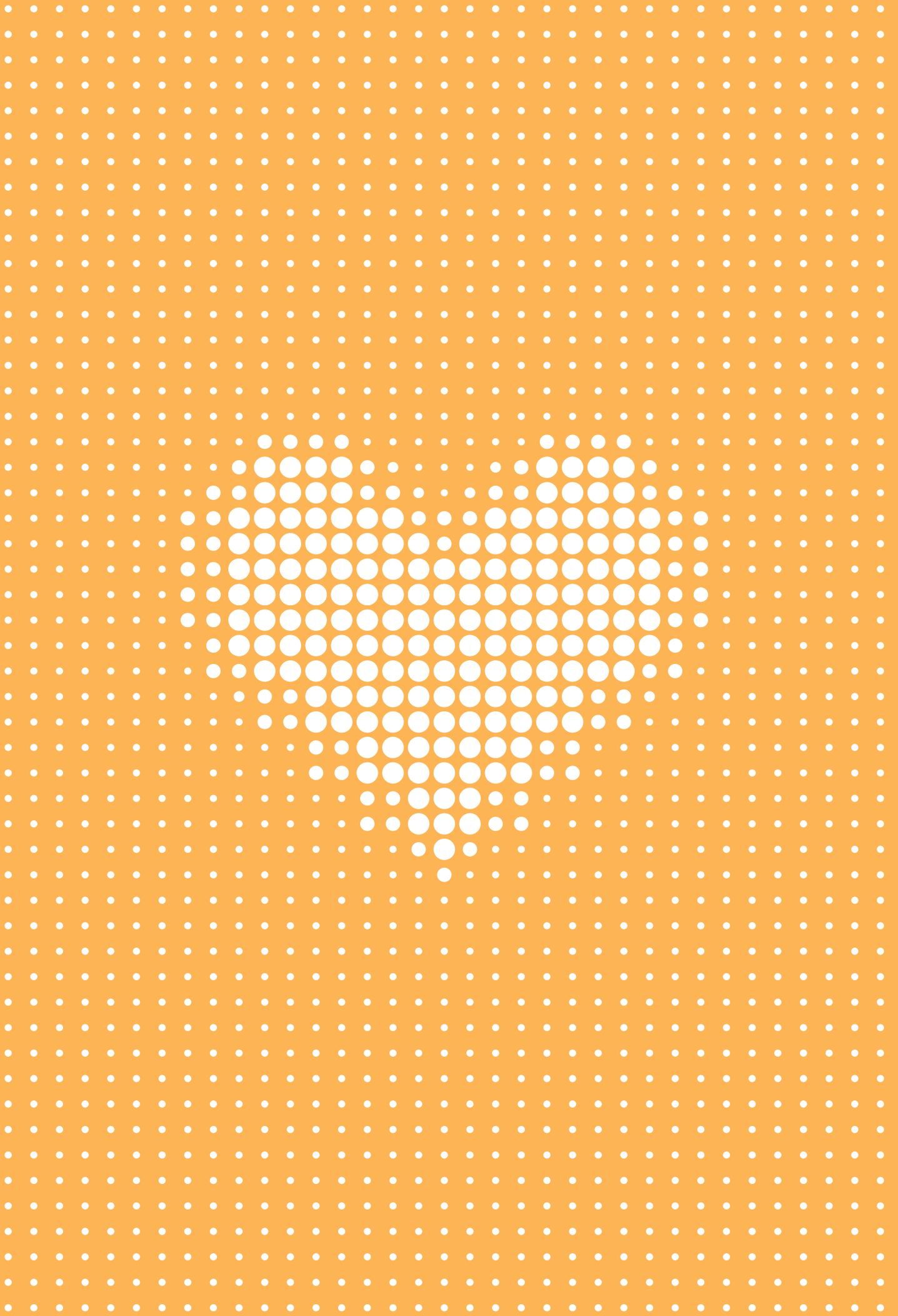


# Information Pack for General Practices



Connected data.  
Healthier NSW.





---

# Contents

What is Lumos? .....	2
The case for data linkage .....	3
The value of the pilot project .....	4
The benefits of participating in Lumos .....	6
What will I receive? .....	8
What data is extracted and how is it governed? .....	10
The end to end de-identified data linkage process .....	12
Required technical specifications .....	14
FAQs .....	15
A final thought .....	16

---

# What is Lumos?

---

How often do your patients use services in other parts of the health system? What types of patients are most likely to run into health problems that need significant unplanned care? How can you be more effective in planning services and improving your patients' outcomes? Lumos sheds light on the patient journey through the NSW health system by "Linking Up and Mapping Of Systems" across NSW. This can provide you with new insights that will benefit your services.

Lumos is an ethically approved program that securely links encoded data from general practices to other health data in NSW, including hospital, emergency department, mortality, and others. This is done under strict data governance processes and in partnership between Primary Health Networks (PHNs) and the NSW Ministry of Health.

For the details of the ethics approval and data sources, please see the separate consent form.

Lumos has arisen from a four year pilot project which linked the GP data of approximately 1 million patients across over 100 NSW practices. It has shown that we can securely extract patient information from GPs, link it with other data collections and generate new insights while ensuring patient confidentiality.

In return for your consent to allow de-identified data about your patients to be extracted, Lumos provides you with unique and valuable information that you can use to plan and deliver your health care services. We have worked closely with GPs to develop information and tools that are relevant.

**Lumos' aims include:**

- Generating information and insights around the patient journey across healthcare services.
- Providing GPs with meaningful information about their patients that can help to improve care.
- Supporting data driven quality improvement in general practice.
- Providing an evidence base to support areas of future investment in primary care.
- Supporting greater collaboration in health to ensure the right care in the right place at the right time.

Your practice's participation in Lumos is entirely voluntary. No financial outlay will be incurred for your participation and your practice can decide to discontinue at any time.

---

# The case for data linkage

---

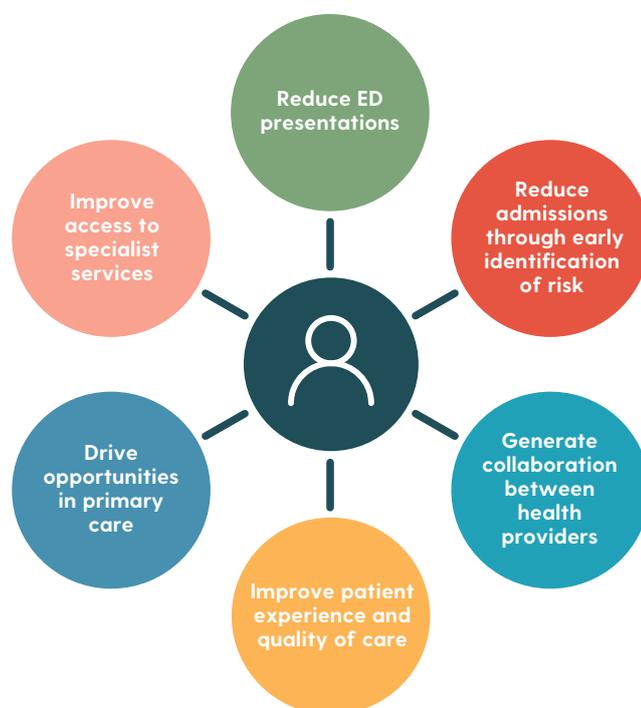
A large gap exists in our understanding of how patients in NSW interact with the health system including the different services used, the care provided and their outcomes. For instance:

- We have a limited view of your patients' journey across the health system.
- To deliver better care we need to understand what patients need, where and when.
- Without a linked view of the patient journey across services, we are managing in the dark.

Lumos presents a unique opportunity to bridge this gap, delivering reliable information to support the right care, in the right setting, enhancing the provider experience and the value of care that is provided to patients.

---

## The Lumos vision



---

There are opportunities to improve patient outcomes and experience by minimising potentially preventable hospitalisations. For example, by 2025-26 the NSW hospital cost for diabetes alone is forecast at \$2.1 billion.

# The value of the pilot project

The pilot project dataset has provided participating general practices with a new picture of patients' journeys through the health system. These data have provided participating general practices with novel insights: how emergency department presentations are related to patterns of patients' visits to their practice, how these patterns compared to their region and how health services could be improved to better meet patient needs.

## The pilot project aims include to:

- assess the feasibility of linking general practice patient data to NSW health related datasets,
- enhance our knowledge of the patient journey through health care systems,
- enhance information from general practices and inform NSW Health policy and planning,
- provide useful information about healthcare use and mortality among general practice patients,
- investigate patterns of acute health service use in relation to patient characteristics.

## The outcomes of the pilot project not only provide proof of concept; they also provide actionable insights:

- The pilot project has generated numerous reports which were returned to each General Practice to support quality improvement.
- GP data variables have been used to improve;
  - understanding of the positive impact of GPs in reducing readmissions
  - risk stratification models,
  - understanding of outcomes in undiagnosed chronic conditions - risk of hospitalisation for diabetes and chronic kidney disease is halved with early diagnoses in primary care.
- We now have an overview of the patient journey across the healthcare system.

## Potentially Avoidable GP-Type ED Presentation by Time of Arrival

Example practice change: As a result of the pilot, one general practice identified an opportunity to meet the needs of their patients by extending their service hours.



---

Lumos has arisen from a four year pilot project which linked the GP data of approximately 1 million patients across over 100 NSW practices.



---

# The benefits of participating in Lumos

---

## The GP perspective

- Participate quickly and easily.
- Gain an unprecedented understanding of your patients and how they are interacting with the health system.
- Understand your patient and practice profile compared to your region.
- Demonstrate and improve the quality of patient care your practice provides.
- Support data driven quality improvement activities and participation in related programs.
- Create an evidence base to support areas of future investment in primary care.
- Inform the development of risk stratification tools to help identify patients at risk of poor health outcomes.
- Identify opportunities to improve the planning of your services.
- Provide a better understanding of the patient experience of health services.
- Improve provider experience through greater collaboration between systems.

---

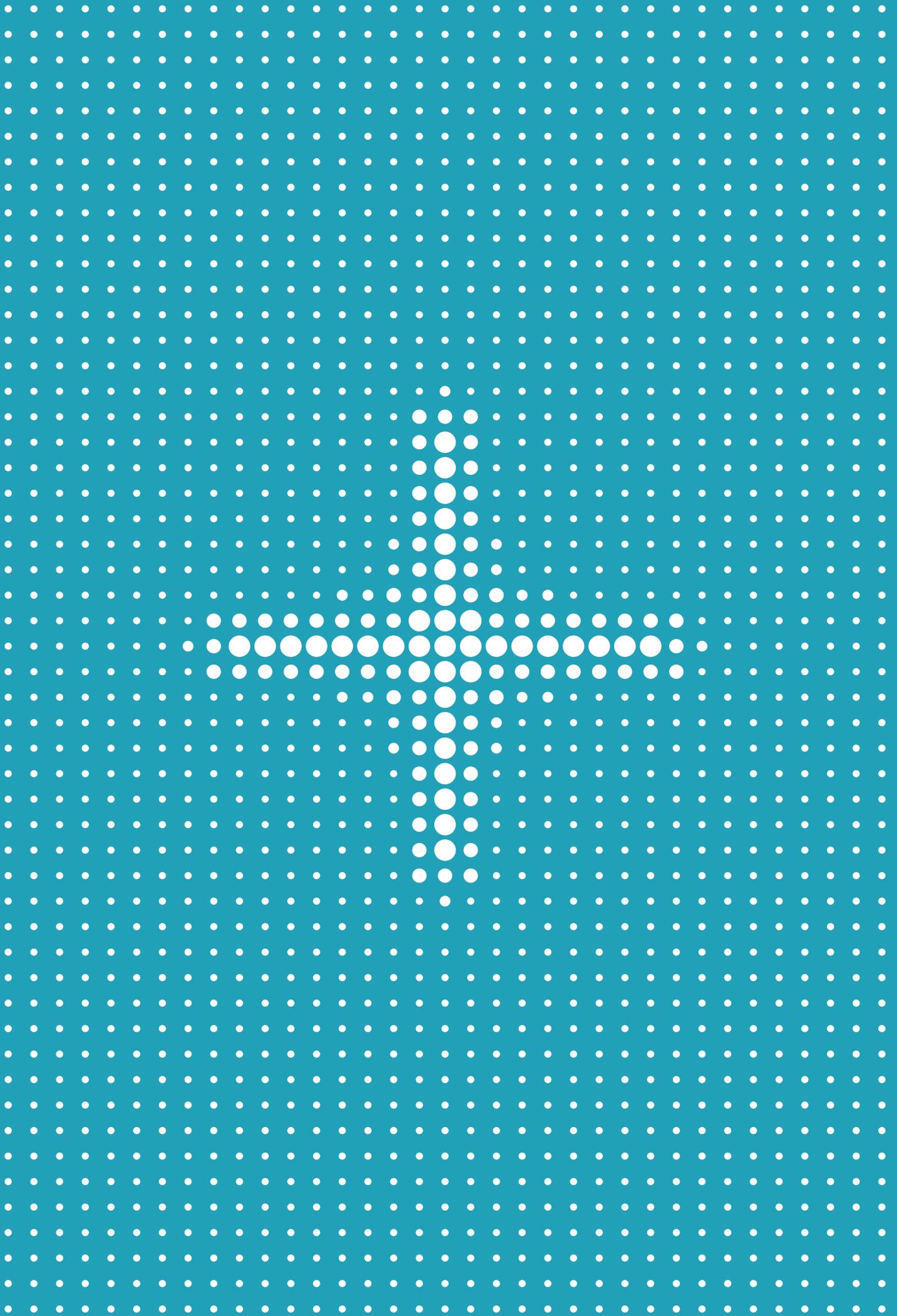
## The patient perspective

- Patients can benefit from health system improvements and services informed or funded as a result of Lumos.
- Applying risk stratification and other tools developed with Lumos can help improve a patient's healthcare trajectory.
- The patient journey is brought to light; through this understanding we can help provide a better patient experience.
- Patient privacy is protected by de-identification, robust ethics and governance.
- Lumos supports quality improvement activities in General Practice which can have flow on benefits to patients.

---

## The system perspective

- Enhance our knowledge of the patient journey through health care systems to inform NSW Health policy and planning.
- Refine risk stratification tools to promote earlier intervention for 'at risk' patient groups.
- Generate an understanding of patient pathways to reduce avoidable system utilisation.
- Demonstrate the impact of managing current and emerging population health issues across the system.
- Inform system design to improve the quality and experience of healthcare consumers and providers in NSW.
- Create an evidence base to support joint needs assessments, decision making and system design.
- Put service integration at the heart of system improvement.
- Facilitate greater collaboration across the healthcare system.
- Reveal the impact of primary care activities on the patient journey in the health system.
- Provide an evidence base to support areas of future investment.



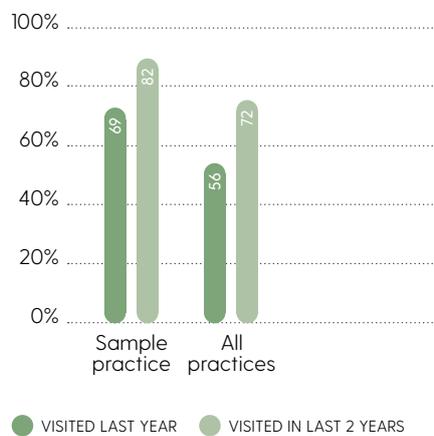
# What will I receive?

## The linked data will be analysed by the investigator team in the NSW Ministry of Health.

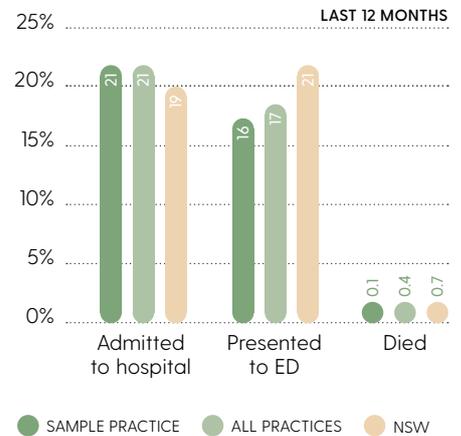
- At least twice yearly, you will receive practice-specific summary reports of your patients (that have visited your practice in the last 5 years).
- Reports will provide insights about the collective journeys of patients at your practice through other services including emergency departments, hospitals and community centres, and will also provide information about mortality.
- The reports will provide a profile of the patients attending your practice.
- Your practice will be presented alongside the combined results of your PHN, and where possible, comparisons will be drawn with the NSW population.
- The identity of your practice will **never** be revealed to any other practice or appear in any reports, and you will not be able to see the identity of any of the other participating practices.
- Risk stratification tools will be developed for future use.

## Example information from the reports – Patient profile

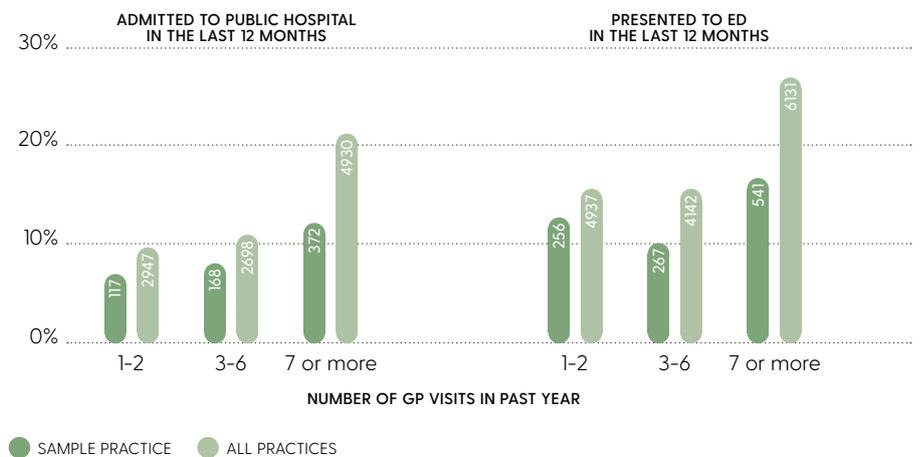
### Who has recently visited my practice?



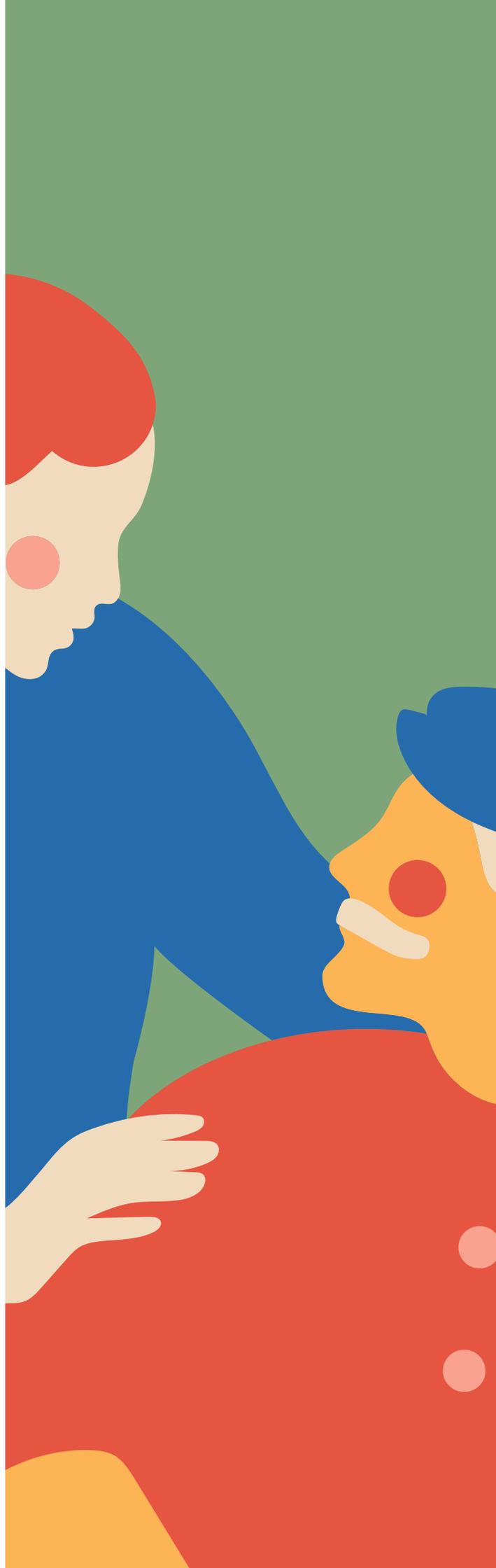
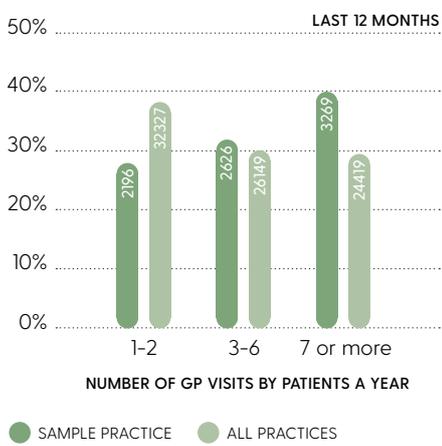
### How commonly do my patients go to hospital?



### How often do my attending patients go to hospital?



How frequently do my patients come to my practice?



---

# What data is extracted and how is it governed?

---

## **Only de-identified data leaves your general practice.**

We adhere to a rigorous set of protocols to ensure data linkage is conducted in a secure, privacy-preserving manner.

Two files are extracted from your clinical software:

### **File 1: Linking file**

A de-identified computer encoded patient ID which can be used to link the NSW Health data sets with your patient records. This allows record linkage without divulging your patients' identity to ensure the privacy of their health information is protected.

### **File 2: Health and service related variables**

Non-identifying patient health-related data including – dates of GP encounters, demographic details, provider type, chronic disease flags and diagnosis dates, dates with each of: generic names of medications, lifestyle risk factors, biomedical measurements, health screens, immunisations, MBS Item Numbers and also My Health Record flags and Shared Health Summary upload dates.

Linkage will be carried out by the Centre for Health Record Linkage (CHeReL). A key component of the linkage protocol is the use of de-identified records along with the “separation principle”, which means that no one working with the data can view both the linking information (File 1) and the analysis data (File 2). These two files will always be kept separate to ensure maximum privacy protection.

Further information is available at [www.cherel.org.au](http://www.cherel.org.au).

Lumos has full ethics approval and operates under a strong governance structure in partnership between PHNs and NSW Ministry of Health.

-  GP Representation
-  GP Partnership

# Lumos Governance Framework

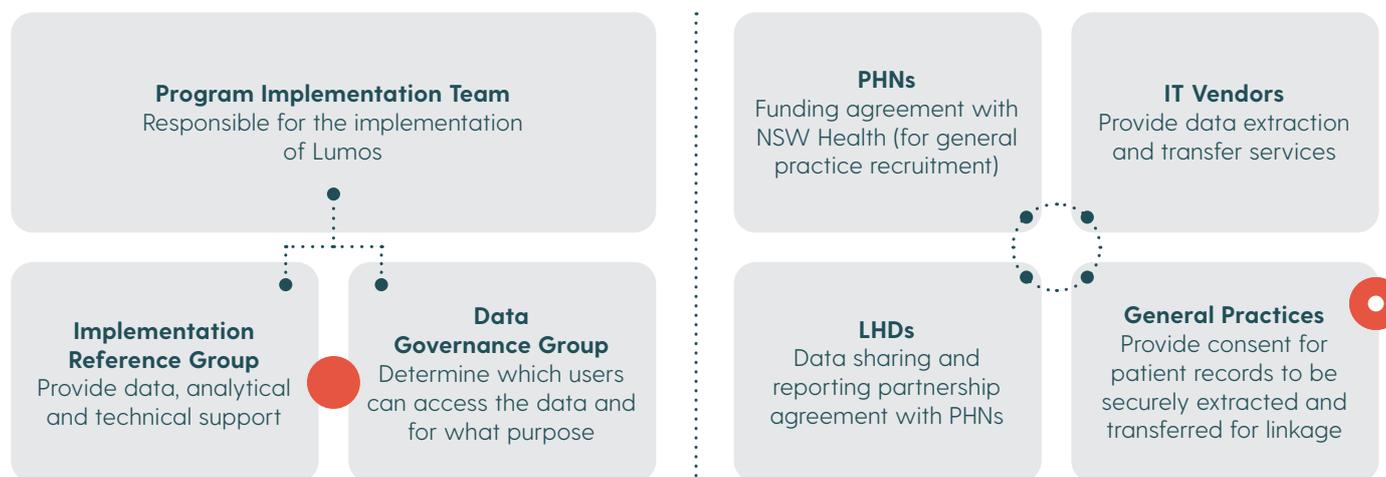
## Senior Executive Oversight



## Strategic Direction



## Implementation



Annual Conference / Symposium

---

# The end to end de-identified data linkage process

---

The data linkage process has been designed to protect the privacy of patients and to make participation by general practices as easy as possible.

---

## 1 GP information & Consent

- General practice provides consent for participation.

## 2 Data extraction

- Automated data extraction will occur at least twice yearly with an extraction tool provided by your PHN.
- All identifiers required for data linkage are encoded at the practice prior to secure transfer. *This means that NO identified data leaves your practice.*

## 3 Data transfer

- To further protect privacy the health records are split into two components for transfer – the linking file and the health content file.
- The encoded linking file is sent to the CHeReL data linkage unit (DLU).
- The health content file is sent to the data integration unit (DIU).

## 4 Data linkage

- The DLU applies matching methods to the encoded patient data to distinguish between individuals then assigns a Unique Person Number.
- The DIU then creates a Project specific Person Number (PPN) and joins it to the health content file. This means the linkage file and the health content file never coexist.

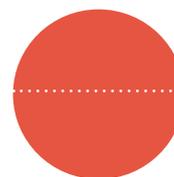
## 5 Secure Storage

- Data is securely stored at the NSW Ministry of Health.
- Any access to data is controlled by data governance in line with ethics approval.

## 6 Analysis and reporting

- Routine, targeted analyses and reporting processes are undertaken to generate insights and to establish a reliable evidence base to inform policy and planning.
- Data reports are provided at least twice yearly.

1.



### What data sets are currently being linked?

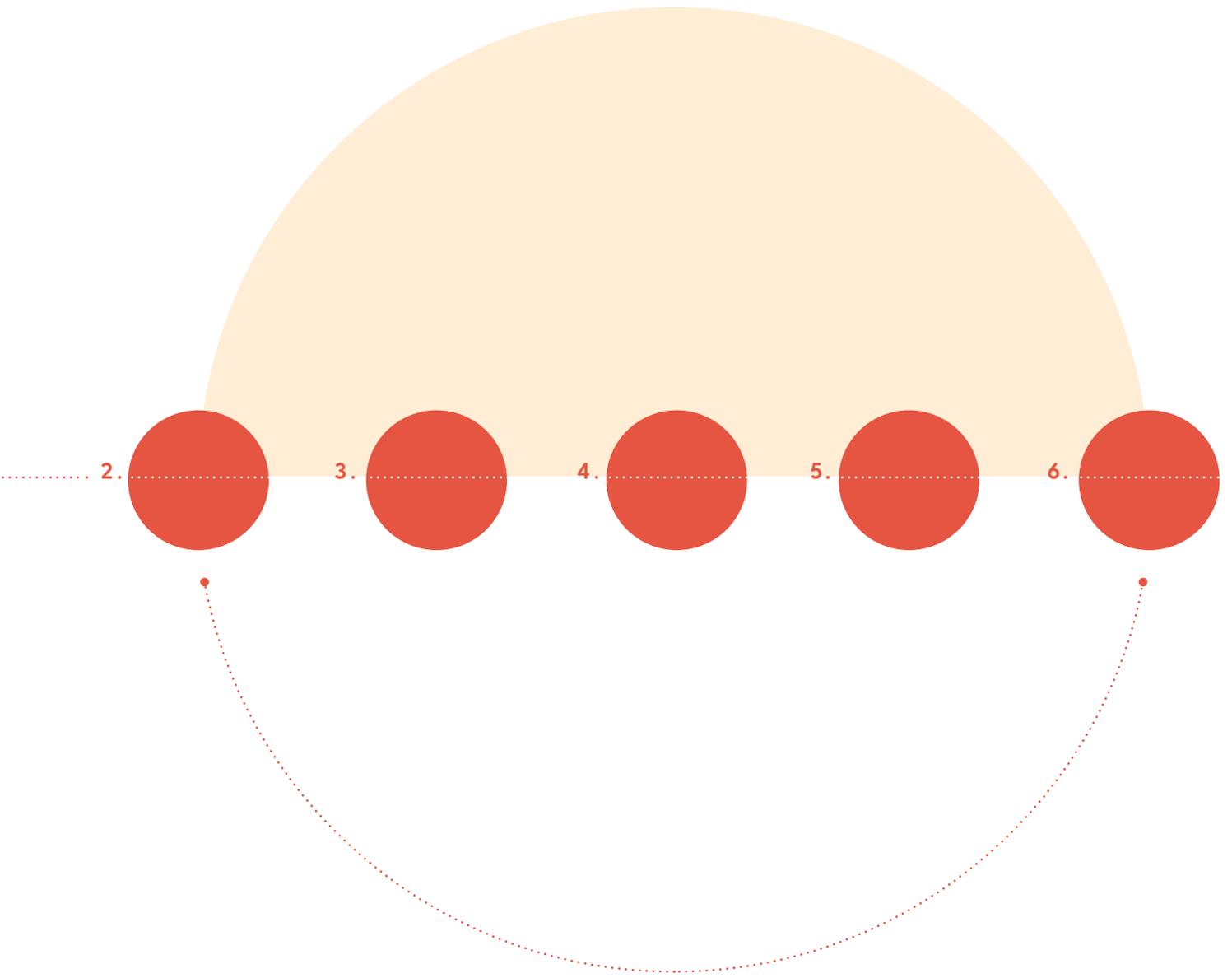
---

- NSW Admitted Patient Data Collection
- NSW Emergency Department Data Collection
- Registry of Births Deaths and Marriages
- NSW Integrated Care Database
- NSW Patient Survey
- General Practice electronic health records

### What data sets do we plan to link in the future?

---

- NSW Mental Health Ambulatory
- NSW Central Cancer Registry
- NSW Ambulance
- Cause of Death
- NSW Non-Admitted Patient Data Collection



# Required technical specifications

The checklist below provides a summary of the technical specifications for participation in Lumos:

- Internet Connection
- Updated version of compatible extraction software – ask for details
- Compatible clinical software – ask for details
- Recent or updated Windows Server or Operating System with Transport Layer Security (TLS) – 1.2 is required
- Before each linkage an automated test connection will confirm if your practice is able to securely transfer data and to identify any technical issues that may require follow up
- Configuration of firewalls may be required
- Have your IT details handy to help facilitate any updates or configuration that may be required
- Should older versions of Microsoft operating systems cease to be supported by Microsoft in the future, the ability for your practice to participate in Lumos might be impacted

Operating system	Action
Windows Server 2003 or Windows XP	Not supported
Windows Vista and Windows Server 2008 SP2	Supported with updates Microsoft KB4019276 must be installed for TLS 1.2 support <a href="https://support.microsoft.com/en-us/help/4019276/updates-to-add-support-for-tls-1-1-and-tls-1-2-in-windows">https://support.microsoft.com/en-us/help/4019276/updates-to-add-support-for-tls-1-1-and-tls-1-2-in-windows</a>
Windows 7 and Windows Server 2008 R2	Supported with updates Microsoft KB3140245 must be installed <a href="https://support.microsoft.com/en-ph/help/3140245/updates-to-enable-tls-1-1-and-tls-1-2-as-a-default-secure-protocols-in">https://support.microsoft.com/en-ph/help/3140245/updates-to-enable-tls-1-1-and-tls-1-2-as-a-default-secure-protocols-in</a>
Windows 8 and Windows Server 2012	Supported No action required
Windows 10 and Windows Server 2016	Supported No action required

# FAQs

## How is the data extracted?

Your practice will be asked to allow the installation of updates, free of charge, to existing software in order to extract and transfer the data.

We have worked hard to minimise the impact on the operation of your practice so that it will not interfere with the usual running of the software nor cause any slowing of your systems.

## What reports will I receive?

We provide you with aggregated reports about the patients at your practice and the range of health services they use. You will be able to use these reports to see where there are opportunities to add value to the care you deliver.

The identity of your practice will never be revealed to any other practice or government agency beyond the NSW Ministry of Health and your local Primary Health Network and you will not be able to see the identity of any of the other practices.

## How will patient data be managed and kept secure and confidential?

All data collected through Lumos will be used and disclosed in strict accordance with the Health Records Information Privacy Act, the Privacy Act (national), related legislation and the conditions of ethical approval.

The Lumos program has been heavily and independently scrutinised to ensure it meets the highest standards of data security and confidentiality.

## Will I be able to directly follow up patients from these reports?

Due to the de-identified nature of the data it is not possible to identify any individual patients or providers from the reports. The reports will give you a unique overview of your patients' journey across the health system in NSW. We will also use the data to develop evidence based resources to assist clinicians, such as tools that will help you identify which patients may be at greatest risk of poor outcomes.

## Does my medical indemnity cover me to participate in Lumos?

Any questions related to medical indemnity should be directed to your indemnity provider. Lumos uses only de-identified data and has ethics approval. Individual patient consent is not required.

## Who is the custodian of the general practice data?

For the purposes of Lumos, you are asked to authorise a named data custodian in your Primary Health Network to be signatory for participation in Lumos. The governance of the resulting linked data set is strictly managed and involves multiple stakeholders that must adhere to the agreed data governance framework.

## How will the Lumos data be used?

The use of the data is strictly confined to the scope of the ethics approval and subject to the strong governance mechanisms in place, for more information contact [lumos@health.nsw.gov.au](mailto:lumos@health.nsw.gov.au)

## What about patient consent?

The Lumos program has been given permission to operate without individual patient consent as we do not extract named data from your practice. This is in accordance with state and federal privacy principles and law and has been reviewed and approved by an accredited ethics committee.

## Hasn't something like this already been done?

There have been primary care data linkages and data collections in the past, but not to the scale of Lumos. Lumos has arisen from a four year pilot project which linked the GP data of approximately 1 million patients across over 100 NSW practices.

## How is Lumos related to MY Health Record?

MY Health Record is a national online summary of key health information which is identified.

Lumos is a linked data program that provides a de-identified view of patient journeys across the health system in NSW (including private hospitals).

## How can I get more involved?

We have GP representation in the program governance structures and always welcome GP input to the project – if you'd like to know more, email [lumos@health.nsw.gov.au](mailto:lumos@health.nsw.gov.au)

## I have more questions or feedback – who can I contact?

Your feedback helps us continually improve our reports. For any additional information or questions please email [lumos@health.nsw.gov.au](mailto:lumos@health.nsw.gov.au)

## How do I participate

- 1 Complete the consent form
- 2 Review the technical requirements (page 14)
- 3 Provide your feedback to help us meet your needs now and into the future

---

# A final thought

---

## What GPs have said about their reports

Being able to put our data against NSW Health is very meaningful - qualifies what you are doing.

Any meaningful trackable data helps us improve our care.

What can we do to change readmissions?

Great to see we are making progress, keeping people out of ED.

Reports are very useful to show how patients move in and out of ED.

---

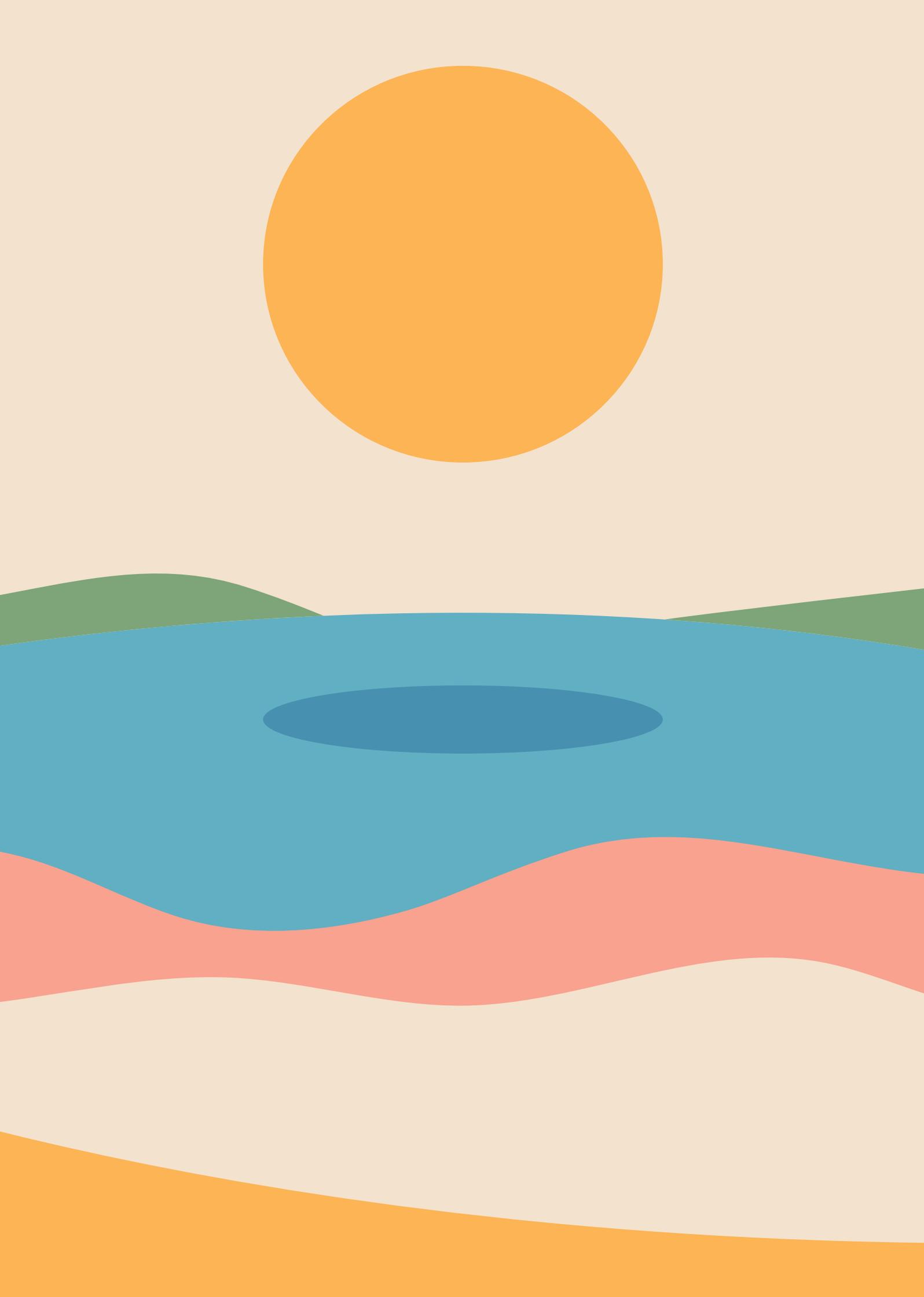
## For more information

If you'd like to know anything more about Lumos, please email: [lumos@health.nsw.gov.au](mailto:lumos@health.nsw.gov.au)



In partnership with the NSW Ministry of Health and your Primary Health Network







Connected data.  
Healthier NSW.

