

# Lumos

## Queensland Data Linkage Symposium 2024

Lumos



phn

An Australian Government Initiative

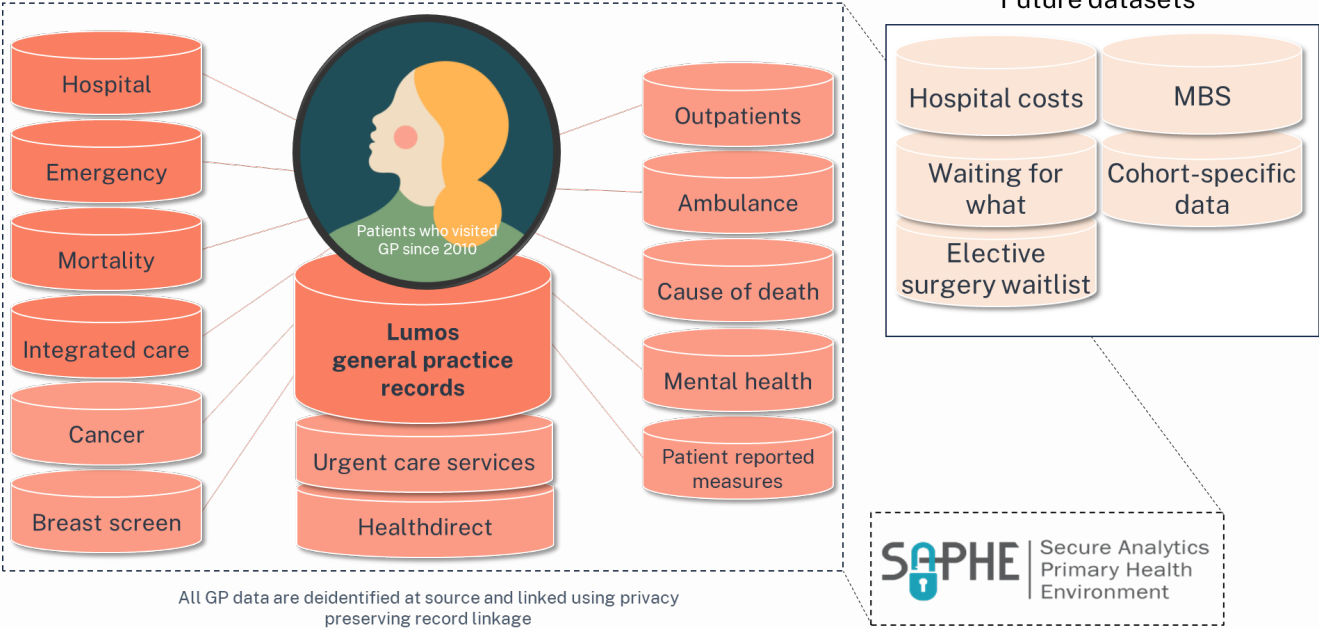


# What is Lumos?

Lumos links GP and NSW hospital data to:

- provide a comprehensive view of patient journeys across health sectors
- drive value-based care and evidence-based system improvement
- inform a health landscape about patients, for patients, with patients
- enable scenario modelling

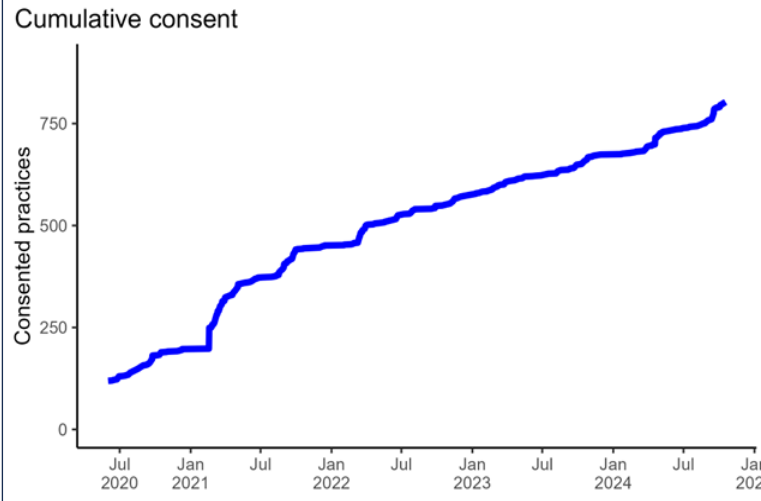
Service dates  
Demographics  
Diagnoses  
Provider type  
Medications  
Immunisations  
Test results  
Lifestyle factors  
Billing information



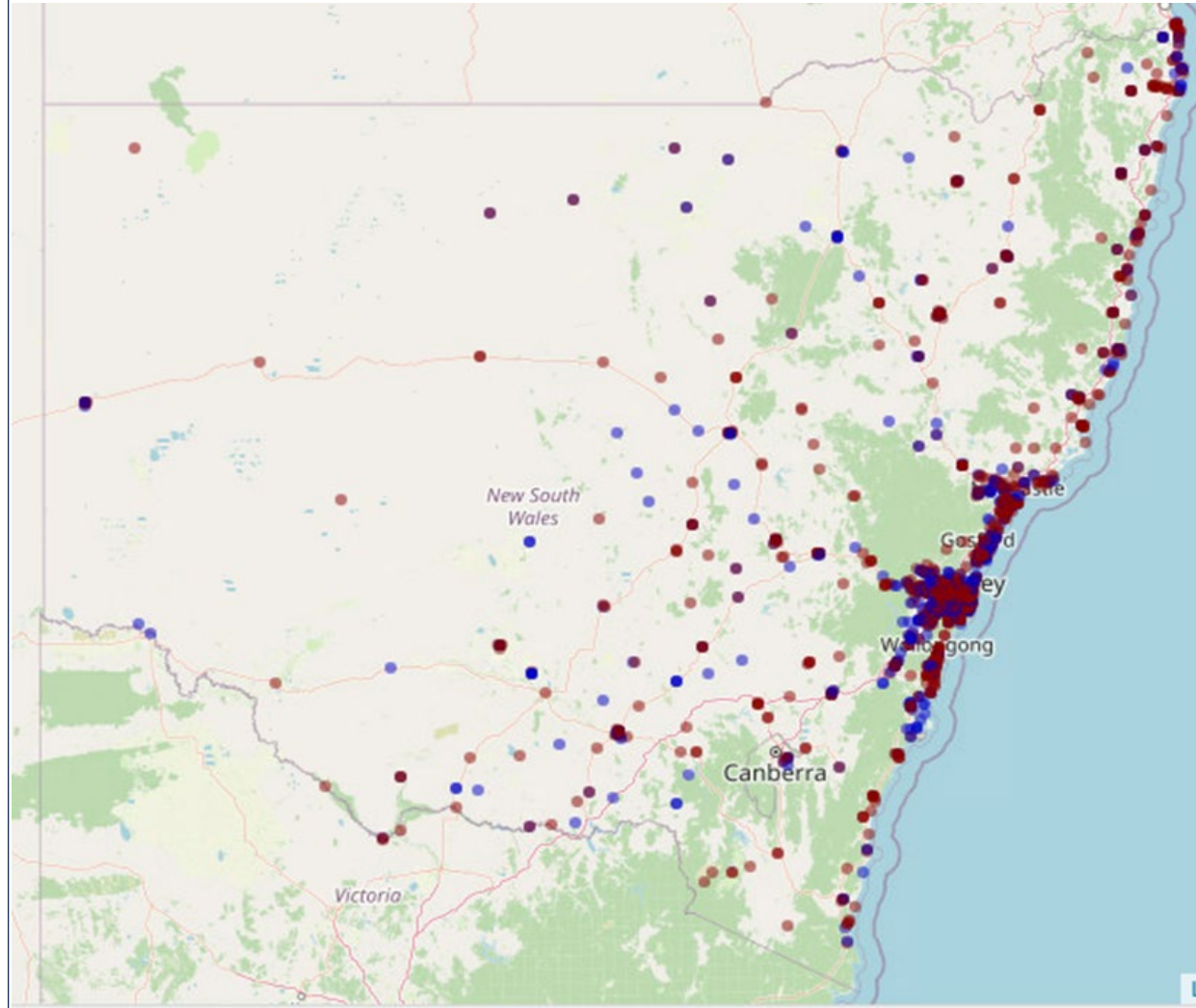
# Lumos Practice Participation

803 general practices consenting as of 1/11/2024. This represents 33.4% of 2400 practices in NSW (per the NHSD as of July 2024)

Over **6 million** patient journeys

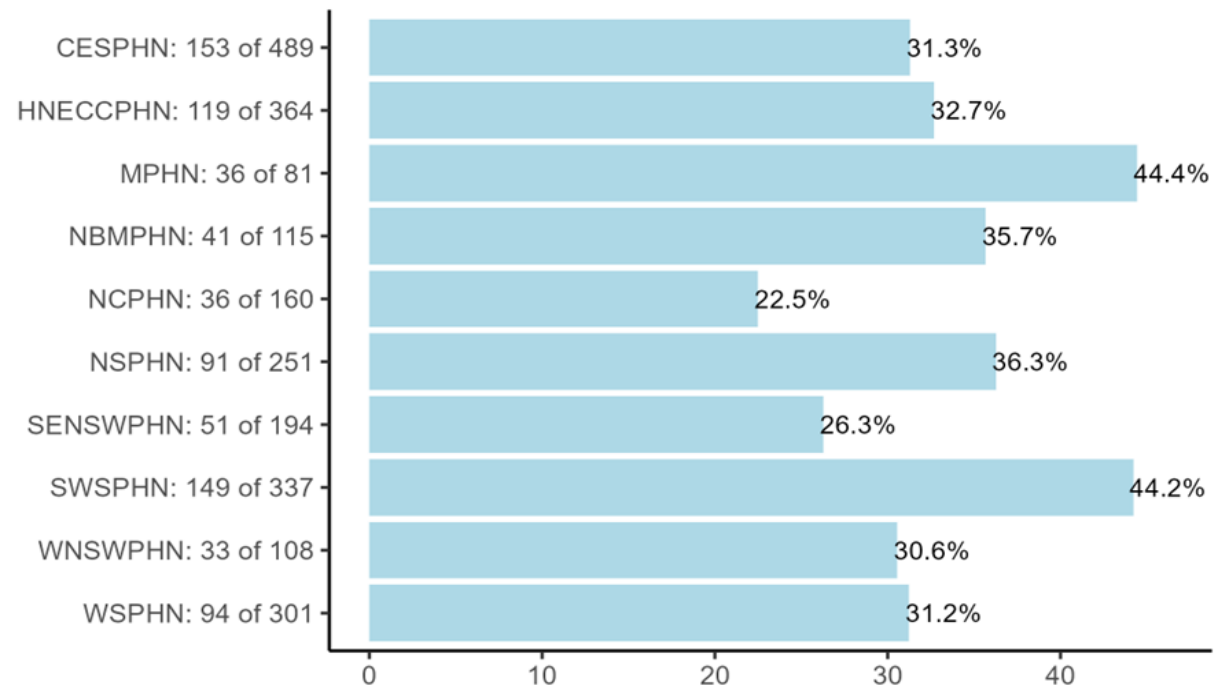


Consent status: ● Consented ● Not consented



The total number of GPs in a PHN may include GPs that are not able to participate in Lumos. This can be due to various reasons such as use of paper based records, non-compliant software or not having data sharing agreements with PHNs. Current ethics approval also does not yet permit participation by Aboriginal Community Controlled Health Services.

## Proportion of participating general practices by PHN



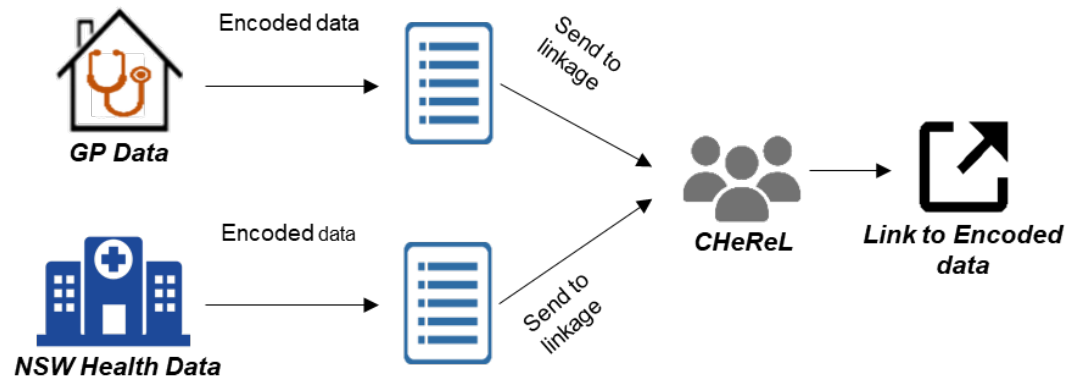
# Ethics and Privacy in Lumos: summary

## Ethics approval

Lumos operates under ethics approval with opt-in consent from general practices and waiver of individual consent

**Use:** management of health services

## Privacy Preserving Record Linkage (PPRL)



Identifiable information removed at source and encoded using Bloom filters developed by Curtin University: i.e. this is not a clinical resource.

**Lumos**

## Secure data storage



Data securely stored using virtual PC solution externally vetted by eHealth.

## Enduring, regularly updated

Data are replaced in their entirety with every refresh – meaning only ever one version that reflects current consents.

## Data Access

Access to data by strict protocol.

All extraction requests are manually vetted to ensure sufficient aggregation.

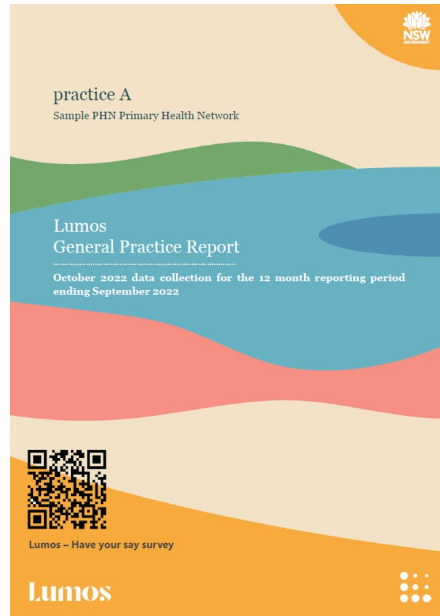
*"The Lumos Program deserves to enjoy a high degree of social licence, given the significant public benefits expected to accrue from operationalising insights derived from the Lumos Data Asset, and the very low privacy risks posed to individual patients."*

- Salinger Privacy

# Lumos insights



# Lumos Insights (GP reports)



Lumos delivers twice-yearly reports to every enrolled GP, comparing their patients to the PHN and statewide.

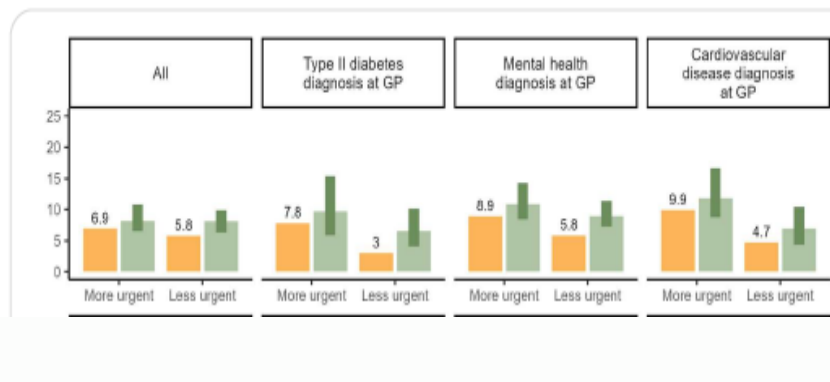
Topics include patient profiles, health service utilisation, ED presentations, hospital admissions and cohort breakdowns



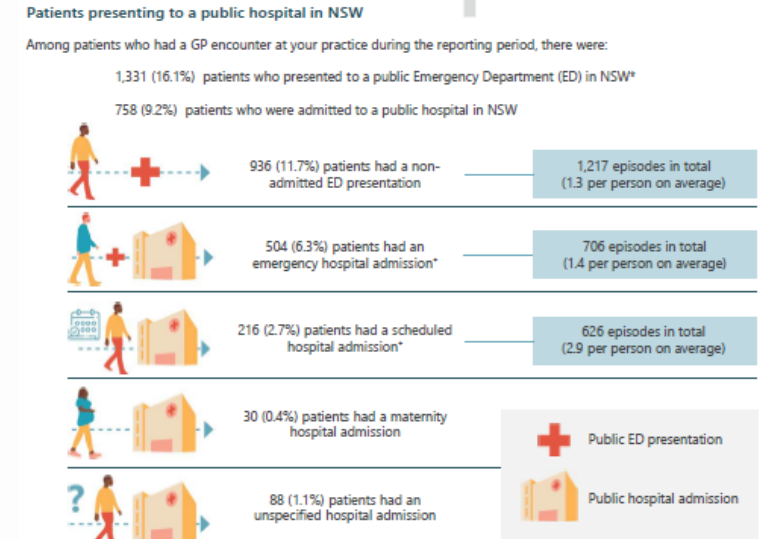
## Patient Profile



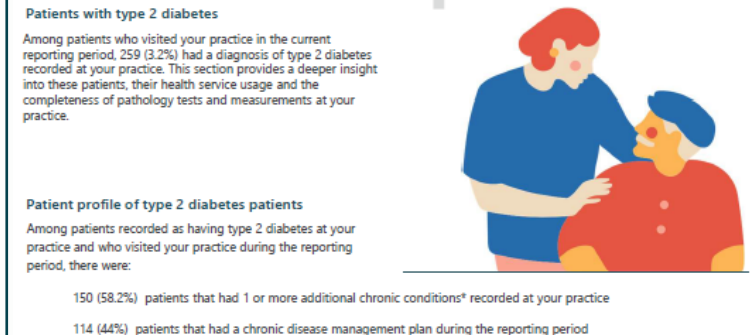
## Non-admitted patients and hospital admissions



## Acute care utilisation



## Conditions in focus



# High connectivity general practices

>30% of patients visited at least 12 times in 2 years

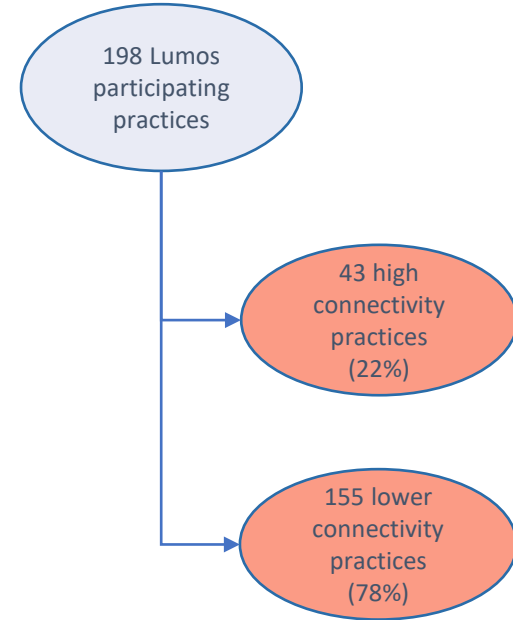
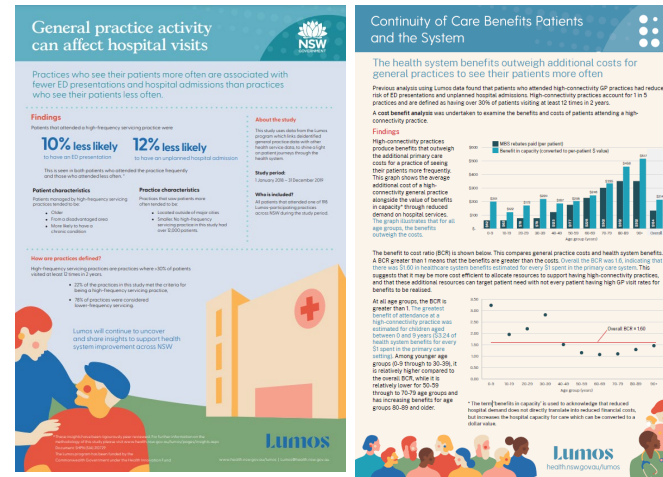
## Continuity of care affecting hospital visits

Patients that went to high-connectivity practices had:

- **10%** less chance of ED presentations
- **12%** less chance of unplanned hospitalisations

*Benefit to both those who attended frequently and those less often.*

“Overall, the benefit to cost ratio [of high connectivity practices] was 1.6, indicating that there are \$1.60 in healthcare system benefits estimated for every \$1 spent in the primary care system.”



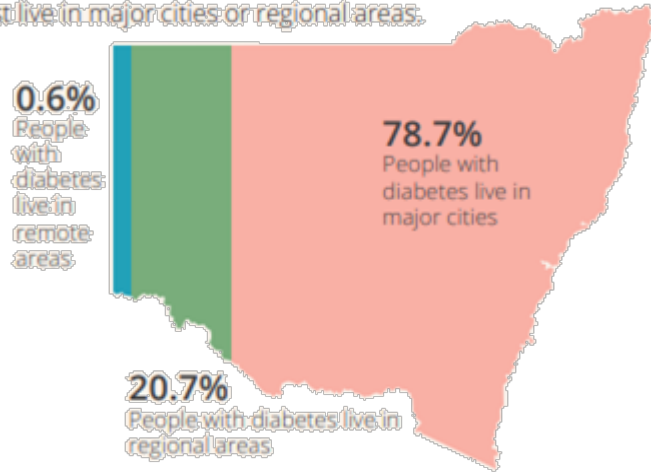
Comparisons are adjusted to account for differences in practice and patient characteristics e.g. socio-demographics. Study period 2018-2019; Population 1,066,203 patients

# Diabetes in NSW

## Impacts of where people with diabetes live and where diabetes is managed

### People with diabetes

Most live in major cities or regional areas.

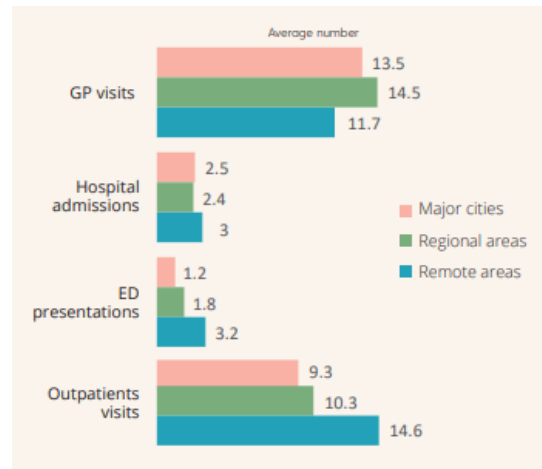
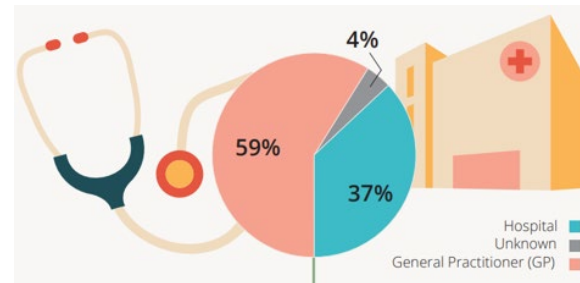


### Diabetes prevalence higher in remote areas

- Remote areas (9.6%) compared to metro areas (8.1%).

### More hospital diagnosed diabetes in remote areas

- Most people with diabetes who live in remote areas, first have diabetes recorded in the hospital setting.
- Most people with diabetes who live in major cities and regional localities first have diabetes recorded in the GP setting.



### Less primary care and more acute care in remote residents

- Over a 2-year period, people with diabetes who live in remote areas had lower utilisation of primary care and higher utilisation of ED and hospital care than those living in major cities or regional areas.

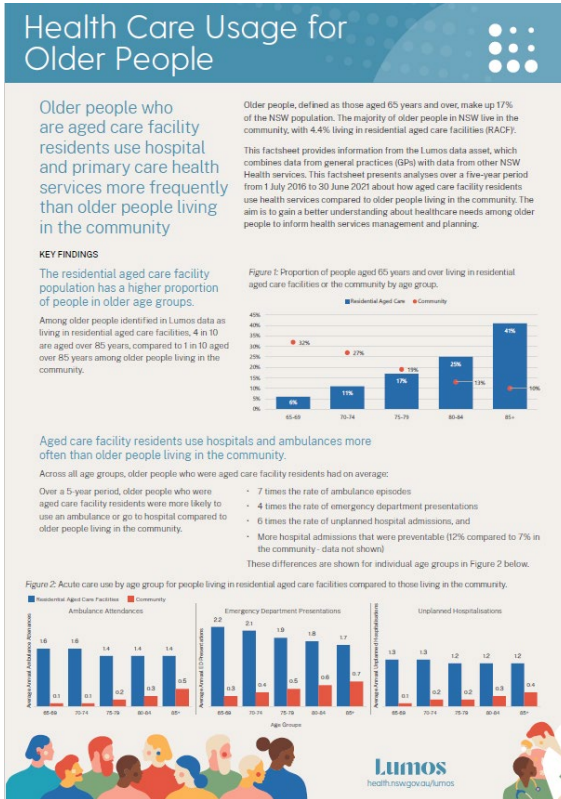
### More proactive diabetes care when diagnosed in the GP

- Twice as likely to have antidiabetic medications prescribed
- More likely have GP management plans
- More have blood pressure, cholesterol and HbA1c recorded



# Health care usage by older people

## How service usage differs for older people living in community vs RACF



### Key findings:

Compared to older people living in community, older people who are RACF residents have on average:

- 7 times the rate of ambulance episodes
- 4 times the rate of ED presentations
- 6 times the rate of unplanned hospital admissions, and
- More hospital admissions that were preventable (**12% vs 7%**)

Top reasons for unplanned hospitalisations were similar among cohorts, except for mental health disorders, primarily dementia (7% of admissions compared with 2.5%).

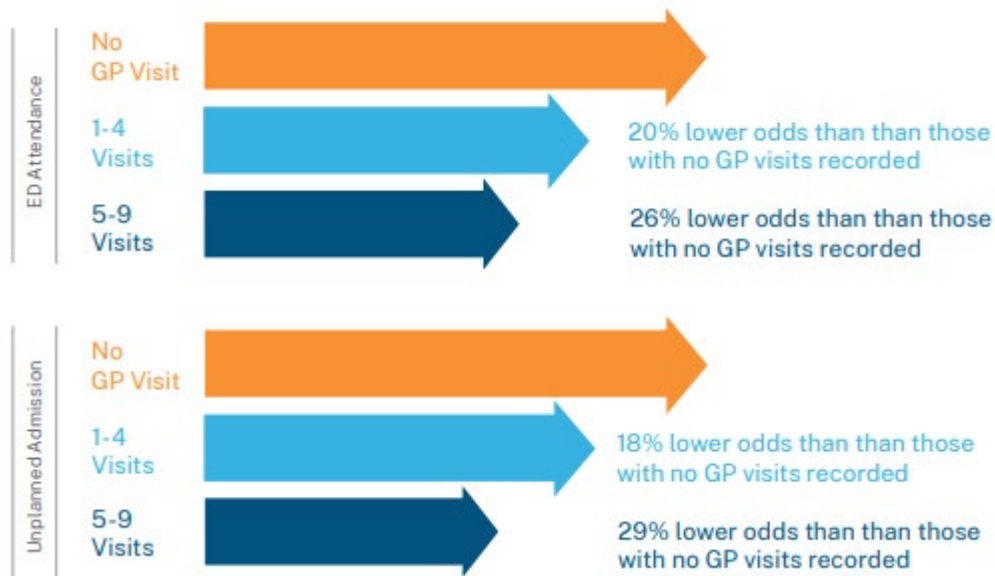
RACF residents see a GP much more frequently: half see their GP 16+ times, compared to 23% for older people living in community

# COPD in NSW


## Deep dive into four factors that affect hospital use

- ❖ Smoking
- ❖ Regular GP care
- ❖ Co-morbidities
- ❖ Location

People with COPD who had **regular GP visits** were less likely to end up in hospital than people with COPD who had no GP visits recorded in the study year



Odds of attending ED or being admitted to hospital also determined based on comorbidities, smoking status and residential location




**Fact sheet**  
**Chronic Obstructive Pulmonary Disease (COPD)**  
 September 2024

Lumos data reveal the impact of GP visit frequency, lifestyle and patient factors on hospital use by patients with COPD.

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**Chronic Obstructive Pulmonary Disease (COPD)** is a chronic inflammatory lung disease, which affects 2.2% of the NSW adult population. Management of COPD is spread across the primary and acute care systems.

This fact sheet outlines factors that affect the use of acute health care services by people aged 45+ living with COPD in NSW. The analysis used patient data from the Lumos data asset, which links data from general practices (GP) with data from other NSW health services. The analysis focuses on the 2019 calendar year to illustrate delivery and access behaviours seen prior to COVID-19 disruptions. The key findings are centred on demographic, health status, and previous health service utilisation. More information on the program and methods can be found on page 4.

The aim of this work is to gain a better understanding about healthcare needs among people living with COPD to inform health services management and planning.

**Key background statistics on people diagnosed with Lumos data - People aged 45+ diagnosed with COPD from Lumos data >500 GP practices, ~5 million people**

- 58% are aged 70 years and over.
- 50% are women, meaning men and women are affected by COPD.
- 35% live in regional or remote areas compared to 37% for the NSW population as a whole.
- 57% of patients with COPD fall into the most second most disadvantaged socioeconomic quintile compared to 37% for the NSW population as a whole.
- 70% have at least two comorbidities in addition to COPD. Most commonly cardiovascular disease (38%), mental health diagnosis (20%), and asthma (18%).
- 18% are daily smokers, 1% are irregular smokers, 18% never smoked while 22% have their smoking status reported in their GP records.

**In the 12 months prior to this analysis:**

- 23% did not have a GP visit recorded.
- 15% had 1-4 GP visits recorded.
- 16% had 5-9 GP visits recorded.
- 45% had 10 or more GP visits recorded.

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**KEY FINDINGS**  
 Four factors that affect demand for acute care services amongst people with COPD

- 1 Smoking Status**  
 People with COPD with no smoking status recorded in their GP records, and daily smokers with COPD, were more likely to end up in ED or hospital compared to people with COPD who have never smoked. Ex-smokers were no more likely to attend ED or have an unplanned admission than a person with COPD who never smoked. There were no notable results found for irregular smokers.

Smoking Status	Odds
No Status	19% greater odds than a person who never smoked
Daily Smoker	6% greater odds than a person who never smoked
Never Smoked	Baseline

Smoking Status	Odds
No Status	24% greater odds than a person who never smoked
Daily Smoker	1% greater odds than a person who never smoked
Never Smoked	Baseline

- 2 Regularity of GP Attendance**  
 People with COPD who had regular GP visits were less likely to end up in hospital than people with COPD who had no GP visits recorded in the past year.

GP Visits	Odds
No GP Visits	Baseline
1-4 Visits	20% lower odds than those with no GP visits recorded
5-9 Visits	26% lower odds than those with no GP visits recorded

GP Visits	Odds
No GP Visits	Baseline
1-4 Visits	18% lower odds than those with no GP visits recorded
5-9 Visits	29% lower odds than those with no GP visits recorded

- 3 Other comorbidities**  
 Having 1 or more other comorbidities previously diagnosed in hospital significantly increase people with COPD ending up in hospital compared to people with COPD who had no additional comorbidities.

Additional Comorbidities	Odds
3 additional comorbidities	3 x greater odds than those with no additional comorbidities
2 additional comorbidities	2.1 x greater odds than those with no additional comorbidities
1 additional comorbidities	1.8 x greater odds than those with no additional comorbidities
No other comorbidities	Baseline

Additional Comorbidities	Odds
3 additional comorbidities	4 x greater odds than those with no additional comorbidities
2 additional comorbidities	2.8 x greater odds than those with no additional comorbidities
1 additional comorbidities	1.7 x greater odds than those with no additional comorbidities
No other comorbidities	Baseline

- 4 Residential Location**  
 People living with COPD in regional or remote areas were more likely to present to the emergency department than those living in a major city. However, people with COPD living in major cities were more likely to have an unplanned hospitalisation than people with COPD living in regional or remote areas.

Location	Odds
Remote	35% greater odds than a major city resident
Regional	18% greater odds than a major city resident
Major City	Baseline

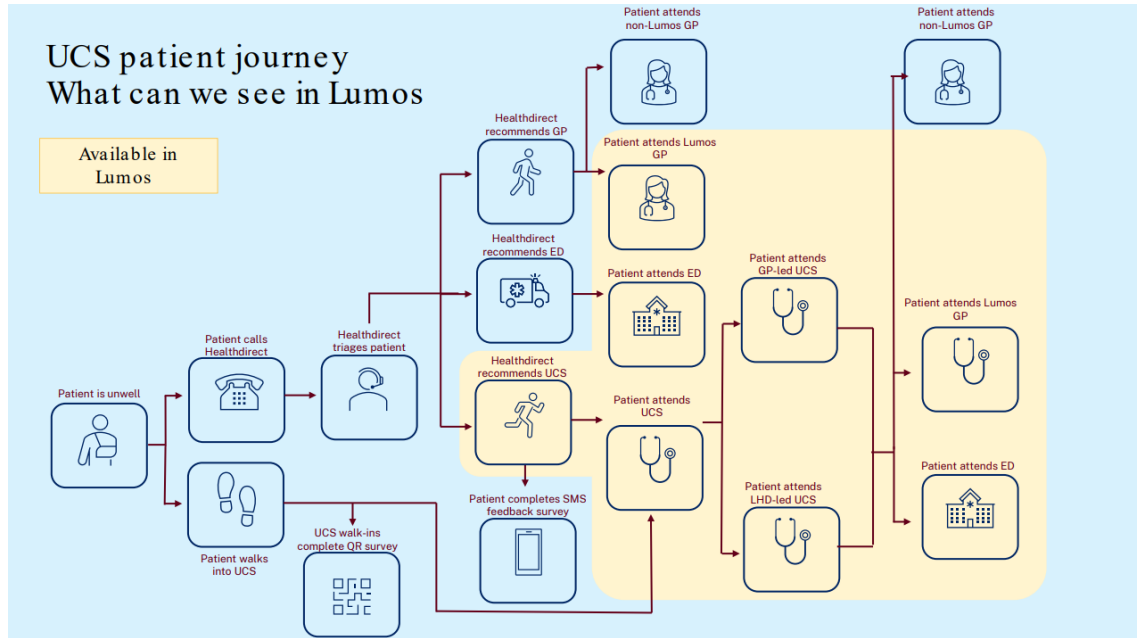
Location	Odds
Remote	24% lower odds than a major city resident
Regional	27% lower odds than a major city resident
Major City	Baseline

Lumos COPD fact sheet | September 2024 | page 2

528 practices, 21% of all NSW general practices; 4,801,341 patients in total Lumos cohort, 51,598 people included in analysis (aged 45 years and over with a COPD diagnosis recorded at GP or in hospital records on or prior to 31 December 2018. Study period 1 January-31 December 2019.

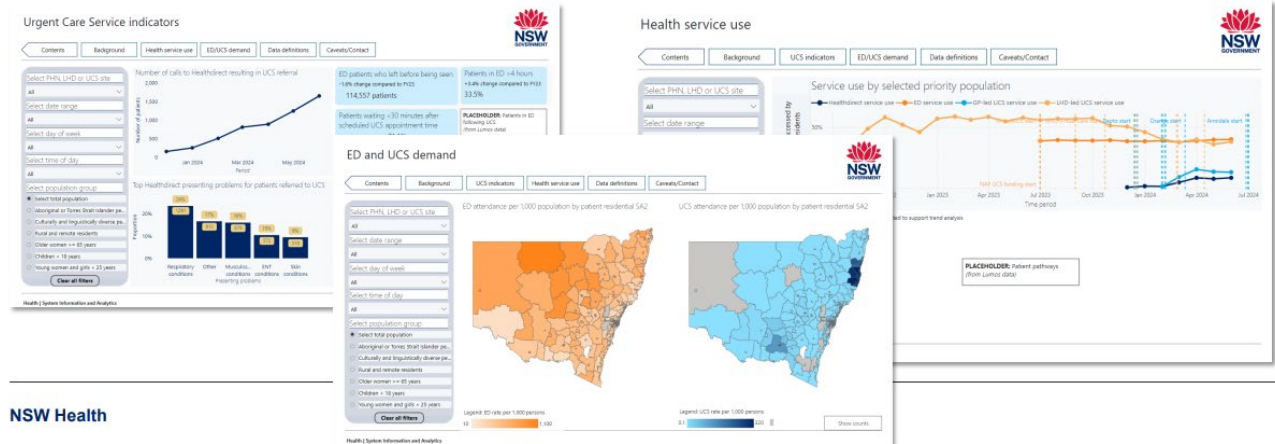
# Lumos analyses by NSW Health

Lumos at the centre of NSW Urgent Care Services roll out, monitoring and evaluation



Lumos underpins analysis of patient flows when referred to or using an Urgent Care Service.

System Information and Analytics Branch, using Lumos, supports the on-going monitoring and evaluation of the program, focused on quality of implementation and program effectiveness.



# Lumos analyses by external parties

## Estimating Five-year Absolute Risk of Cardiovascular Disease Using Routinely Collected Electronic Medical Records from Australian General Practices

Nic Kuo, Sebastiano Barbieri, Clare Amott, Blanca Gallego-Luxan, Ziba Zandomkar, Shahana Ferdousi, Kirsty Douglas, Mark Woodward, Louisa Jorm

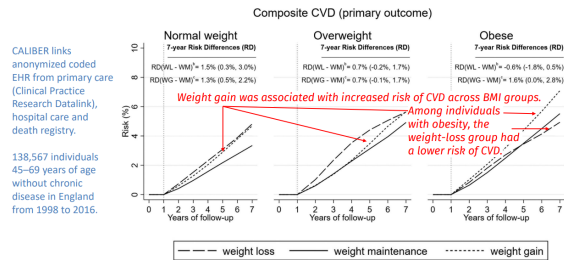
Funded through MRFF Cardiovascular Mission Grant 2020-2025  
Partnership with WentWest PHN



## Motivation...

- ~70% of Australian adults have 3+ modifiable risk factors for CVD<sup>1</sup>
- From 2019, MBS funds free annual Heart Health Check for people aged 45+ (30+ for Aboriginal and Torres Strait Islander peoples)
- In 2023-24, 1.7% of women and 1.4% of men aged 45+ had a GP claim for this item (699)<sup>2</sup>
- Australian CVD risk calculator (AusCVDRisk)<sup>3</sup> launched mid-2023
  - Based on PREDICT<sup>4</sup> equations developed for NZ
  - Not validated using Australian data

<sup>1</sup>National Heart Foundation. HeartWatch Survey, customised data. 2019.  
<sup>2</sup>[http://medicarestatistics.humanservices.gov.au/statistics/mbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/mbs_item.jsp)  
<sup>3</sup>Australian CVD Risk Calculator, <https://www.cvdcheck.org.au/calculator>  
<sup>4</sup>Pyypchuk R, et al, The Lancet, 2018



Katsoulis, M, et al. Epidemiology 32(5):744-755, September 2021.  
doi: 10.1097/EDE.0000000000001393

**DAP+**  
Diabetes Alliance Program Plus

LHD, PHN, HMRI and UON Collaboration Project -  
Spotlight on The Diabetes Alliance Program

Associate Professor Shamasunder Acharya  
Clinical Director Endocrinology and Diabetes,  
John Hunter Hospital HNEL HD |  
Clinical Lead, DAP+ | Conjoint Associate  
Professor, University of Newcastle

## DAP+ Evaluating Health Service Level Impact

Collaboration with NSW Health LUMOS team to answer the question:  
**Does DAP+ improve longer-term health outcomes of patients with type 2 diabetes (T2DM) attending GP practices?**

- DAP+ evaluation includes data for >22,000 patients belonging to practices who have participated in the DAP+ model (1100 pts were seen directly as DAP+ intervention patients)
- Propensity matched practices across NSW will also be analysed

## DAP+ Downstream DAP+ intervention outcomes

- Research Question:**  
Does DAP+ improve longer-term health outcomes of patients with type 2 diabetes (T2DM) attending GP practices?
- Method:** Applying a Target Trial Protocol for Emulating a Cluster RCT using Lumos data for active GP patients with T2DM
- Primary outcome:** three-year hospitalisation rates
- Secondary outcomes:** preventable admissions and ED presentations, length-of-stay, lower limb loss, and metabolic markers

What's next?



# Aboriginal Community Engagement - Prioritising Indigenous Data Sovereignty

## Current situation:

No Aboriginal Medical Services enrolled;  
Aboriginality flags not available for use

## Aims:

- Operational model that meets community priorities for data collection, storage, access and products targeting their evidence needs
- Support Priority Reform 4

## Approach:

- Leadership from the ACE Working Group
- Pilot approach with co-design
- Community consultation (facilitated by Indigenous thought leaders on IDS)
- Scale up to state-wide and support national discussions



*"[Lumos] is the standard of effective use of data which the Australian Government would like all regions around Australia to reach."*

Australia's Primary Health Care 10 Year Plan 2022-2032

**Lumos**

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