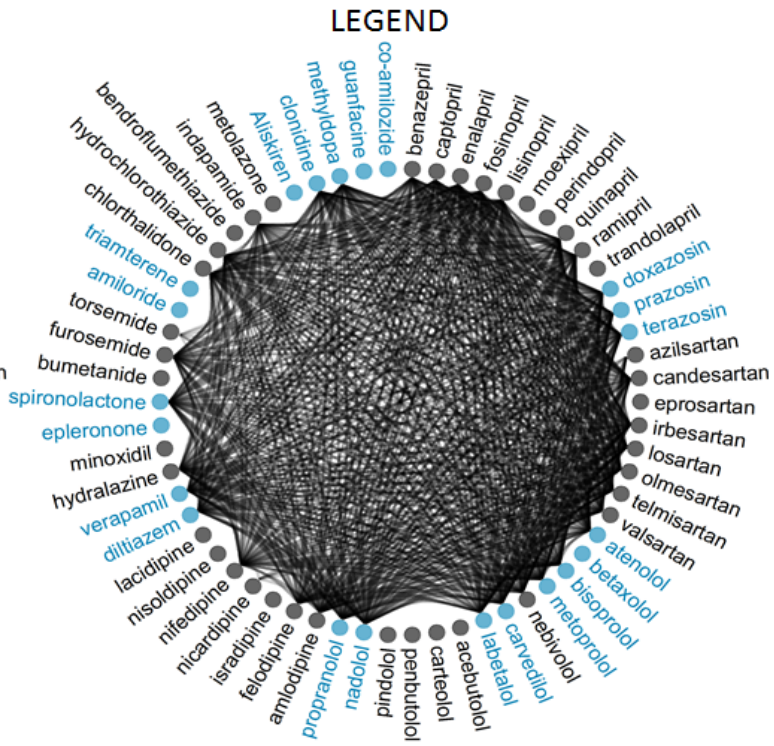


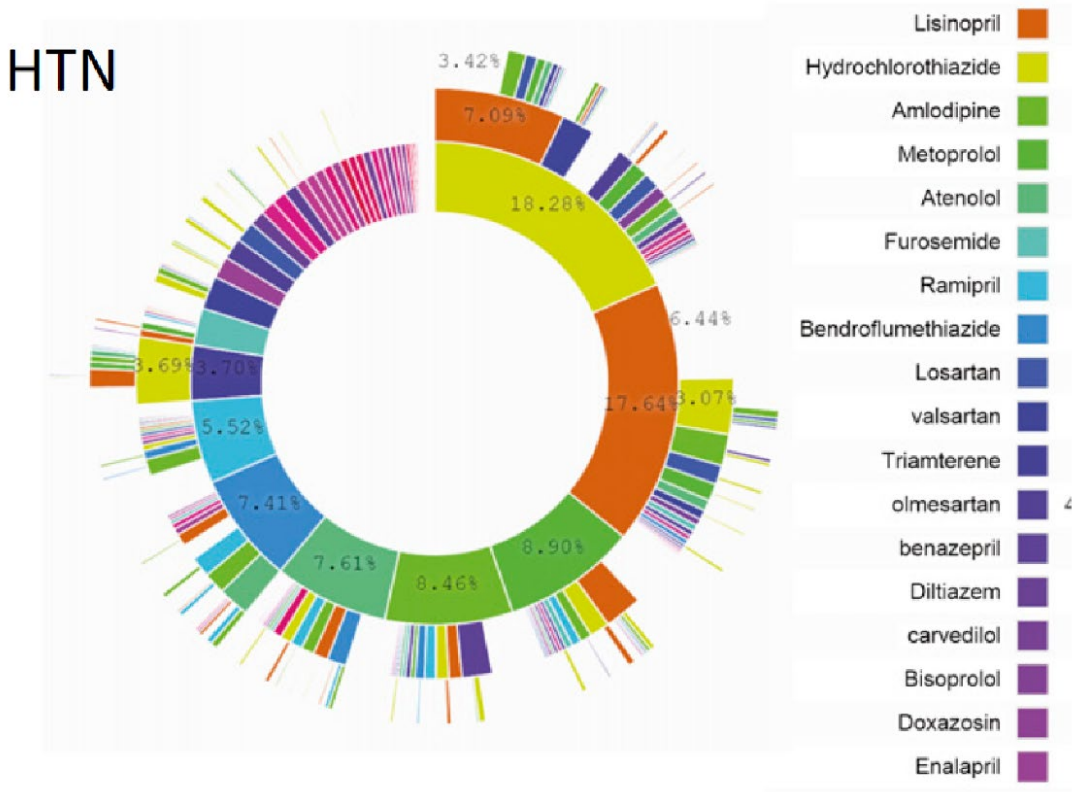
Table 2. Health outcomes of interest

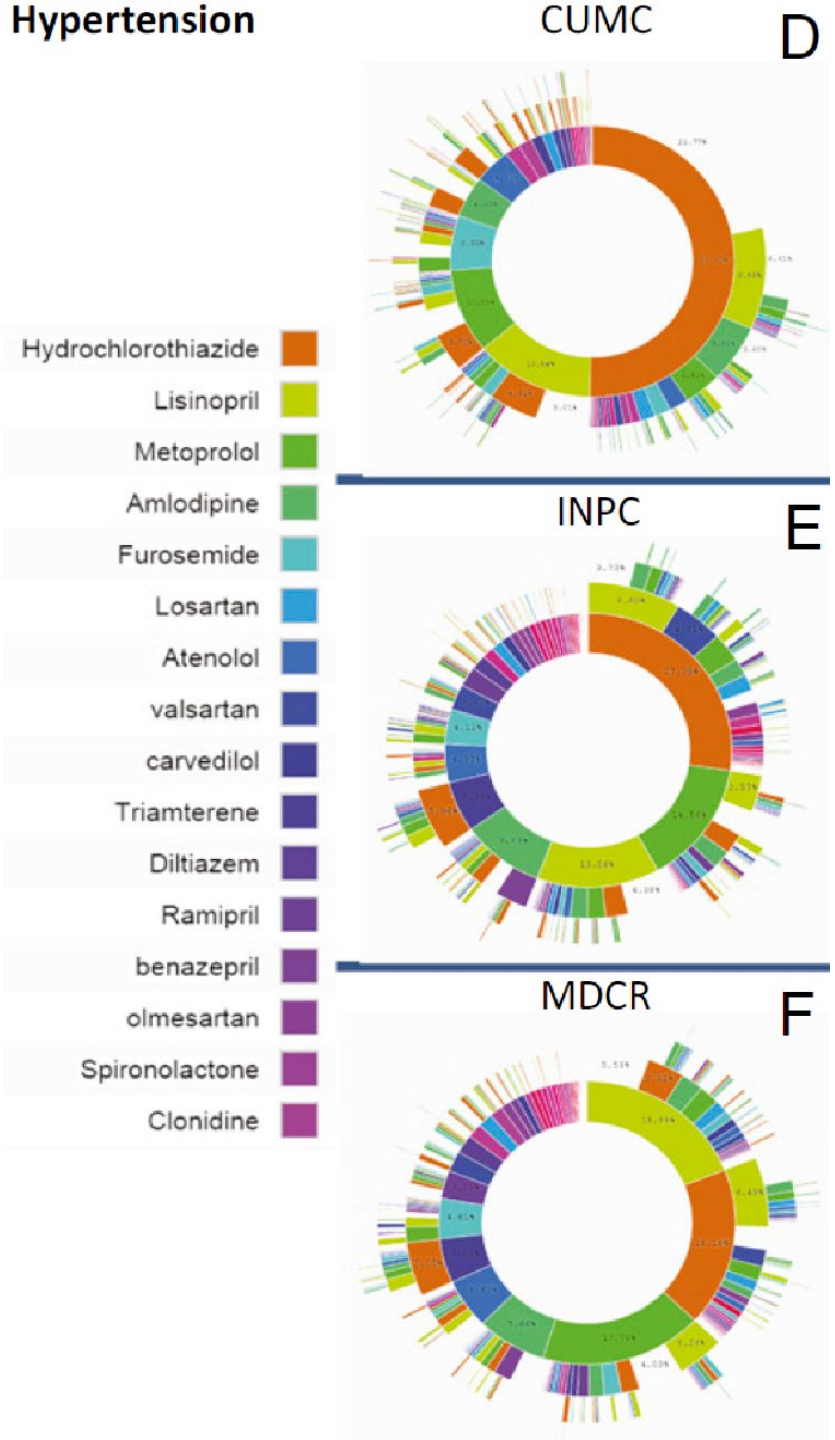
Abdominal pain	Dementia	Ischemic stroke
Abnormal weight gain	Depression	Malignant neoplasm
Abnormal weight loss	Diarrhea	Measured renal dysfunction
Acute myocardial infarction	End stage renal disease	Nausea
Acute pancreatitis	Fall	Neutropenia or agranulocytosis
Acute renal failure	Gastrointestinal bleeding	Rash
All-cause mortality	Gout	Rhabdomyolysis
Anaphylactoid reaction	Headache	Stroke
Anemia	Heart failure	Sudden cardiac death
Angioedema	Hemorrhagic stroke	Syncope
Anxiety	Hepatic failure	Thrombocytopenia
Bradycardia	Hospitalization with heart failure	Transient ischemic attack
Cardiac arrhythmia	Hospitalization with preinfarction syndrome	Type 2 diabetes mellitus
Cardiovascular event	Hyperkalemia	Vasculitis
Cardiovascular-related mortality	Hypokalemia	Venous thromboembolic events
Chest pain or angina	Hypomagnesemia	Vertigo
Chronic kidney disease	Hyponatremia	Vomiting
Cough	Hypotension	
Decreased libido	Impotence	

Enhancing the evidence base for choice of first line hypertension treatment

Standardised Outputs

N=250 million, 11 different databases, 4 countries





Hripcsak G. *et al.* Characterising treatment pathways at scale using the OHDSI network PNAS 2016

THE LANCET

Comprehensive comparative effectiveness and safety of first-line antihypertensive drug classes: a systematic, multinational, large-scale analysis

Marc A Suchard, Martijn J Schuemie, Harlan M Krumholz, Seng Chan You, RuiJun Chen, Nicole Pratt, Christian G Reich, Jon Duke, David Madigan, George Hripcsak, Patrick B Ryan

Summary

Background Uncertainty remains about the optimal monotherapy for hypertension, with current guidelines recommending any primary agent among the first-line drug classes thiazide or thiazide-like diuretics, angiotensin-converting enzyme inhibitors, angiotensin receptor blockers, dihydropyridine calcium channel blockers, and non-dihydropyridine calcium channel blockers, in the absence of comorbid indications. Randomised trials have not further refined this choice.

Published Online
October 24, 2019
https://doi.org/10.1016/S0140-6736(19)32317-7

See Online/Comment
https://doi.org/10.1016/S0140-6736(19)32461-4

4.9M patients, 22 000 calibrated, propensity score adjusted hazard ratios

Patron OMOP via ATLAS – Data Snapshot – June 2022

Highlighted in green on left-hand navigation

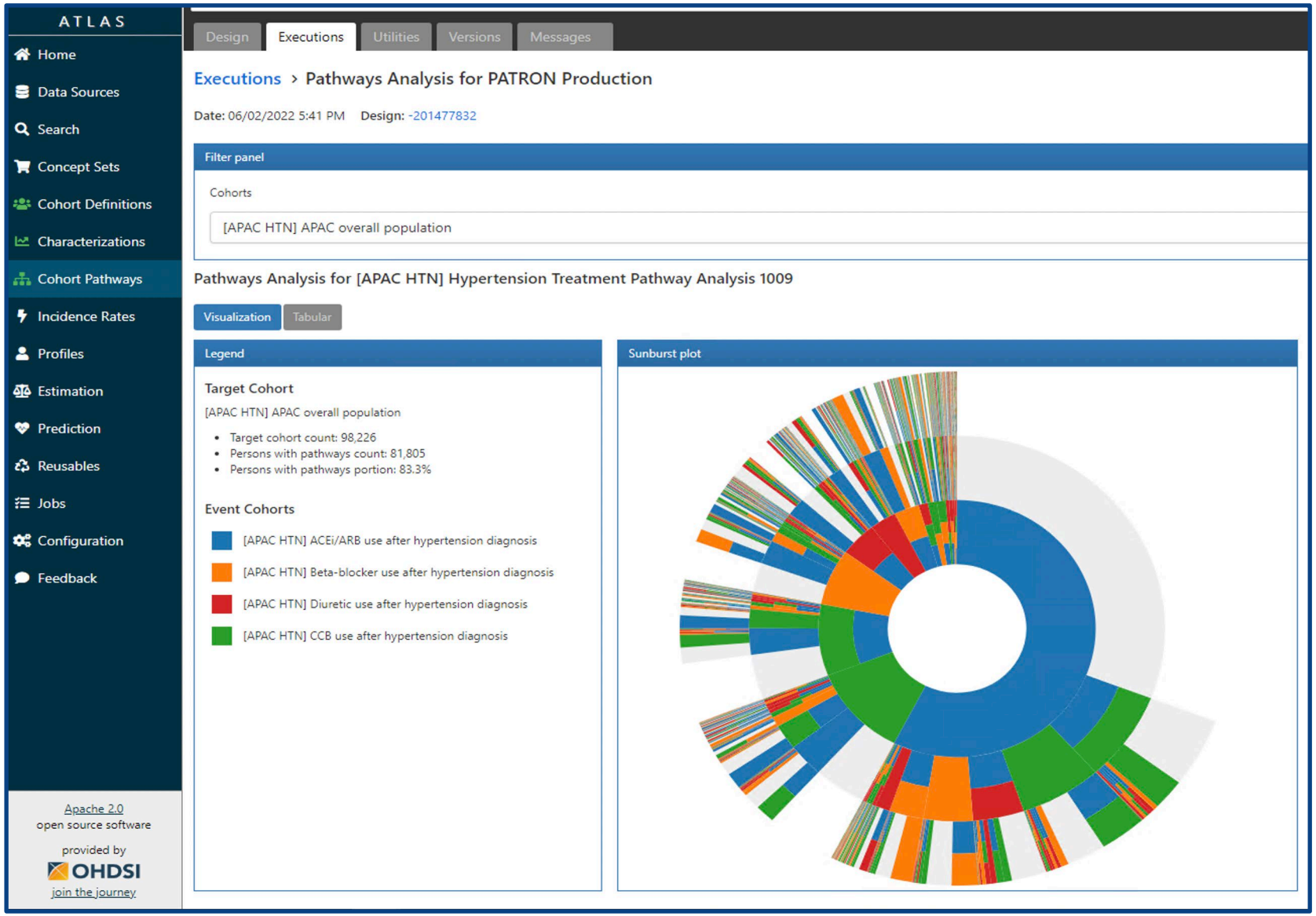
Cohort Definitions
Asia Pacific Community (Australia, China, Japan, Singapore, South Korea, Taiwan)

Characterisations
Hypertension

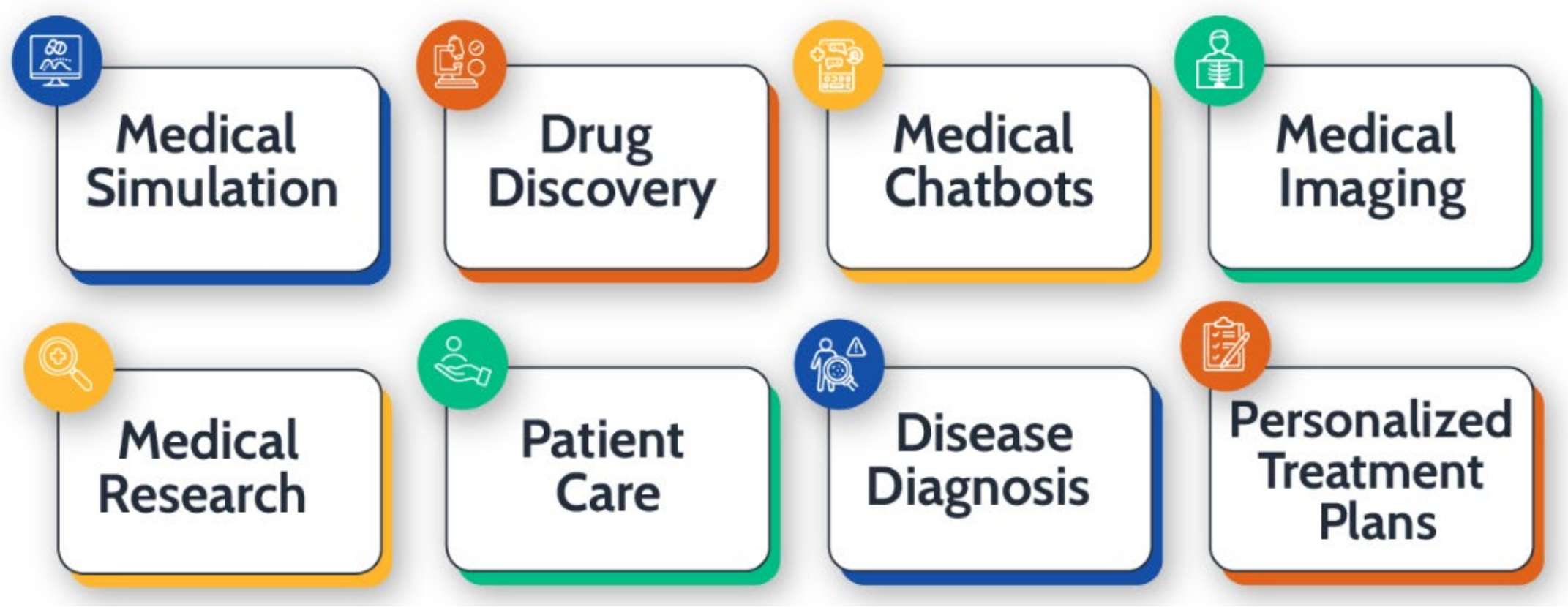
Cohort Pathways
Hypertension ACE/ARB, Beta-blocker, Diuretic, and Calcium Channel-blocker treatment pathway

Output
Provides cohort treatment pathways across time.

Top treatment pathway
Most common first line therapy for the whole cohort is ACE/ARBs
These plots can be split to demonstrate treatment pathways for each of the different countries in the study.



Generative AI – Top AI Use-Cases in Healthcare



AI.Care 2023 Agenda - Program (digitalhealth.org.au)

https://www.xenonstack.com/blog/generative-ai-healthcare

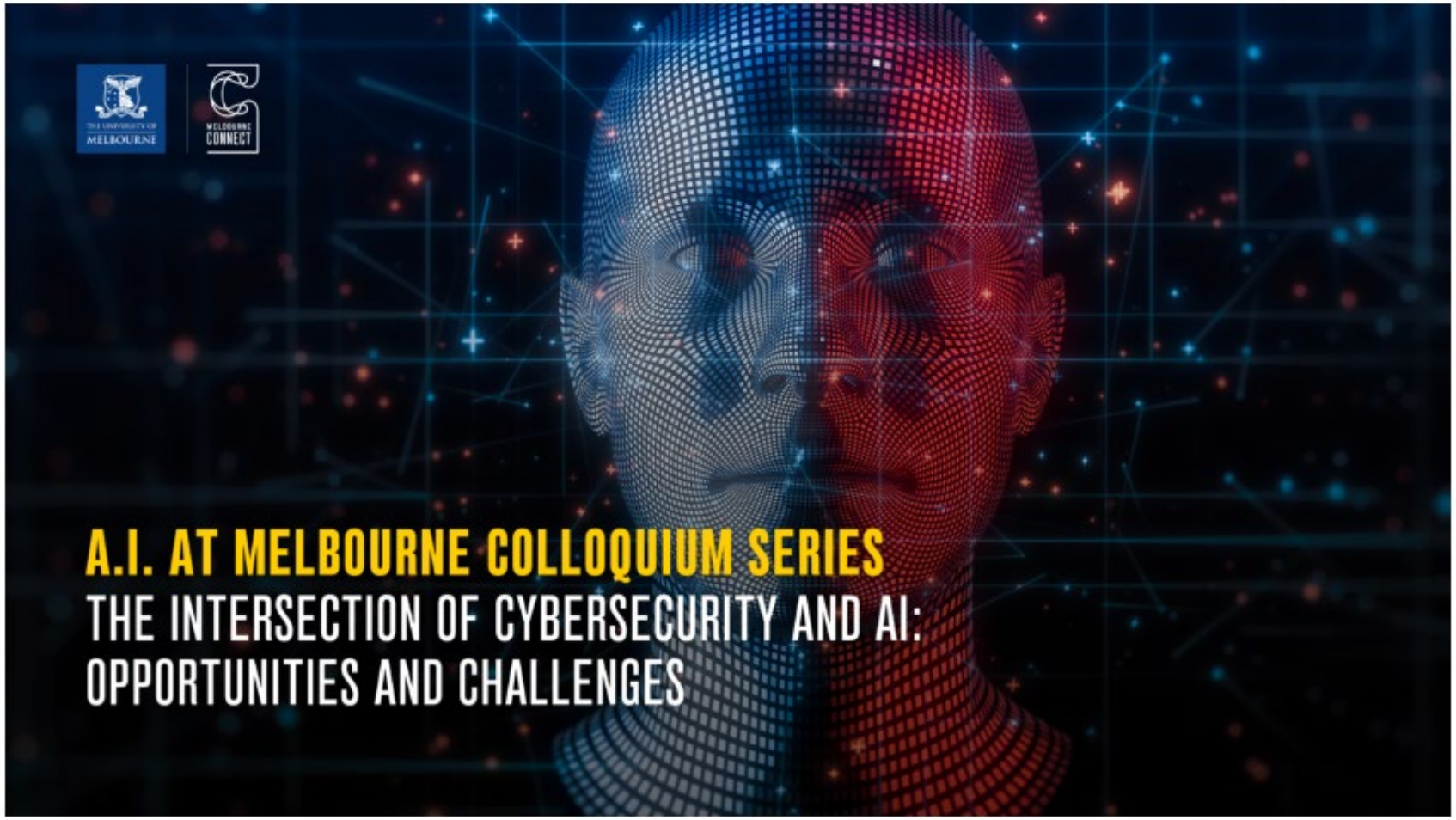
AI+ CARE
ADVANCING DATA-DRIVEN HEALTHCARE

When and where

AI.Care 2023 will take place at **Crown Melbourne on Wednesday 22 November and Thursday 23 November 2023.**

https://digitalhealth.org.au/ai-care/

AI@Melbourne Colloquium Series - The Intersection of Cybersecurity and AI: Opportunities and Challenges



WHAT IS IT

In today's digital economy, where data breaches plague industry and government alike, the fusion of Cybersecurity and Artificial Intelligence (AI) has emerged as a potent defense strategy. This talk explores the symbiotic relationship between AI and cybersecurity, delving into both its promises and perils.

WHEN

27/10/2023 10:30am - 11:30am

WHERE

Melbourne Connect, The Studio (Ground Level)

https://melbconnect.com.au/events/ai-melbourne-colloquium-series-the-intersection-of-cybersecurity-and-ai

Thank you

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