

Lumos Evaluation

Report 1 December 2021





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From the Executive Sponsor

I am excited to release the first evaluation report for Lumos, following on from the Progress Report published in early 2021. This year has seen Lumos go from strength to strength despite the challenging circumstances the year has brought to us all. The ongoing support for Lumos has demonstrated that there is enthusiasm and demand for system-wide data now more than ever.

The Lumos program has been in the scale-up phase for over 18 months, and it has continued increasing the number of participating general practices and the associated data included in the linkage. At time of reporting, over 500 general practices were enrolled across all 10 Primary Health Networks (PHNs) in NSW, which is three times more than those enrolled at last report.

This year has also seen the Secure Analytics Primary Health Environment (SAPHE) go live. The SAPHE was custom-built by the Lumos program for PHN, Local Health District (LHD) and Ministry of Health stakeholders, marking the first time a linked data asset containing NSW Health data has been made accessible to our PHN partners.

This marks a significant step in our collaboration with PHNs and supports the essential joint planning work that takes place across the state including the intent of the NSW Health/PHN Joint Statement.

We now turn our attention to the use of the data more broadly to support whole of system reform, answer fundamental questions around patient journeys across the system, offer insights on innovative funding models and support quality improvement to deliver better health outcomes. We will work closely with the partnership network that Lumos has created to collectively plan how we approach this work and deliver the best outcomes for providers and patients.

There is still work to be done to secure Lumos as an enduring data asset and ensure its existence into the future. We will be working with stakeholders over the next 12 months to determine what Lumos should look like beyond our existing funding cycle in order to deliver for our customers.

This first evaluation report explores the success of the program's implementation, progress and achievements to date. We could not have achieved so much without the support of our partners, and thank all those we have worked with to get to this point over the past 18 months.

Sharon Smith

Lumos Executive Sponsor and Executive Director System Information and Analytics NSW Health

This Report

This report evaluates the establishment of Lumos as a key data asset made possible through the collaboration of multiple stakeholders. It measures our success to date against four key domains considered integral in meeting program objectives. The evaluation has triangulated routine program data (e.g. participation rates, use cases), commissioned reviews (e.g. the Privacy Impact Assessment) and a purpose-specific, key informant survey of a broad range of stakeholders to understand perspectives and opportunities for improvement. Where existing publicly available reports have been used, hot links are provided.

The Lumos Program

The Lumos program began as a pilot project in 2016 then transitioned to scale-up in early 2020. Data for patients attending participating general practices across NSW are linked to administrative data held by NSW Health. The ambition of the Lumos program is to deliver a data asset to underpin state-wide priority programs and act as a system-wide enabler that accelerates Value Based Healthcare, through creating a reliable evidence base to inform decision making and policy across the system.

KEY FINDINGS

The foundations are established

- Governance is strong The Privacy Impact
 Assessment indicated strong confidence in the
 Lumos data asset. Aboriginal governance and data
 sovereignty are being established to complete
 best practice governance
- Technical solutions to ensure secure and efficient data acquisition and access have been established; including state of the art privacy protection
- Key stakeholders are strongly engaged and supportive

Participation is high, reflecting the strong foundations

Targeted scale of data capture across NSW is being achieved



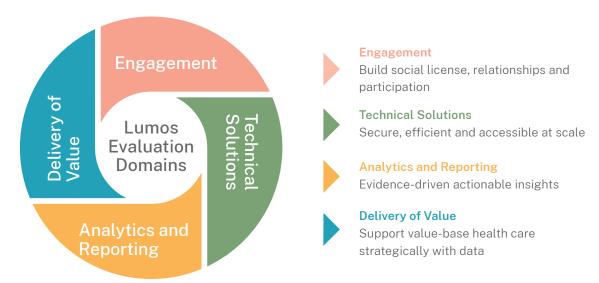


The Lumos Evaluation

The Lumos Monitoring and Evaluation Framework describes the program aims, evaluation questions, evaluation domains, implementation approach and data sources for assessing the impact of Lumos. The framework spans the Program scale-up which is funded by the Commonwealth Government under the Health Innovation Fund (HIF) for 2019-23.

Monitoring and evaluating the Lumos program is structured around four domains that provide the foundation for translation of the framework's overarching evaluation questions into detailed measurable objectives and milestones (Figure 1)

Figure 1 Four Evaluation Domains are structured around the Lumos Program



Measurement approach - monitoring against the indicators

For this interim report, data were collected through stakeholder interviews conducted by an independent third party, and from existing program data such as registers and routine reporting.¹

The data presented here are not intended to be comprehensive, rather provide an interim snapshot as the program becomes established.

The report will systematically address a set of subquestions for each of the domains and then present evidence in support.

As part of monitoring against the indicators, an overview of maturity of achievements is included



Domain 1

Engagement to build social license, relationships, and participation

Overarching goal: To achieve strong stakeholder endorsement, trusting relationships and partner participation

OVERVIEW

The Lumos program vision supports a broad range of stakeholders. Given the large scale and transformational nature of the Lumos program, strong governance structures that reflect and garner collaboration are crucial to successful engagement. The program seeks to build:

- · Trusting, committed relationships across a comprehensive range of stakeholders
- Strong relationship capital with key stakeholders
- · High rates of participation

Measurement of achievement of engagement against its objectives was guided by the following sub-evaluation questions as described in the Monitoring and Evaluation Framework.

- Is stakeholder engagement becoming comprehensive and inclusive?
- Is best practice governance in place?
- Is participation reaching expected levels with the appropriate jurisdictional and sociodemographic spread?
- Are appropriate foundations for Aboriginal data collection and use being established?
- Are stakeholders satisfied?



KEY FINDINGS

Stakeholder engagement is broad, and satisfaction is high

41 key stakeholders were interviewed during July and August 2021 by an independent consultant, using semistructured interviews, and including representatives from all ten NSW PHNs, a sample of Local Health Districts (LHDs) and key system and external stakeholders. Thematic analysis consolidated views under four emerging areas (Figure 2).

The interviews sought to identify:

- views of the program from a strategic perspective,
- satisfaction with the relationship to the Lumos Program, and,
- opportunities for improvements in the program.



Relationships and engagement have been key to success

High level of GP trust exists, underpinned by security, confidentiality and use of the data for agreed purposes.

Strong brand awareness exists among priority stakeholders.

Strong relationships between the program and the PHNs are key drivers of recruitment success.

Strengthening engagement with LHDs and MoH stakeholders is a priority.

The potential of Lumos to underpin whole-of-system collaboration is well-recognised.



There is a rich value proposition

Value of a linked data set-providing new and unique insights.

Value to the consumer-potential to inform improved patient care.

Value to GPs-providing a more complete picture of care across the system.

Value at the system level-supporting strategic reform and measurement of outcomes.

Technical value of Lumos-contribution to direction of system data management.

Figure 2

Four emerging themes from interviews on stakeholder engagement



Lumos outputs are seen to provide value and their future potential recognised

Reports to GPs produced after each linkage are seen as valuable and accessible.

Access and use of the data in the secure environment (SAPHE) is still in its early phases.

Apart from technical challenges, stakeholders recognise that analytical capability at local levels is also a challenge.

Early case studies published on the website and through the newsletter were seen as a valuable way to access insights from Lumos.

The potential opportunities for Lumos outputs to support broader strategic priorities is recognised.



The evolutionary nature of process and operations was recognised

Timelines of the data is challenging - the timeline of extraction, processing and output release imposes constraints; clarity about the process is important for stakeholders.

Strong governance is recognised as a hallmark of Lumos but can prove burdensome, streamlining access processes for approved purposes for the use of data are valued.

Technical advancements has brought with it some challenges including the complexity of the data and the power required to analyse it.

Key stakeholders directly involved in operationalising Lumos expressed commitment to work collaboratively on reviewing and streamlining current arrangements where possible.

Lumos is working with end users to support meaningful use of the data through activities such as a community of data practice.



Best practice governance is being established

Lumos was established under ethical approval obtained from the NSW Population and Health Services Research Ethics Committee. ² At inception, as part of that ethical approval process, the Lumos program envisaged a comprehensive data governance approach recognising a broad range of stakeholders as outlined in the program governance structure. Key components of the governance structure have been fully established, including a Stakeholder Committee, a Data Governance Committee, and a Data Governance Framework.

Building leading practice foundations for Aboriginal data collection and analysis is also a priority of Lumos. Preparations are underway to establish an Aboriginal Data Governance Committee, to develop a data sovereignty plan, and to appropriately strengthen the investigator team to include Aboriginal team members at all levels.

Practice participation is fulfilling expectations, both in quantum and reach

At the time of writing, 524 practices were participating in the Lumos program, with 344 of these having contributed data in time for the most recent linkage. Analysis to understand the degree to which Lumos data is representative of the NSW community suggests the data is well aligned with NSW population features.

As Figure 3 shows, jurisdictional coverage has become increasingly comprehensive: practice participation spans all 10 PHNs in NSW and includes metropolitan, rural, and remote practices.

Based on the data provided in the most current linkage (mid-2021), sociodemographic coverage is representative of the NSW population. Analysis indicates that overall, at the state level the demographic distribution of Lumos patients was greater than 95 per cent aligned to the demographic distribution in the NSW population (age, sex, regional distribution, and socioeconomic status). Alignment also appears to be high within each PHN catchment. Preliminary work suggests that the coverage varied between 83 per cent and 96 per cent aligned to the demographic distribution of the region. 4

Lumos



Key learning / looking ahead

- Strengthening relationships with LHDs and the Ministry of Health is a focus for the immediate future. This will allow Lumos to operate in a truly 'one-system' stakeholder environment.
- As participation and engagement ramps up, so too should production of Lumos outputs to underpin stakeholders' strategic endeavours.
- More broadly, enhancing use of the data remains a priority. Working collaboratively with end users will support meaningful use of the data through activities such as a data community of practice.

Domain 2

Technical Solutions: secure, efficient, and accessible at scale

Overarching goal: Data transfer, storage and access that is secure, efficient, accurate and scaled.

OVERVIEW

Lumos is the first of its kind in Australia, bringing together data from different health settings to support policy, evaluation and reform. The ability for non-NSW Health employees to access data from NSW Health services breaks down barriers and supports partnership work that is informed and evidence based. Achieving this has required extensive technological innovations that directly impact program success and sustainability.

Measuring success of technological solutions was guided by the following sub-evaluation questions:

- Is data transfer and linkage occurring for the expected number of practices (10 per cent of NSW practices)?
- Can stakeholders access Lumos data?
- Is patient and practice privacy optimised throughout the data lifecycle?







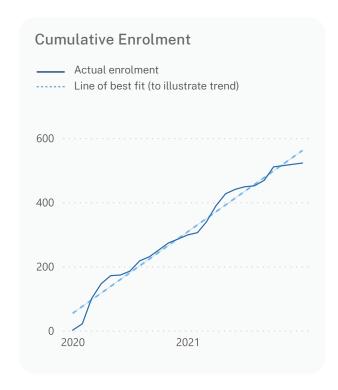


KEY FINDINGS

Accurate and efficient data transfer and linkage is occurring at scale

Data from over 3 million people across 344 practices were included in the mid-2021 linkage. At the time of reporting the level of participation had increased to 524 practices enrolled. This represents an exponential growth in participation and data transfer in the scale-up phase, from three practices in January 2020 (Figure 4).

Figure 4



There are:

524 general practices enrolled in Lumos as of September 2021.

This represents 19.5% of 2,689 practices in NSW.

Secure access to the data for stakeholders has been established

The Secure Analytics Primary Health
Environment (SAPHE) was developed in 2020
to allow secure access to the Lumos data
asset. It is a custom cloud solution with built-in
analytics tools and extensive privacy and security
measures that meet the NSW Health Privacy
Security Assurance Framework (PSAF). The
SAPHE allows approved employees outside NSW
Health to access this type of data for the first
time in NSW.

By August 2021 there were 56 active users of the SAPHE from PHNs, LHDs and the NSW Ministry of Health (Figure 5). To facilitate use of the SAPHE, and strengthen the collaborative relationships among users, a community of practice including all NSW Health and PHN SAPHE users was established in early 2021. Through the community of practice, experience and feedback to underpin continuous improvement was informally collected in the second half of 2021. SAPHE users reported high satisfaction with their onboarding experience and the potential of the SAPHE to inform their work:

"[Onboarding for the SAPHE] was the easiest transition I have ever undertaken...MPHN is excited about the possibilities of using the SAPHE to work with our General Practitioners (GPs) and Local Health District partners to inform and reshape healthcare in the future. In this fast-paced data world we are now working in, this data is revolutionary in terms of linked up healthcare data."

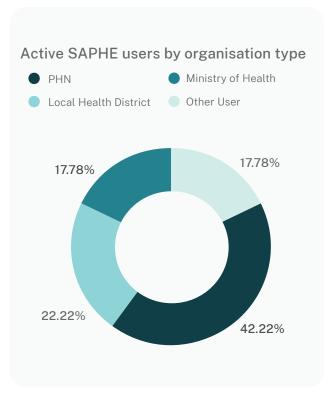
Dr Alison Koschel -Murrumbidgee Primary Health Network (MPHN), one of the first SAPHE users

An independent end-toend technical review has been commissioned on the Lumos architecture

An independent end-to-end technical review of the Lumos program was performed in 2021. The purpose of the review was to map the current technology and data processes. This map was reviewed against the background of the available technology landscape, to allow consideration of the quality of the Lumos technical design and to identify potential areas for improvement.

The review found no risks that threatened Lumos' short term ability to operate within the current solution design. Seven recommendations were made, highlighting opportunities to improve on the overall solution design, for example automation of manual processes. These are currently under review and provide useful input to continuous improvement. ⁵

Figure 5





Patient and practice privacy is optimised throughout the data lifecycle

Protection of privacy has been central to the technical developments of the Lumos data asset. An independent Privacy Impact Assessment (PIA) undertaken in 2020 commended the program's stewardship of privacy. The PIA assessed the privacy impacts across the program's lifecycle including a detailed assessment of privacy and security protections during data extraction, linkage, storage, governance and communications.

In particular, the review highlighted the strength of the technical design to ensure that named information never leaves the general practice (as intended under the ethical approval provisions to scale-up Lumos from a pilot program). Privacy Preserving Record Linkage has been successfully implemented. Specifically, the extraction process, developed in conjunction with Curtin University in Western Australia, replaces patient details such as name and address, with encoded information, using Bloom filters at the source. The software automates regular encoding, extraction and transfer of data as per the Lumos protocol. Linkage files and content files are transferred separately via secure file transfer. GP data extracts contain a range of healthrelated data from patient GP records to be linked to health, service use, demographic and mortality data in other NSW Health data collections.

impacts on individuals' privacy. to the extent that its use of innovative privacy-preserving linkage techniques such as bloom filters could drive the broader uptake of such practices within the medical software sector." Privacy Impact Assessment of the Lumos Program

"The Lumos Program has

the potential to have positive

To ensure that Lumos maintains this favourable assessment, thirteen recommendations were made all of which are under implementation.

"In our view, the Lumos Program has been well designed to protect patient privacy to a very high degree. and does not give rise to any likely negative impacts on individuals during the data extraction, data linkage or data analysis stages."8

Privacy Impact Assessment of the Lumos Program



Key learning / looking ahead

- Feedback from SAPHE users indicates that analytics capacity and capability among users is challenging; in response to this feedback, a range of strategies to better support users are being designed and implemented.
- Explore other options for extraction long-term.

Domain 3

Analytics and Reporting

Overarching goal: Creation of practice relevant evidence base that is accessible and used for continuous improvement.

OVERVIEW

For the Lumos data asset to support better value care, analytics and reporting must provide relevant, reliable, and actionable insights that can be used to measure value across the system and support continuous improvement. There must also be opportunities to interact with the data at practice and regional levels, to drive local improvement initiatives. Measuring success of Lumos analytics and reporting was guided by the following sub-evaluation questions:

- Does the Lumos data asset link a range of relevant health data sets?
- Can Lumos data reliably inform improvement strategies?
- Are unique and actionable insights revealed and disseminated?
- Has a community of practice been established with members from an appropriate range of organisations?
- Does the Lumos asset underpin improvements in practice?









KEY FINDINGS

Lumos reliably links a substantial range of data sets to produce a high value data asset

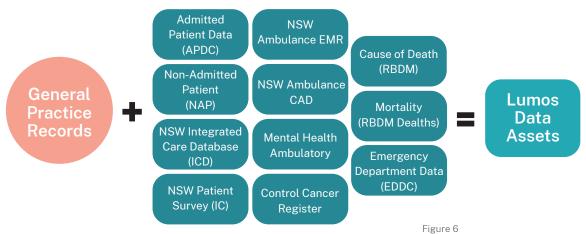
At the time of reporting, the Lumos data asset links 11 data sets to general practice records (Figure 6).

The quality of the linkages is high, with extensive data cleansing and audits performed after data extraction and linkage.

Inclusion of additional data sets for linkage is under development. Principal among these is the inclusion of data from Aboriginal Community Controlled Health Services (ACCHSs). At the time of reporting, there has been no active targeted recruitment of ACCHSs to contribute data, although it has been possible for ACCHSs to contribute data to Lumos under the principle of self-determination. Nor have any disaggregated analyses on contributed data been undertaken, prior to appropriate governance being established.

It is the ambition of the Lumos program to foster a state-wide Indigenous perspective, and to build strong Indigenous-led data governance including development of a Data Sovereignty Plan together with strong Aboriginal leadership and capacity building.

The inclusion of Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Schedule (PBS) data is a priority. These data capture all service events (MBS) and dispensed pharmacy prescriptions (PBS) paid for by the Australian Government. This data would allow almost complete capture of primary, specialist and pharmaceutical service use by patients of participating Lumos practices. The value of including these data to complement the rich clinical primary care data currently in Lumos was highlighted by stakeholders as part of the stakeholder evaluation.⁹



Data sets linked to general practice records to form the Lumos data asset

Lumos data has potential to reliably inform improvement strategies

Custom practice reports are produced for each participating practice after each linkage, twice per annum, and provide a range of data comparing patients of the practice with the PHN and state level (Figure 7). The reports explore how patients of the practice interact with different health services and include a unique condition in focus each linkage. GPs and PHNs find the reports to be high quality with valuable content about their patients:

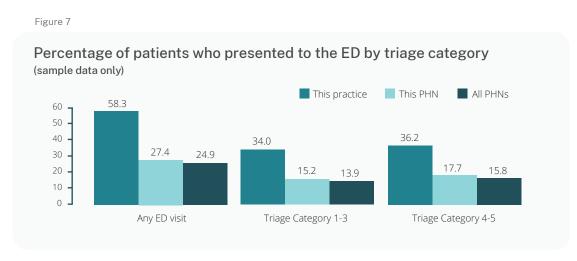
"Lumos provides us with the most interesting and amazingly detailed reports about our patients and their interaction with local health services. Through reading our report we have a much better understanding of what our patient cohort "looks like" and how this compares both locally and within the state."

Dr Charlotte Hespe-Glebe Family Medical Practice Stakeholders clearly see the value of being able to understand their patients' journey more completely, and the potential value this understanding can add to improvement processes:

"Lumos provides us with significant insights into how our patients interact with the health system outside of our own practice...this has allowed us to focus our quality improvement processes where they're most needed."

Dr Nuwan Dharmaratne -Hills Family GP

Participating GPs have been using their practice reports to inform quality improvement work. One practice used diabetes data with comparisons of their patients against averages in their local PHN and across NSW to identify an opportunity to improve annual rates of HbA1c testing (a measure of a patient's diabetic condition). The practice followed up patients who had not received an annual HbA1c test and implemented multiple strategies to increase rates of routine testing, including having nurses triage patients presenting to the practice and advised the GP of outstanding tests.





Unique and actionable insights are being revealed and disseminated

Even at this early stage in its evolution, the Lumos data asset is showing its potential to reveal unique insights, insights that can only be seen at the intersection of health care settings.

Lumos analytics discovered that patients who attended a high-frequency servicing practice were:

This is seen in both patients who attended the practice frequently and those who attended less often.

High-frequency servicing practices are defined as practices where greater than 30 per cent of patients visited at least 12 times in two years.

10 / less likely to have an ED presentation

12 'less likely to have an unplanned hospital admission

An analytics community of practice has been established

The SAPHE community of practice was launched in March 2021. Each month it brings together approximately 20 PHN, LHD and other NSW Health SAPHE users to share ideas and upskill in using the Lumos data asset.

Key learning / looking ahead

- Additional focus is required to realise the full value of the data asset to deliver actionable insights across the range of stakeholders.
- Lumos continues to prioritise accessible ways of providing data including development of interactive dashboards.
- Addition of MBS and PBS data is critical to the enhancement of Lumos.



Domain 4

Delivery of Value

OVERVIEW

Lumos supports the design, delivery and evaluation of models that aim to deliver Value Based Healthcare (VBHC). The value of Lumos is in the program's ability to influence change at a policy and system level through the provision of a unique evidence base. Scale in the Lumos program has only just been achieved, yet its potential to deliver value to support decision making and investment is already emerging. Assessing the delivery of value was guided by the following sub-evaluation questions:

- Have there been any insights? Are they policy ready?
- Do policy makers and decision makers know about the insights?
- Are insights being used to underpin and support Value Based Healthcare?
- What is the value to the Commonwealth? What is the value to NSW? What is sustainable business-as-usual?







KEY FINDINGS

Lumos data have informed discussions at State and National levels with policy ready insights

In early 2021, NSW Health was considering policy reform concerning the supply of medications to patients at the time of their discharge from a NSW hospital. The policy question concerned the appropriate duration for supply of medication to patients, at discharge, to ensure that the supply would see patients through to their first GP visit (when the medication could be reviewed and extended as needed).

Lumos was able to provide information on rates and timing of GP follow-up after hospital discharge. This information provided evidence to better inform consideration of optimal medication supply to patients at discharge. Lumos data provided unique information about how best to meet patient needs.

The Lumos insights are invaluable. They really helped focus executive discussions on how to improve the patient journey; there are a range of funding reform opportunities that the Lumos evidence base could inform

Ryan Broom, A/ Director Policy and Funding Reform, NSW Ministry of Health

The following examples illustrate the value Lumos is delivering to the VBHC initiatives

1. Evaluation of Integrated Care Initiatives being implemented by Local Health Districts (LHD) 10

In the second half of 2020, 1.3 million patient journeys had been captured in Lumos. Among these, 10,000 patients had been enrolled in Integrated Care initiatives. Integrated Care seeks to support the provision of seamless, effective and efficient care that reflects the whole of a person's health needs. This includes state-wide strategies coordinating better communication and connectivity between health care providers in primary care, community, and hospital settings, and providing better access to community-based services closer to home.

Data for patients participating in the Western Sydney Local Health District (WSLHD) Diabetes initiative provide an example of how the data can be used to measure value.

At the time of the analysis in 2020, there were approximately 350 WSLHD diabetes patients enrolled in the Diabetes initiative for at least 12 months who also had a clinical encounter in the Lumos data.

There was a sharp increase in the number of GP visits immediately after enrolment in Integrated Care by the LHD, and then a gradual return to pre-enrolment visit numbers over the next 12 months.

In this group of patients, 82 per cent had at least one HbA1c result recorded in Lumos and 53 per cent had HbA1c results pre and post enrolment. HbA1c level measured in the blood is a key biometric indicator of health risk and diabetes managent.

Figure 8 shows the latest HbA1c result recorded in the 12 months pre-enrolment and the latest in the 12 months post-enrolment. There was a significant mean reduction in HbA1c by (95% CI) -0.71 (-0.98, -0.45). This reduction indicates an improvement in health outcome through better management of the patients' diabetes.

This example shows the potential of Lumos to look at the effect of initiatives across the patients health care journey and the impact of health interventions of clinical outcomes. For the local providers in WSLHD, we can measure success, namely engagement with primary care following enrolment, with the likely outcome that patients' diabetes was better managed in the community setting.

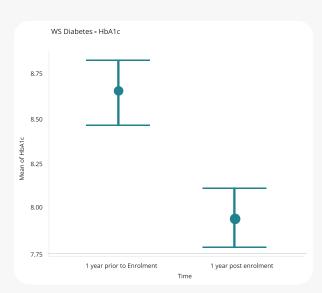


Figure 8 HbA1c results 12 months before and after enrolment in WSLHD's Diabetes initiative

2. Supporting planning, monitoring and evaluation of Collaborative Commissioning

Collaborative Commissioning supports partnerships between LHDs and PHNs in Patient Centred Cocommissioning Groups (PCCGs). PCCGs focus on local health needs and develop interventions to improve patient and community outcomes. At the time of reporting, there were three partnerships in the process of operationalising their models of care (Western Sydney LHD and WentWest PHN, Northern Sydney LHD and Sydney North PHN, and Western NSW and Far West Local Health Districts, Western NSW Primary Health Network and NSW Rural Doctors Network).

Lumos has provided the basis for the LHD/ PHN partnerships to have, for the first time, data showing trends in supply and demand across settings, underpinning joint planning, funding and delivery of value based care. The Lumos data allows a Dynamic Simulation Model (DSM) approach to provide endto-end care pathway modelling, across settings to support joint planning. Taking real information about a target cohort, the DSM uses modelling technology to test different potential scenarios over time to help understand the range of likely impacts of a service innovation before implementation. The scenarios incorporate typical patient flows through the healthcare system to predict the impact of innovation in services, for example alternative care models, on supply and demand.

The value of Lumos to the Commonwealth is increasingly evident

The recent Commonwealth Primary Health Care 10 Year Plan specifically highlighted the value of Lumos. The Plan recognised the critical importance of capturing better health data and using it well, to underpin high quality primary care and continuous improvement in delivery of care to meet the health needs of the Australian population.

"This is the standard of effective use of data which the Government would like all regions around Australia to reach." $^{\rm 11}$

Additionally, the Productivity Commission included Lumos as a case study in their Innovations in Care for Chronic Conditions report.¹²

In the long-term Lumos provides a unique evidence base to provide support across the reform agenda outlined under the 2021 National Health Reform Agreement, and in particular the enhanced health data reform. By providing access to system wide data, Lumos enables local partnerships through an evidence base to underpin joint planning, implementation and evaluation of new models of care.

Learnings from Lumos can and will be used to support reform activities at a national level and move Australia closer to system wide national linked data solution.

Key learning / looking ahead



- · Support national reform
- Explore the options for ensuring that Lumos becomes an enduring data
- Embed Lumos in measurement of value across NSW Health





Appendix

April 2021 Lumos Data

Measure of representativeness: histogram intersection

Male & Female 5-year age groups, SEIFA, ARIA

Code	PHN	% Practices	% Population	Average
PHN101	CESPHN	7.9%	40.8%	91.7%
PHN102	NSPHN	12.5%	43.3%	91.6%
PHN103	WSPHN	17.0%	40.2%	95.2%
PHN104	NBMPHN	10.9%	28.1%	94.2%
PHN105	SWSPHN	17.4%	45.5%	95.8%
PHN106	SENSWPHN	2.5%	4.6%	86.7%
PHN107	WNSWPHN	6.5%	33.9%	83.8%
PHN108	HNECCPHN	18.8%	44.9%	93.4%
PHN109	NCPHN	6.9%	27.1%	83.1%
PHN110	MPHN	8.3%	14.3%	86.6%

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Lumos