

Lumos Progress Report · Year 1

Integrating health data to enable better care

RELEASE DATE: DECEMBER 2020



Glossary

The following table contains the definition of terms, abbreviations and acronyms used in this report.

TERM	DESCRIPTION
AH&MRC	Aboriginal Health and Medical Research Council
AMA	Australian Medical Association
CHeReL	Centre for Health Record Linkage
GP	General Practice
LHD	Local Health District
NSW	New South Wales
PHN	Primary Health Network
PPRL	Privacy Preserving Record Linkage
RACGP	Royal Australian College of General Practitioners
SAPHE	Secure Analytics Primary Health Environment
VBHC	Value Based Healthcare

For more information

If you'd like to know anything more about Lumos, please email:
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From the Executive Sponsor

I am pleased and proud to provide this first Lumos progress report. Lumos is a groundbreaking initiative that aims to bring together patient information from across the general practice sector and the public health system. The vision of Lumos is to integrate health data to enable better care. Lumos delivers a unique evidence base about patient journeys that can be used to provide actionable insights and underpin patient-centred, efficient and effective care across the healthcare continuum.

Lumos commenced as a pilot project by NSW Health with ethics approval in early 2016. The pilot shed light on the complex roles of technological infrastructure, confidentiality and collaboration and the solutions required to take the project from pilot to scale up.

As Lumos has transitioned from pilot to scale-up, it has rolled out to all PHNs and Local Health Districts (LHDs) / Specialty Health Networks of NSW and demonstrated the efficient and secure data extraction, transfer and implementation of the highest standards of privacy and security currently available. It has been 12 months since the receipt of funding through the Commonwealth Government's Health Innovation Fund (HIF) for the scale-up of Lumos and now is the time to reflect on our successes and challenges.

The contribution of the data to understanding patient journeys across care settings is clear, even at this early stage. Early insights are already being generated from the data asset, relating primary care services to outcomes in other parts of the health system. The insights so far underscore the potential of the data asset to be a game changer for achieving integration and value-based care with the patient at its centre.



This first report gives an overview of progress made in translating the ambitious vision of Lumos into action. This is an exciting opportunity in the NSW health system: we are establishing partnerships with consumers, general practitioners (GPs), PHNs, and LHDs, to deliver evidence driven integrated care across the hospital and community settings.

A handwritten signature in black ink that reads "Sharon Smith".

SHARON SMITH
Lumos Executive Sponsor and Executive Director
System Information & Analytics
NSW Health

The Lumos Program

BACKGROUND

Policy context

With the growth and ageing of Australia's population and a changing disease burden, people are using services more frequently and require more dynamic management of their chronic and complex conditions. To respond to these challenges, the NSW health system is shifting focus from volume-based to value-based healthcare that delivers better patient outcomes and experiences of care, while at the same time improving the effectiveness and efficiency of care.

Value based healthcare (VBHC) is an over-arching approach to healthcare delivery and system design that will support NSW Health achieve its vision. In NSW, value based healthcare means continually striving to deliver services that improve the four essentials of value:

- the health outcomes that matter to patients
- the experience of receiving care
- the experience of providing care
- the effectiveness and efficiency of care

System-wide data is a critical enabler to the planning and implementation of value based models of care. NSW Health's approach to VBHC involves scaling and embedding identified statewide programs, while supporting the necessary structural and cultural change through a range of system-wide enablers.

Whole of system change can only be achieved in partnership with the Commonwealth, PHNs and GPs. The NHRA, signed in June 2020, includes a commitment to reform how we use health data to deliver better care, Lumos will serve as an exemplar for a national approach to data integration and data sharing to drive better health outcomes and deliver effective, safe and efficient healthcare for all Australians.

However, accessing health information is complicated in Australia because it is collected in different care settings as well as by private organisations. Therefore, 'whole of system' information is not available in one place. Because the data remain separated, the view of the patient journey – the care that patients receive and the outcomes that they experience – is fragmented.

By bringing together 'whole of system' information, Lumos provides a more comprehensive view of the patient journey across the continuum of care, which can help identify the best places and times to intervene or influence health care practices to improve patient outcomes, patient experiences, and the efficiency of health services. Lumos delivers a reliable evidence base that can be used to inform data driven decision making to guide coordinated, patient-centred and outcome-focused healthcare that ultimately benefits patients and the broader community.



The Lumos Program

BACKGROUND

What is Lumos?

Lumos is a new and ethically approved program that sheds light on the patient journey through the NSW health system by securely linking encoded and de-identified data from general practices to other health data in NSW, including hospital, emergency department, mortality, and others. Lumos is delivered as a collaborative partnership between the NSW Health, all 10 NSW PHNs and participating general practices. The Program will deliver the first state level primary and acute care linked data asset using state-of-the-art technology and processes, marking it as the first of its kind at scale in Australia.

Lumos is funded through the Commonwealth Health Innovation Fund from January 2019 to July 2022, and aims to link data from 500 NSW general practices; shedding light on up to four million patient journeys through the NSW health system.

The Pilot Project

Lumos stems from a four-year NSW GP Data Linkage Pilot Project which ran from 2016 to 2019. The Pilot Project comprised five tranches of data linkage (see Figure 1) to explore the feasibility of linking general practice electronic health records to multiple NSW health-related datasets, and to explore the utility of such a linked dataset for informing health policy and practice. Leveraging the technology of the Centre for Health Record Linkage (CHeReL) and industry IT vendors used by the primary care sector and NSW Health, the Pilot successfully linked the data of approximately one million patients from over 100 NSW general practices across all 10 NSW PHNs. The Pilot showed that patient information can be securely extracted from general practices and linked with other data collections to generate new insights while safeguarding patient confidentiality.

The evolution of Lumos from pilot to state-wide scale has enabled the Program to grow from:

- Four participating PHNs to partnerships with the entire NSW PHN Network
- 40 to 100+ participating general practices
- 200,000 to over one million linked patient journeys
- Establish a growing state-wide data asset that will support future implementation of system-wide VBHC

Figure 1. Pilot Project Data Linkage Tranches

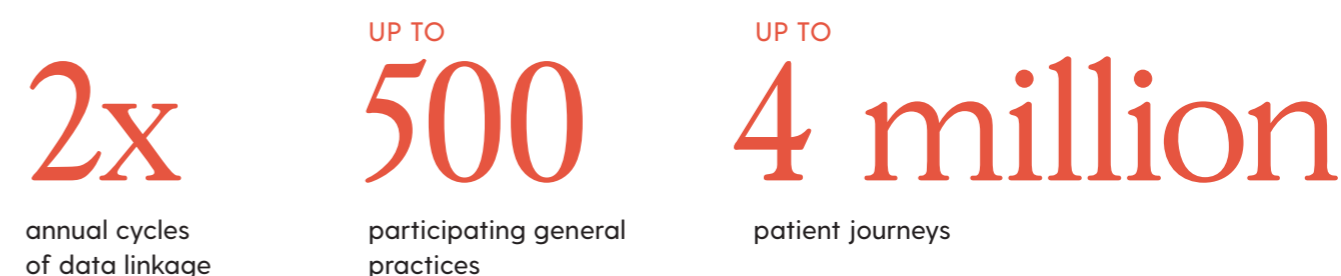


Current state of play

In the last year the Lumos program has achieved:



Over its lifecycle, the Lumos program will involve:



The Lumos Program

ASPIRATION & DESIGN

THE VISION:

To integrate data and deliver a data asset that makes available reliable information to NSW Health, PHNs and GPs to guide service design and integration, the commissioning of services, improved patient experience and outcomes, and the strategic directions of the health system across primary, secondary and tertiary care.

How it works?

Patient privacy is at the forefront of the Lumos program which has been designed to make participation by general practices as easy as possible. The end-to-end Lumos data lifecycle comprises 6 key steps:

1 GP information & consent

- General practice provides consent for participation.

2 Data extraction

- Automated data extraction from GP Practices occurs at least twice yearly with the GP patient management system.
- All identifiers required for data linkage are encoded and de-identified at the practice prior to secure transfer.
This means that NO identified data leaves the 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 two files are sent to the CHeReL (the NSW independent linkage authority) and are managed separately.

4 Data linkage

- The CHeReL applies matching methods to the encoded patient data to distinguish between individuals then assigns a Unique Person Number.
- A separate team in the CHeReL 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.

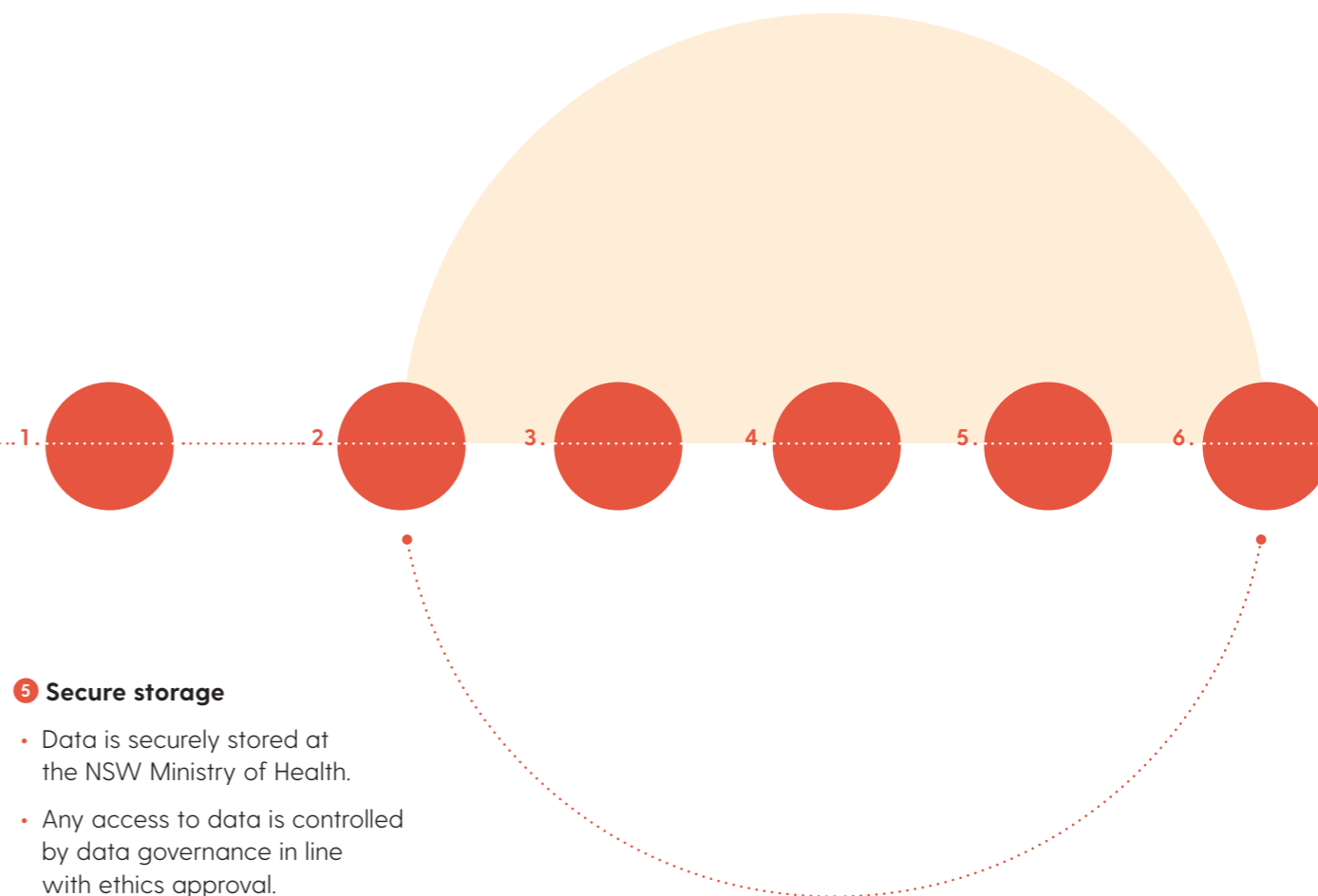
5 Secure storage

- 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 to participating general practices at least twice yearly.

Figure 2. Lumos data lifecycle



Implementation of the Lumos Program

ACHIEVEMENT TOWARDS THE PROGRAM'S OBJECTIVES

Building sustainable partnerships and collaboration

Lumos is a joint, strategic and collaborative partnership between the NSW Ministry of Health, the NSW PHN Network and their participating general practices. The successful roll-out of the Lumos program relies heavily on this partnership, and the co-operation and support of a broad range of stakeholders to ensure the sustainability of the Program.

KEY ACHIEVEMENTS

- **In the last 12 months, all 10 NSW PHNs were recruited to the Lumos program.** These collaborative partnerships were formalised through funding agreements to ensure appropriate resourcing provisioned to PHNs to recruit general practices to the Program.
- **A fully resourced and dedicated approach to building collaboration and partnership was implemented.** An experienced Lumos Collaboration Lead was recruited to the Program to support with collaboration building activities. Activities included co-ordinating training of participating PHNs; liaising with GPs, NSW Health and software vendors; and providing operational support to relevant stakeholders throughout the Program. A two-day Lumos Workshop was held in August 2019 with PHNs, GPs and other key stakeholders.
- **Lumos branding and communication materials were developed.** The materials provide key stakeholders with an overview of program objectives and information to enhance program understanding, awareness and recognition.
- **Additional key stakeholders were identified and engaged to guide successful program implementation.** This allowed concerns, risks, opportunities and other considerations to be identified and addressed. Stakeholders consulted to support the implementation of the state-wide rollout of Lumos include: NSW Ministry of Health executives, NSW Health Pillars, LHDs, PHNs, GPs, the Royal Australian College of General Practitioners (RACGP), the Australian Medical Association (AMA) NSW, Health Consumers NSW, and the Aboriginal Health and Medical Research Council (AH&MRC) of NSW.
- **Communication with the broader community of interested parties commenced.** Presentations were provided at a number of conferences to introduce Lumos and provide the opportunity to understand how the program could be used locally.



Establishing program and data governance that is strategic, collaborative and inclusive

Given the large scale, transformational nature of the Lumos program, strong and clearly defined program governance structures that reflect joint partnership and collaboration are crucial to successful implementation. These structures provide a framework within which implementation activities can operate, new and innovative ideas can be shared, issues can be addressed, and key insights and findings communicated. Key partners and collaborators will gain clarity and confidence that the program is working towards achieving its objectives in an efficient and effective manner, while satisfying community, ethical and legal requirements.

KEY ACHIEVEMENTS

- **The Lumos program was granted approval by the NSW Population & Health Services Research Ethics Committee to expand state-wide.** Approval has been granted with a waiver of individual patient consent because Lumos data will serve the interests of public good while minimising any risks to patient confidentiality.
- **Consumer engagement has been embedded into the governance of the Program.** Raising awareness about the Program, and about how patient information is being used is central to building and retaining a social license and underpins meeting community expectations, public acceptability, trust and integrity in the Program.
- **The Lumos program governance structures were established and endorsed by key partners.** New Committees include the:
 - Stakeholder Reference Group
 - Implementation Reference Group
 - Data Governance Group
- **Bilateral funding agreements were entered into by the NSW Ministry of Health with each of the 10 NSW PHNs.** The agreements outline the objectives of Lumos, the spirit of the collaborative partnership, and expectations on the services to be provisioned by both parties with relation to the funding.
- **The Lumos Data Governance Framework was developed.** It outlines the overarching guiding principles to data governance, the key components to ensuring the effective management of the Lumos linked data asset, and the legal and regulatory compliance requirements in the acquiring, handling, storing and releasing of data.

Implementation of the Lumos Program

ACHIEVEMENT TOWARDS THE PROGRAM'S OBJECTIVES

Implementing state-of-the-art technical solutions to data management; providing assurance of rigour of process, protection of privacy and data security

A rigorous approach to data linkage is a cornerstone of the Lumos program as it ensures the resulting linked primary and acute care data asset provides a reliable evidence base that can be used to inform health policy and planning. State-of-the-art technology provides automated solutions to support the secure extraction, transfer and storage of information that safeguards patient privacy at all times. A core objective of the Lumos program is to facilitate access to a trusted information source to allow insights to be generated and shared with the system to effect change.

KEY ACHIEVEMENTS

- **PPRL was successfully implemented².** PPRL involves permanent one-way encoding of data at the point of extraction which means no patient identifying information leaves a general practice. It will underpin all future Lumos data linkages.
- **A secure cloud-based data storage and analysis environment has been designed; its development is underway.** The Secure Analytics Primary Health Environment (SAPHE) is a multi-user cloud solution that will provide authorised users with secure access to Lumos linked health data and reports. This is the first time a linked dataset, including NSW Health data, will be shared routinely with non-NSW Health entities/ individuals.
- **Technology was developed to enable automation of business processes for participation in the Lumos program.** This technology has enabled automatic and secure data extraction and transfer from participating GPs, replacing manual processes used during the Pilot Project.

Using data analytics to provide insightful information about patient journeys across the healthcare continuum

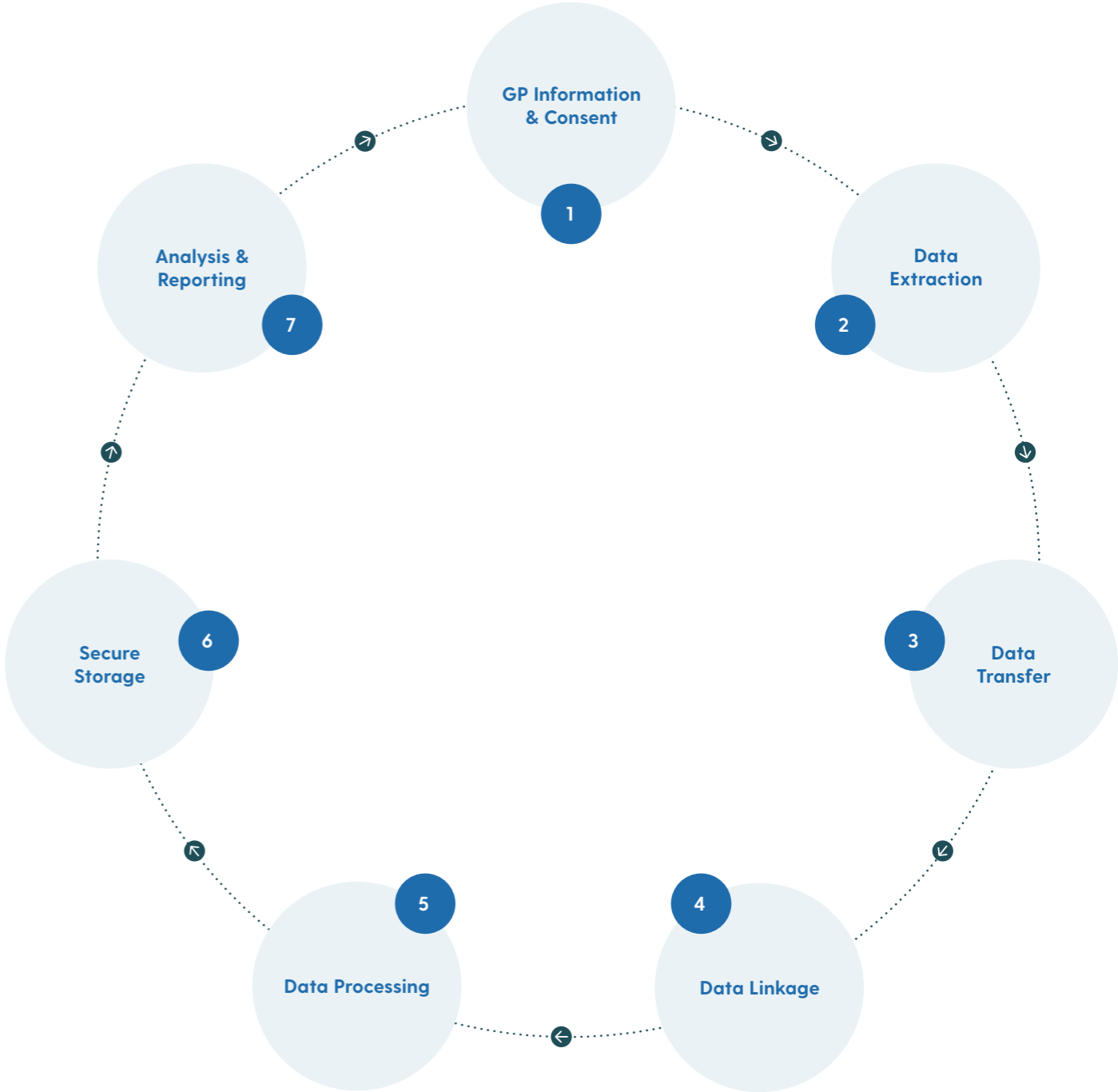
A core objective of the Lumos program is to use the linked data asset to provide regular, reliable and insightful information about patient journeys across primary, acute and other healthcare services. Specifically, the generation of insights relevant to decision making is paramount to achieving program success and realising the value of the linked data asset. Areas explored include: service design and integration; commissioning of services; improving patient experience, quality and outcomes; and the strategic directions of the NSW health system. To gain insights, routine and targeted analyses need to be conducted and findings shared with key stakeholders.

KEY ACHIEVEMENTS

- **Innovative analytical techniques were implemented to perform targeted analyses using Lumos linked data.** Early insights and findings have been obtained through analysis of the linked data from the Pilot Project. Even these early insights demonstrate the substantial value that these data will be able to bring to system transformation from volume to value.
 - Insights generated have been communicated to key stakeholders. Consultations and focus groups will take place in the coming months to inform the Lumos analysis plan moving forward. This will ensure that analyses are targeted and produce relevant and actionable insights that are meaningful to key stakeholders.

Lumos is establishing the evidence base for generating reliable insights, for informing and validating health service improvement, and decision-making.

Figure 3. Enhancing the Lumos data lifecycle with state-of-the-art technical solutions



² PPRL was achieved using technology developed by Curtin University's Centre for Data Linkage.

Implementation of the Lumos Program

ACHIEVEMENT TOWARDS THE PROGRAM'S OBJECTIVES

KEY INSIGHT 1

Early recognition in Primary Care can provide measurable benefits to patients and the system

- Building on the risk stratification work introduced in the NSW Integrated Care Strategy, risk stratification was enhanced using Lumos.
- Using the linked data asset, a Dynamic Simulation Model was developed to forecast future health system interactions for diabetes patients.
- Modelling (illustrated in Figure 4) suggests the high value impact that could be obtained through early recognition in Primary Care:
 - When a patient is recognised early in primary care, and has regular primary care attendances their diabetes journey is more likely to be managed over time in the community setting.
 - In contrast, when a patient condition is recognised later in a hospital setting and experiences reduced engagement with primary care, this could result in poorer management of Diabetes and increased interactions with hospital.

KEY INSIGHT 2

After hospital discharge, timely interactions with Primary Care can impact future interactions with Hospital Care

- Through the Lumos data, preliminary analysis of the impact of care in different settings on outcomes for patients and for the system has become possible.
- Data mining techniques allowed rapid exploration of anomalies, patterns and correlations; these techniques have been applied to the Lumos data asset to identify patterns in patient journeys and inform how care can be better delivered.
- The Lumos data indicates a strong relationship between GP visits and unplanned hospitalisations. The analysis suggests a GP visit within one week of discharge of an unplanned admitted patient episode can substantially reduce the risk of an unplanned hospitalisation in the 5 – 12 weeks following discharge (see Figure 5).
- Even at this early stage of its evolution, innovative analysis approaches can be applied to the Lumos data to provide specific insights to understand and improve patient journeys.

Figure 4. Condition Trajectory

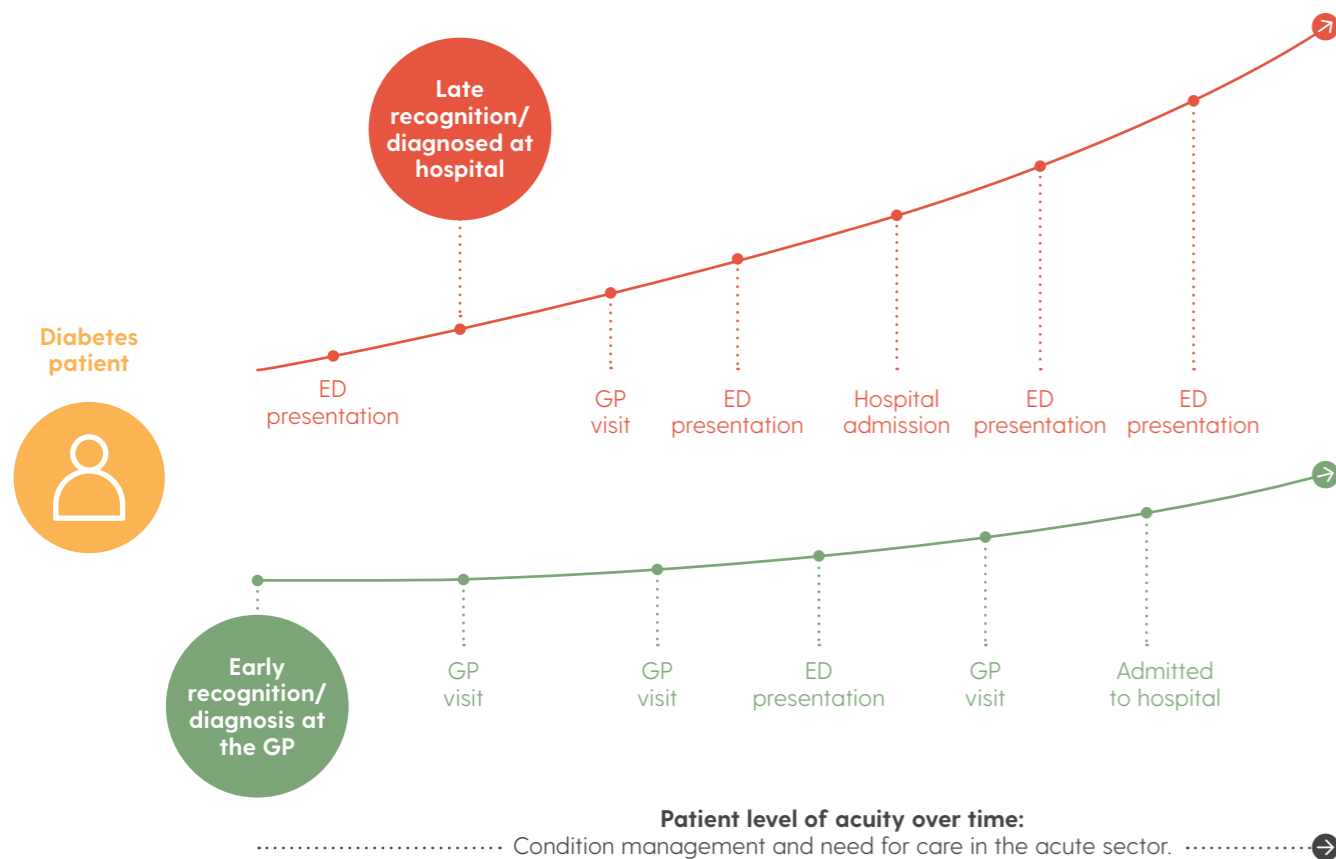
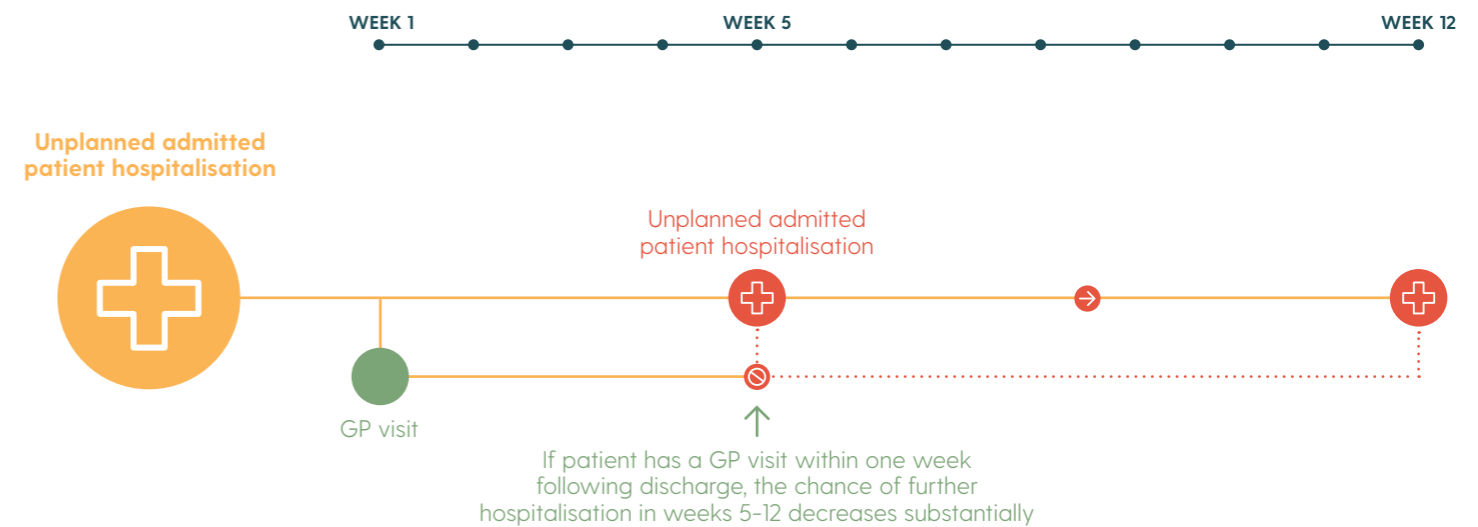


Figure 5. Relationship between GP visits and Unplanned Hospitalisations



Implementation of the Lumos Program

ACHIEVEMENT TOWARDS THE PROGRAM'S OBJECTIVES

Providing ongoing program monitoring and reporting to identify value

Another cornerstone of the Lumos program is giving data and information back to the health system. Regular program-level tracking, updating and reporting are crucial to ensure that stakeholders across the healthcare continuum remain informed and engaged. This will help identify and demonstrate value to the NSW health system.

Figure 6. Lumos Practice Report.



KEY ACHIEVEMENTS

- Customised general practice reports were developed and distributed to participating GPs.**
 The reports - containing descriptive results about the characteristics of patients, and their interactions with the broader health system - have been iteratively refined to reflect GP and PHN feedback. The reports (see Figure 6) provide GPs with access to information to better understand their patient cohort and how they compare to other practices in their region and across the state.
- The provision of regular information about their patients' journeys empowers GPs.**
 Participating practices have reported that the information is supporting improvements in:
 - Data quality
 - Care planning
 - Service planning
- Providing relevant and timely insights from the Lumos data asset provides a foundation for continuous improvement across the continuum of care.
- The Lumos program will provide an evidence base to support joint needs assessments, regional planning and decision making.**
 As the Program evolves dynamic reports will be made available in the SAPHE allowing PHNs and LHDs to securely drill-down and navigate patient characteristics and patterns of service utilisation across healthcare settings for their region.
- The Lumos program will deliver an evidence base for the evaluation and monitoring of state-wide strategic programs.**
 By providing authorised users with access to the SAPHE, the Lumos data asset can be used to generate insights to support the ongoing monitoring and evaluation of strategic endeavours such as the NSW Integrated Care Strategy, collaborative commissioning initiatives between healthcare partners, and other value-based healthcare initiatives.
- The Lumos newsletter was developed and delivered quarterly to key stakeholders.**
 The newsletter provides program updates and implementation information. Communication channels will expand to include an annual forum mid-way and at the conclusion of the Program.

The Lumos Roadmap

NEXT STEPS

As Lumos moves into its second year of implementation the focus will be on the following:

Building sustainable partnerships and collaboration

- Build GP participation
- Actively engage with core implementation stakeholders – GPs, PHNs, LHDs, MoH, Consumers
- Monitor and continuously improve the quality of stakeholder relationships
- Build a community of practice through an annual Lumos Forum

Establishing program and data governance that is strategic, collaborative and inclusive

- Embed all governance elements as business as usual and ensure they meet functional requirements

Implementing state-of-the-art technical solutions to data management; providing assurance of rigour of process, protection of privacy and data security

- Conduct two cycles of state-wide data linkage per annum
- Enrich the Lumos data asset
 - Add additional data sources to the linked data asset, including: Non-Admitted Patient data; NSW Ambulance data; Cause of death data; Central Cancer Registry data; and Mental Health Ambulatory data
- Establish the secure cloud-based data storage and analysis environment (SAPHE) and ensure its ongoing operation and functionality
- Expand the potential reach of Lumos through various GP data extraction capabilities
 - Pilot the Lumos data collection, extraction and transfer process with other IT vendors

Using data analytics to provide insightful information about patient journeys across the healthcare continuum

- Embed routine analysis of the scaled linked data asset
- Develop innovative and/or targeted analysis approaches to fully utilise the power of the scaled data asset

Providing ongoing program monitoring and reporting to identify value

- Expand general practice reporting to accommodate all GPs to meet scale up of participation
- Develop dynamic regional reporting to help inform the strategic priority areas and needs assessment of PHNs and LHDs
- Provide an evidence-base to support informed decision making regarding statewide initiatives and programs



Following patient journeys



Better population health



State of the art data analytics



Cloud based data integration platform



Descriptive statistics



Safeguarding patient privacy



Automated processes



Expand reach



State of the art record linkage to many data sources



Working collaboratively

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SHPN (SIA) 210004
ISBN 978-1-76081-561-5 (print)
ISBN 978-1-76081-562-2 (online)

This document can be downloaded from the
NSW Health website: www.health.nsw.gov.au