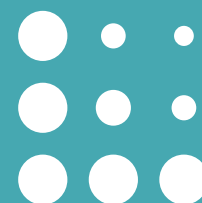


Lumos Evaluation

Report 2
October 2022



Lumos



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From the Executive Sponsor

I am excited to release the second evaluation report for Lumos, following on from the [Lumos Evaluation Report-1](#) published in December 2021. This year has seen Lumos exceed its participation targets, despite the challenging circumstances the year has brought to us all. Stakeholder engagement is stronger, increasingly comprehensive and the value of the data asset is universally recognised. The level of support for the Lumos program reflects, now more than ever, the enthusiasm and demand for system-wide data.

The Lumos program has been in the scale-up phase for approximately 3 years, and it has continued increasing the number of participating general practices and the associated data included in the linkage. At the time of reporting, over 600 general practices were enrolled across all 10 Primary Health Networks (PHNs) in NSW, 100 more than those enrolled at last report.

This year has seen substantially increased stakeholder engagement with the Secure Analytics Primary Health Environment (SAPHE) a little more than a year after going 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. Increasing interaction with the data in the SAPHE has been facilitated through business intelligence tools created by the Lumos team to support capacity and capability among end-users.

This past year has seen increasing focus on the use of the data to support Value Based Healthcare in NSW, and more broadly to support whole of system reform. Unique and actionable insights have been harvested from the data to answer fundamental questions around patient journeys across the system and its interfaces, to offer insights on innovative funding models and to support quality improvement to deliver better health outcomes.

In the current era of generational health reform, specifically the 10 Year Primary Health Care Plan, and the Strengthening Medicare Taskforce, Lumos is increasingly at the forefront of providing policy-ready data-based evidence. The first survey of Lumos participating practices reported here, reveals the extent of commitment of our General Practice partners not only to better healthcare journeys for their patients but also to making a contribution through data to system reform. We will work closely with the extended network that Lumos has created to collectively plan how we approach this work and support the best outcomes for the system, for providers and for patients.

The successful establishment of Lumos 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. The partnership with General Practice has provided the proof-of-concept: routine data linkage of acute and primary care data can be safely and securely undertaken at scale. 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 on its potential to contribute to system-wide data.

This second 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 3 years.

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

KEY FINDINGS

The Lumos program has demonstrated the feasibility of safe and secure primary care and acute care data linkage at scale.

Participation in the scale-up of Lumos has exceeded expectations



participating in the Lumos program at the time of reporting, capturing information on more than 4 million patient journeys across NSW.

This represents

23.2%

of **2619** practices
in NSW



and exceeds the
2023 target set
for the program

20%

Governance is strong, and endorsed by stakeholders

- An updated Privacy Impact Assessment has again provided a favourable review of the program, albeit making recommendations that will continue to improve governance.

“We believe that 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.”

- Equally importantly, stakeholders report improved understanding of ethics and privacy constraints, compared to the first evaluation period, recognising the value to the data asset of strong governance.
- Establishment of appropriate foundations for Aboriginal data collection and use is in development, although this important aspect of the program has progressed more slowly than envisaged.

KEY FINDINGS

Stakeholder engagement is strong, increasingly comprehensive and the value of the data asset is well-recognised

- The strength and reach of stakeholder relationships is increasingly comprehensive; relationships with PHNs and GPs continues to be strong, and the relationships with the Ministry of Health (MoH), Pillars and others is maturing.
- Stakeholder endorsement of the value of the Lumos data asset is unanimous.
- Stakeholder engagement with the data asset is increasing; by August 2022 active users of the SAPHE increase by 30% compared to the same period in 2021.

The first survey of participating general practices indicates that the majority of GPs value the importance of the data and using it well.

- Positive views of the data and its presentation in the Practice Reports
- Being confident in the program's privacy and security measures
- The importance of more comprehensive visibility of the patient journey and its role in healthcare delivery and reform
- Being motivated to participate in the Lumos program to identify areas for improvement and to provide insight to the patient journey across the system

The value of the Lumos data asset is evident: the program is producing high quality, policy relevant and system reform focused insight and contributing to delivery of Value Based Healthcare (VBHC) at local, NSW and national levels

- Actionable insights to inform NSW Health's VBHC initiatives are being regularly generated and disseminated by the Lumos Program
- Lumos data being used for design/ implementation/ evaluation of local initiatives (Eg Hunter New England Diabetes Alliance Program)
- Lumos is built into the evaluation plan for statewide VBHC initiatives (Eg the NSW Statewide Diabetes Initiative; NSW Collaborative Commissioning Program)
- Lumos is a central part of the national reform agenda, in particular primary care reform (Eg implementation of the 10 Year Primary Health Care Plan, the Strengthening Medicare Taskforce)

The Lumos Program Evaluation

This Report

This report presents the second evaluation of the establishment of Lumos as a key data asset made possible through the collaboration of multiple stakeholders. It reports progress of the Program against its ambitions at the end of the third year of its funding.

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. It also includes a statewide survey of participating general practices across all ten Primary Health Networks (PHNs).

Where existing publicly available reports have been referenced, 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 in primary and acute care, and to act as a system-wide enabler that accelerates NSW Health's Value Based Health Care initiatives, through creating a reliable evidence base to inform decision making and policy across the system.

The Lumos Monitoring and Evaluation (M & E) Framework

The [Lumos Monitoring and Evaluation \(M & E\) 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. It foreshadowed annual evaluation reports in late 2021, 2022 and 2023. This is the second of those reports.

The M & E Framework was based on a detailed Program Logic that identified short and medium

term impacts against the program's overarching ambitions. The detailed Evaluation Plan specified the domains for monitoring and evaluation, along with measurable indicators of increasing impact over time. The Framework provides the guide for the data captured and reported here.

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).

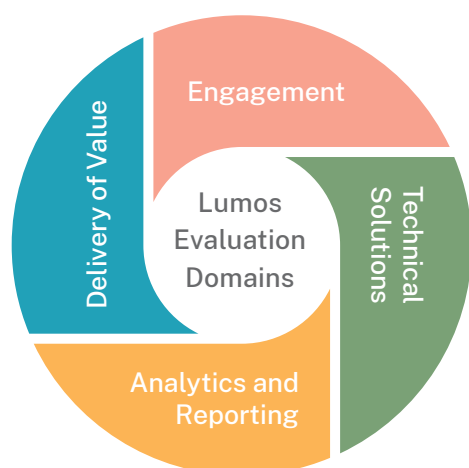


Figure 1
Four Evaluation Domains are structured around the Lumos program

- Engagement**
Build social license, relationships and participation
- Technical Solutions**
Secure, efficient and accessible at scale
- Analytics and Reporting**
Evidence-driven actionable insights
- Delivery of Value**
Support value-base health care strategically with data

Measurement Approach

The measurement approach was guided by the M & E Framework. Original data were collected through two sources: stakeholder consultations conducted by an independent third party, and a survey of participating general practices.

Stakeholder Consultations

Key stakeholders were interviewed during August and September 2022 by an independent consultant, using semi-structured interviews, and included 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.

Consultations were conducted by Health Consulting Collaborative, as an independent party, and findings have been de-identified and presented as a thematic analysis in this second Lumos evaluation report. The purpose of the consultations was to understand the value and benefits of Lumos, the use of Lumos outputs, any challenges associated with Lumos, and any opportunities for the future.

The topics explored in the consultations followed the same themes as the consultation 12 months ago. Accordingly, it was possible to consider the findings in terms of changes in views and experiences, from the views expressed by stakeholders in the first consultation ([Evaluation report 1](#)).

More than 40 stakeholders participated in the consultations, spanning the full range of interested parties with whom the program seeks to engage (see Appendix 1 for list of consultees).

The findings of the stakeholder consultations are reported in each of the four evaluation domains as relevant. In addition, opportunities for the future of the program identified by stakeholders are also reported.

GP Survey

All participating Lumos General Practices were invited to complete a short self-report survey (see Appendix 2 for a summary of the survey results). The survey sought views on:

- Relevance of the GP reports
- Confidence in the privacy and security of Lumos
- The motivation for participation in the Lumos program
- The perceived value of the Lumos data for the system, for the profession and locally

In all, 94 Lumos practices responded to the survey, from across all 10 PHNs, approximately a 15% response rate. Of these, 74 across 9 PHNs provided completed surveys, providing an effective response rate of approximately 12% of participating practices. The headline results of useable surveys are reported in the Engagement domain chapter.

Existing Program Data

Data such as registers and routine reporting were used to document achievements of the program, again discussed as relevant to the four evaluation domains.

This Report

This report will systematically address a set of sub-questions 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 building social licence, 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

Strong relationships were noted in the first [Lumos Evaluation Report 1](#). At the same time, strengthening relationships with LHDs and the Ministry of Health was identified as an important focus, to allow Lumos to operate in a truly 'one-system' stakeholder environment.

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?
 - PHNs and GPs
 - MoH, LHDs and others
- 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?



..... In development



..... Maturing



.....Mature

KEY FINDINGS

Stakeholder engagement is broad, and satisfaction is high

Enabling Lumos to operate in, and to provide support to a truly 'one-system' stakeholder environment was seen as a program imperative. Accordingly, strengthening relationships with LHDs and the NSW Ministry of Health and Pillars alongside maintaining the strong relationships that already existed with PHNs and GPs, was a focus over the last year. The data suggest that the relationships with PHNs and GPs continues to be strong, and that relationships with MoH, Pillars and others is maturing.

Stakeholder consultations indicated a range of new, continuing and changed perceptions, alongside identification of several opportunities for engagement in the future from each of their perspectives.



PHN and GP Stakeholders

PHN stakeholders continue to be well connected with the Lumos program through several engagement strategies, and consequently, recruitment of general practices continues

- The Lumos Community of Practice continues to be a strong and valuable forum for stakeholders to communicate, share updates and progress, and discuss the practical application and future changes to Lumos.
- General communication with Lumos team members to provide feedback and seek support is seen as a successful engagement mechanism.
- All PHNs were noted to have strengthened their engagement with general practices.
- Some PHNs identified that they had increased the number of participating general practices through alignment with specific programs, for example Collaborative Commissioning, and the LHD Winter Bed Strategy.
- Some PHNs also expressed concerns that particular groups of consumers, such as those from lower socio-economic bandings might be underrepresented in the data.
- Positive progress in recruiting some corporate general practices was also noted.

PHNs and GPs highlighted potential opportunities for strengthening Lumos through continued focus on recruitment of general practices and through empowering general practitioners and PHNs around the data analytics

- Strengthening the Lumos data asset through recruitment efforts was highlighted (particularly focusing on PHNs where recruitment is low and / or less representative of the population) and the ability to use the Lumos data for regional planning and quality improvement activities. Suggestions included:
 - accountability for Lumos recruitment and use in performance agreements for their CEO and Managers.
 - timing recruitment drives to align with imminent linkage and reports allowing engagement and feedback to newly participating practices to coincide.
- Development of mechanisms that will support general practitioners to utilise the data, were seen as another opportunity to strengthen engagement with the Lumos data. Suggestions to achieve this included the provision of tools to interrogate local data, the sharing of lessons learned, of quality improvement initiatives and case studies in Lumos insights leading to practical change.
- Creating collaborative working relationships between clinicians and data analysts was identified as strategy to support the most relevant uses of the data.

LHDs, MoH, Pillar and other Stakeholders

LHD stakeholders reflected increasing awareness of the potential value of the Lumos data asset in the context of their programs

- While LHD stakeholders interviewed were aware of the potential value of the Lumos data asset, they also identified lack of clarity about how to use the data to support their priority needs.
- Difficulty in ready access to the data remains a significant challenge: of the three LHDs interviewed, at the time of the consultation none of these LHDs had access to the SAPHE, with several citing challenges with LHD systems (e.g. firewalls).
- LHD engagement to date has been through specific programs including Collaborative Commissioning and Integrated Care, which both continue to be a priority focus for Lumos, facilitated by regular meetings between program and Lumos teams to better understand the data.

LHD stakeholders also identified opportunities for support to enable them to better harness the value of the data

- LHDs interviewed indicated their desire to understand more about the potential value of Lumos and the use of Lumos to support both LHD priorities and joint planning and priorities with the PHN. Suggestions included:
 - Promoting Lumos use in joint needs assessment between the PHN and LHD.
 - Establishing LHD Lumos Champions alongside PHN Lumos Champions and include both in forums like the Community of Practice.
 - Explore promoting Lumos at existing LHD data and analytics communities, and networks.
 - Developing information and case studies for LHDs on using Lumos to support LHDs.

Active engagement with an increased range of NSW Health stakeholders has been a focus for Lumos in the past 12 months; increased use of the data is evident

- The Agency for Clinical Innovation (ACI) and the Strategic Reform and Planning Branch (SRPB) are undertaking their own analytics using Lumos; access to the Lumos data asset through the SAPHE has enabled these teams to undertake their own data exploration and analytics work to support priority programs.
- The Collaborative Commissioning team has established a data analytics team and is using the Lumos data in their Dynamic Simulation modelling to assist LHD/PHN partnerships with joint regional planning and identification of priority population needs, to inform investment decisions and monitoring of outcomes.
- Stakeholders noted that efforts to forge stronger engagement with the parts of the MoH responsible for important populations of need (e.g. Mental Health, Aboriginal Health) are evident and continue to be enthusiastically pursued. At the same time, stakeholders reflected that capacity constraints and competing priorities presented challenges.

Development of new and strengthening of existing partnerships with NSW Health stakeholders present significant opportunities for Lumos

- Stakeholders from MoH branches and Pillars emphasised the opportunity to embed the value of Lumos at a whole of system level through internal relationships and more seamless ways of working. This is seen as an important factor in the sustainability of the program.

Consumer Stakeholders

The consumer stakeholder group – pivotal to the Lumos program since inception – provided a unique perspective regarding the opportunities presented by broader engagement with the media and general public

- Consumer stakeholders indicated awareness of the sensitivities with health data sharing and privacy concerns; however they saw greater general exposure of Lumos, its value and the various outputs and insights being of importance for the future of the program.
- Strategies for engaging consumers to identify relevant research questions was seen as an important opportunity for supporting consumer advocacy with data.

Participating General Practices

As reported, 94 practices across all 10 PHNs responded to the survey, with 74 providing useable information. These useable surveys provided the basis for the information reported below. The survey and responses can be found at Appendix 2.

Approximately half of the sample reported that the Practice Report distributed in August 2022, immediately prior to completing the survey, was the first report that they had received, suggesting that there was a mix of older and newer enrolees to the program participating in the survey.

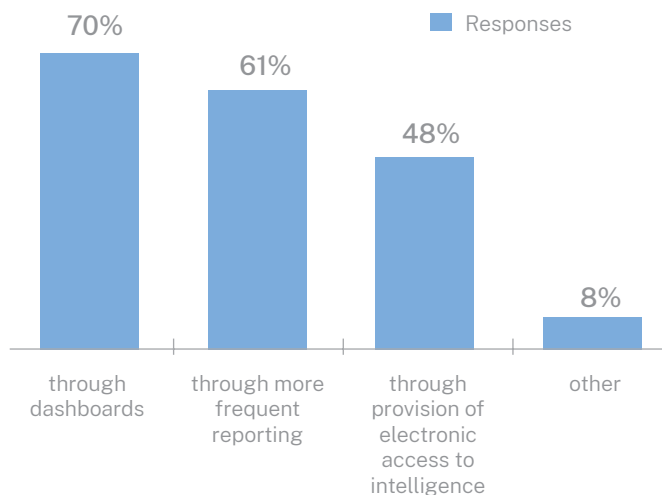
Disseminating the data and its insights: the majority of GPs reported positive views of the data and its presentation in the Practice Report

- Approximately 70% agreed that the information in the report is easy to digest.
- Approximately 85% reported that the information is valuable.
- Approximately 75% reported that the information has – or has the potential to – improve their practice.
- Approximately 75% of those who had attended an information session about the Practice Reports found them helpful.

Disseminating the data and its insights: the majority of GPs support making insights from the Lumos data more accessible through dashboards

See Figure 2 below. A large number of responses recommending dashboards likely reflects a preference for easily interpreted information. In addition, GPs also support more frequent dissemination of insights, suggesting that the value of the insights outweighs the information burden.

Figure 2: GP survey question: How do we make the unique insights from Lumos more accessible (select as many as relevant)



Ensuring safe and secure data capture, storage and use of the data: the majority of GPs reported being confident in the program's privacy and security measures

- 78% reported confidence in the program's measures to protect patient confidentiality, and to securely store and use the data.
- A significant minority of GPs, approximately 20%, were neither confident nor lacking in confidence.
- Only a small minority of GPs (<5%) reported lack of confidence in the program's privacy and security measures.

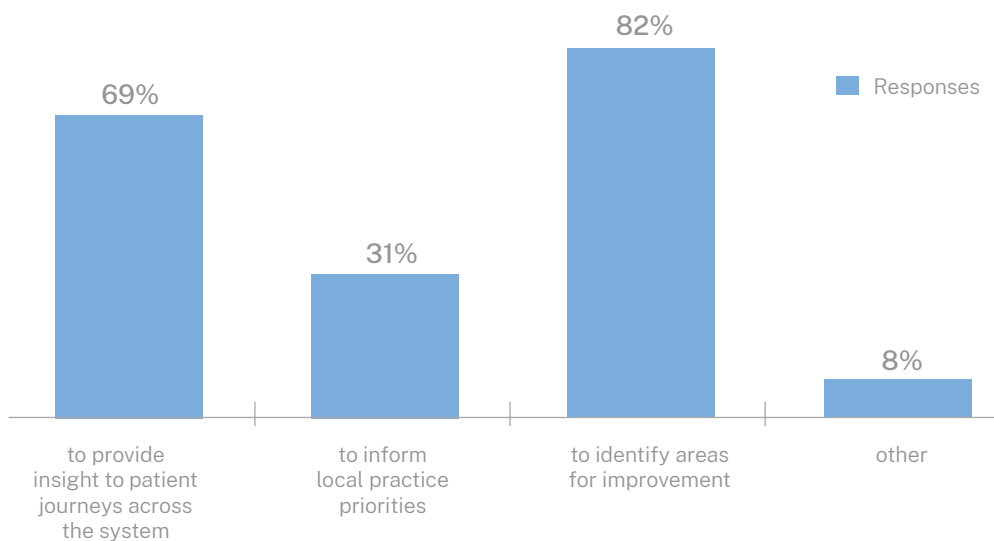
Using the data well is important to GPs

The guiding principle underpinning the creation of the Lumos data asset has been the imperative to have better visibility of the patient journey across care settings to more effectively support improvement and reform. GPs reported being both aware of this agenda and supporting its importance.

The majority of GPs reported being motivated by the importance of more comprehensive visibility of the patient journey and its role in reform and practice improvement (Figure 3):

- There was near unanimous agreement among the GPs responding to the survey (approximately 90%) that access to comprehensive information about the patient journey is important for healthcare delivery.
- The most common motivation reported for participating in the Lumos program was to identify areas for improvement and to provide insight to the patient journey across the system.

Figure 3: GP survey question: What was the motivation for you to engage your practice in the Lumos program? (select as many answers as relevant)

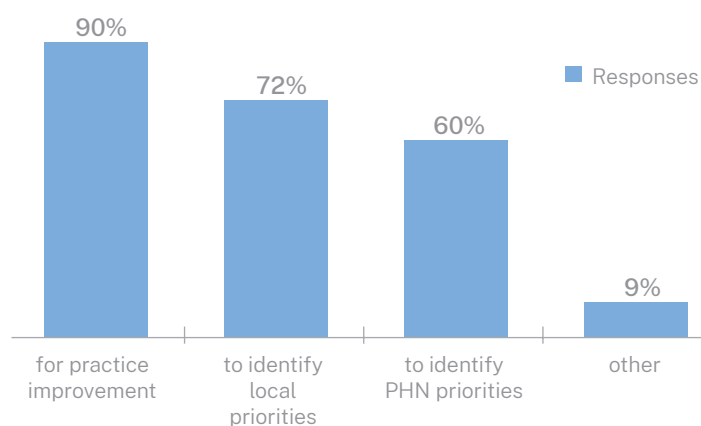


GPs participating in Lumos reported consistent views about their aspirations for the use of the data: to support practice improvement and to support state and national reform (Figure 4)

Figure 4: GP survey question: How would you like to see the Lumos data being used across the profession/ across the system? (Select as many answers as relevant)

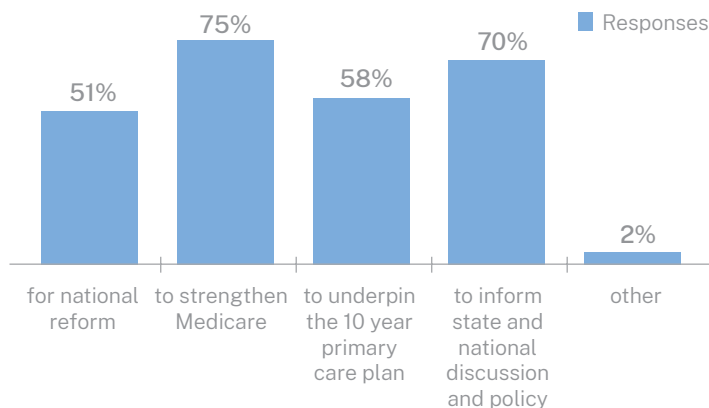
At the level of the general practice there was almost unanimous support for using the data for practice improvement.

How would you like to see the Lumos data being used across the profession (select as many answers as relevant)?



At the level of the system there was strong support for using the data to strengthen Medicare and inform policy discussions at state and national levels.

How would you like to see the Lumos data being used at a system level (select as many answers as relevant)?



Best practice governance has been established

Lumos was established under ethical approval obtained from the NSW Population and Health Services Research Ethics Committee. 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 [\[Link\]](#). Key policy capital has been developed, for example Data Breach Policy and Data Retention Policy.

As reported in the first monitoring and evaluation report, a privacy impact assessment (PIA) of the Lumos program was carried out in late 2020 following recommendations from the ethics committee when granting approval for Lumos to scale-up statewide. The PIA report provided a largely favourable assessment of the Lumos program design for protecting patient privacy.

However, to remain best practice, the governance continues to evolve as necessary to respond to the challenges that emerge with the evolution of the program. A clear example of the need for adaptive evolution of governance relates to recent discussions with the Australian Department of Health and Aged Care (DoHAC) proposing linkage of data from the Medical Benefits Scheme (MBS) to Lumos. As part of these discussions, DoHAC requested the Lumos PIA be revised to ensure privacy impacts have been thoroughly considered.

The PIA was reviewed and updated in August 2022¹, and endorsed by the Lumos Data Governance Committee with a view to developing an action plan to address the report recommendations. Further details of the updated PIA are considered as part of the Technical Solutions Domain because protection of privacy has been central to the technical developments of the Lumos data asset.

Building leading practice foundations for Aboriginal data collection and analysis is also a priority of Lumos. The Aboriginal health sector is actively being engaged to agree on acceptable approaches including to establish an Aboriginal Data Governance Committee, to develop a data sovereignty plan aligned to the NSW plan being developed, and to appropriately strengthen the investigator team to include Aboriginal team members at all levels. Progress on the engagement strategy has recommenced following the necessary hiatus due to COVID-19, and the heavy work-load it imposed on stakeholders. Four virtual workshops with Aboriginal Community Controlled Health Services in collaboration with the Aboriginal Health and Medical Research Council have been delivered and also a face to face meeting between NSW Health and Aboriginal Health Services in the NSW North Coast. Following these activities a working group is being created to collaboratively develop an appropriate model for engagement with the Indigenous health sector. It will include representation from Aboriginal Community Controlled Health Services, the Aboriginal Health and Medical Research Council, Lumos and others as deemed appropriate.

Practice participation is exceeding expectations, both in quantum and reach

As at September 2022, 607 general practices were participating in the Lumos program, which represents 23.2% of 2619 practices in NSW (as per the September 2022 National Health Services Directory (NHSD)²). The level of participation exceeds the 2023 target set for the program (20% of NSW practices). Of these, 470 contributed data in time for the April 2022 linkage.

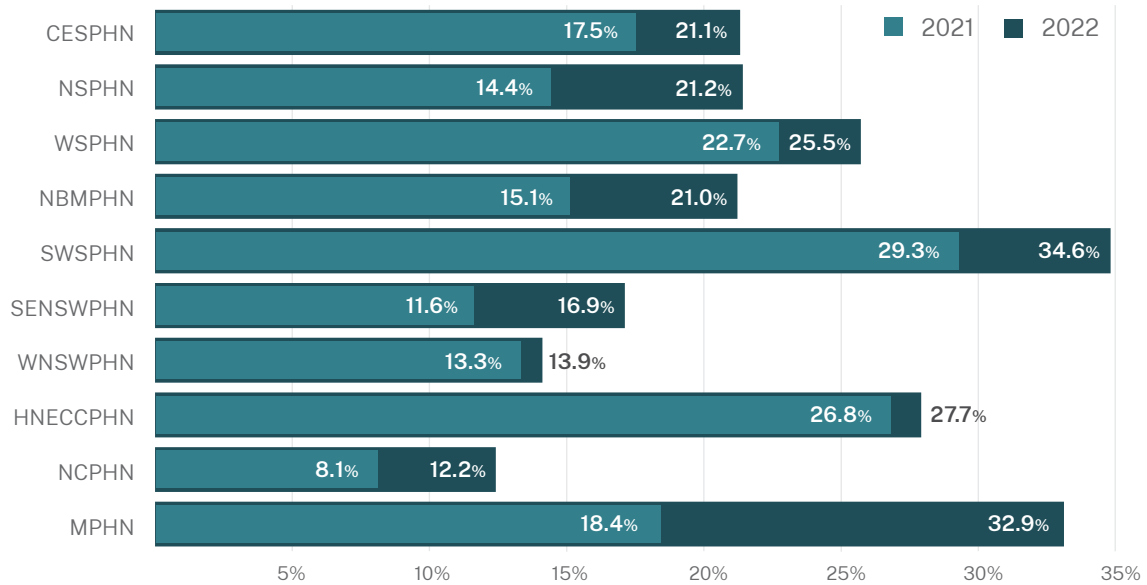
Improved Lumos participation and associated value of the data asset.

A number of stakeholders described the increased participation of GP practices in Lumos over the past year and how this contributes to the “increasing materiality of the data asset”.



As Figure 5 shows, jurisdictional coverage has become increasingly comprehensive: practice participation spans all 10 PHNs in NSW and includes metropolitan, rural, and remote practices.

Figure 5: Participation in Lumos by PHN, geographic location and regionality of practices



Stakeholders noted the increased power and relevance of the data as participation has continued to grow.

- The value of increased participation is seen to support sustainability of the program (as a part of primary care BAU).
- The increased ‘power’ of the data is seen as providing opportunities for future comparative analysis: across PHNs and LHDs; by geographic and socio-economic peer groups; and practice and population characteristics.

Analysis indicates that overall, at the state level the demographic distribution of Lumos patients was greater than 95% aligned to the demographic distribution in the NSW population (age, sex, regional distribution, and socio-economic status)³.

Alignment also appears to be high within each PHN catchment. As at October 2021, analyses found coverage is more than 90% aligned to the demographic distribution of the region in most cases.

These estimates of representativeness will be updated with each linkage as the data become available and anticipated to improve as greater coverage of the NSW general practice population continues at pace.

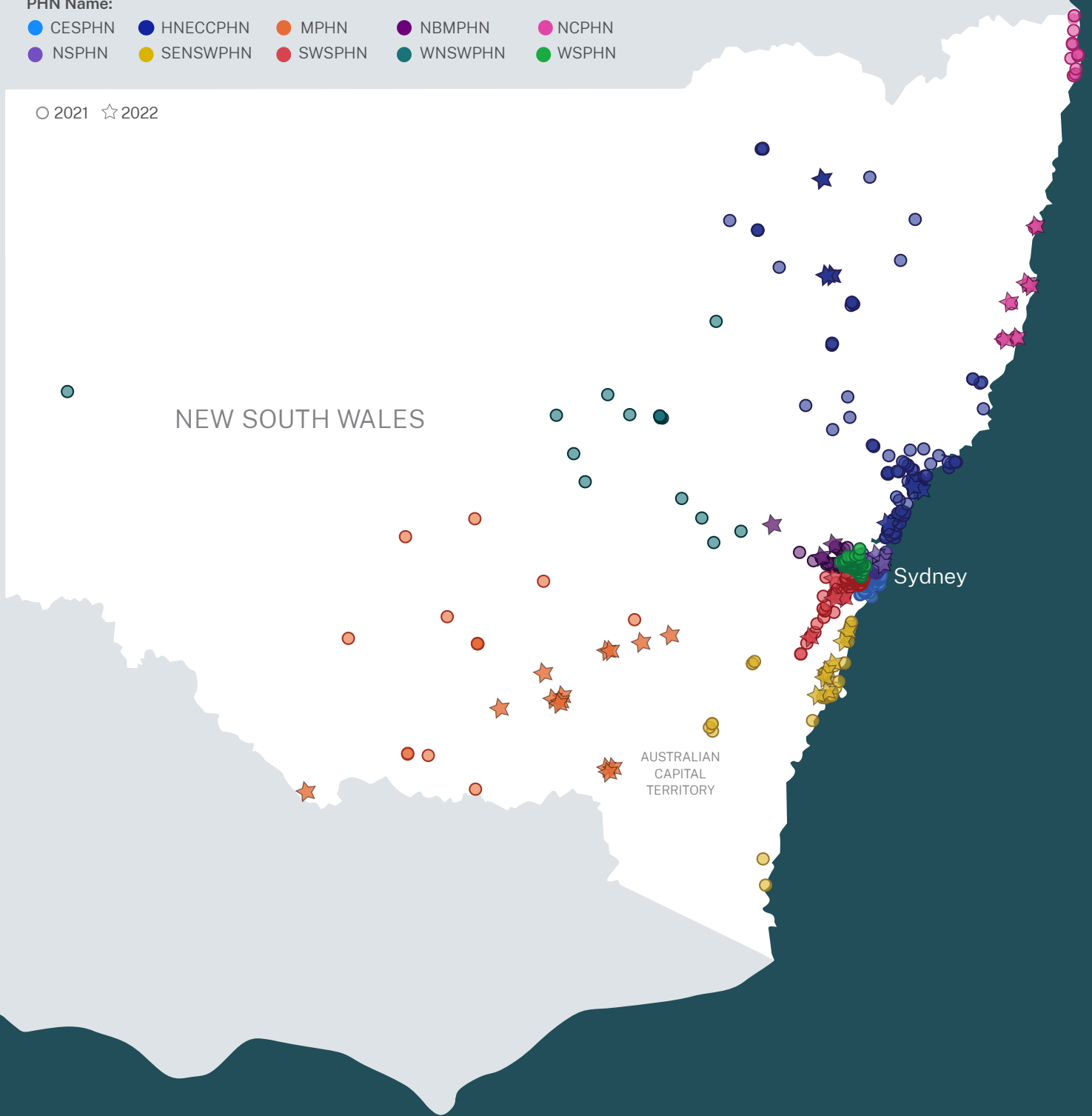
Figure 6
Participation in Lumos by PHN, geographic location and regional proportion of practices

Practice Participation by PHN

PHN Name:

- CESPHN
- HNECCPHN
- MPHN
- NBMPHN
- NCPHN
- NSPHN
- SENSWPHN
- SWSPHN
- WNSWPHN
- WSPHN

○ 2021 ☆ 2022





Domain 2

Technical Solutions

Proof of concept: linked primary and acute care data operationalised as business-as-usual

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% of NSW practices)?
- ◐ Can stakeholders access Lumos data?
- Is patient and practice privacy optimised throughout the data lifecycle?



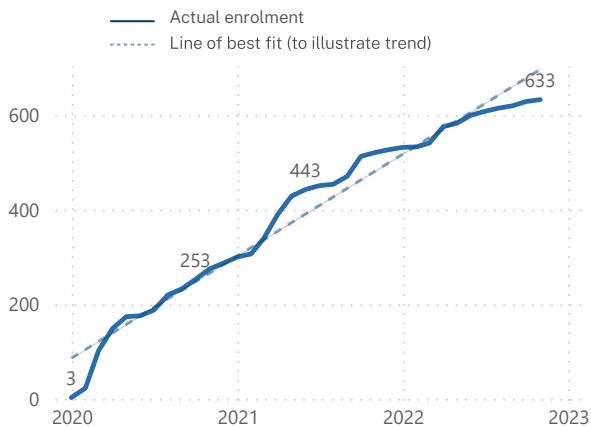
KEY FINDINGS

Accurate and efficient data transfer and linkage is occurring at scale

Data from over 4 million people across 470 practices were included in the April 2022 linkage. At the time of reporting the level of participation had increased to 607 practices enrolled. This represents strong growth in participation and data transfer in the scale-up phase, from three practices in January 2020 (Figure 6).

Figure 6

Cumulative Consent (total)



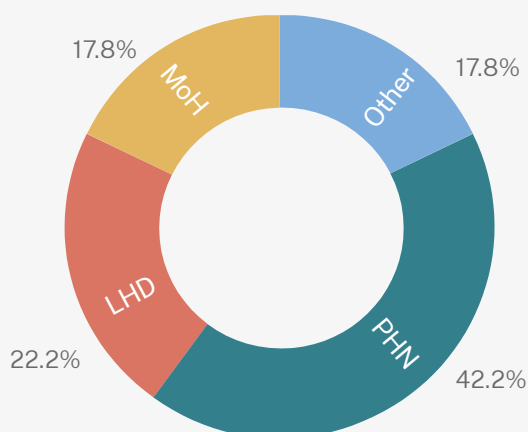
Secure access to the data for stakeholders has been established

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 and authorized organisations outside NSW Health, and their employees, to access this type of data for the first time in NSW.

By August 2022 the proportion of users from the Ministry of Health/ Pillars had increased, while PHNs and LHDs represented a smaller proportion compared to the same period in 2021. Active users had also increased by 30%. (Figure 7)

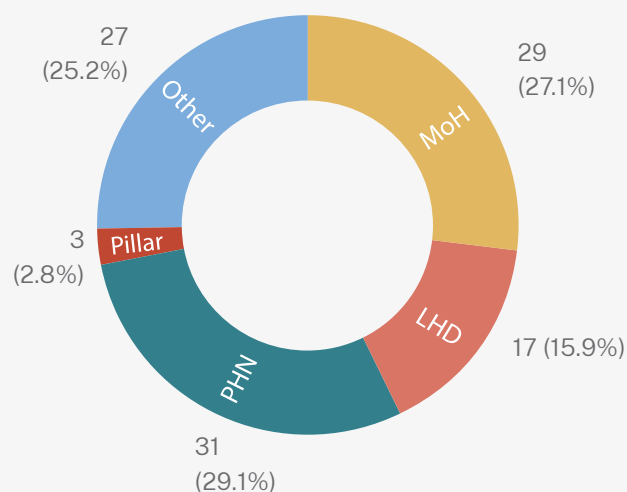
Figure 7: Active SAPHE users by stakeholder group

Users by organisation type in 2021



Note: The category Pillar was created in 2022

Users by organisation type in 2022



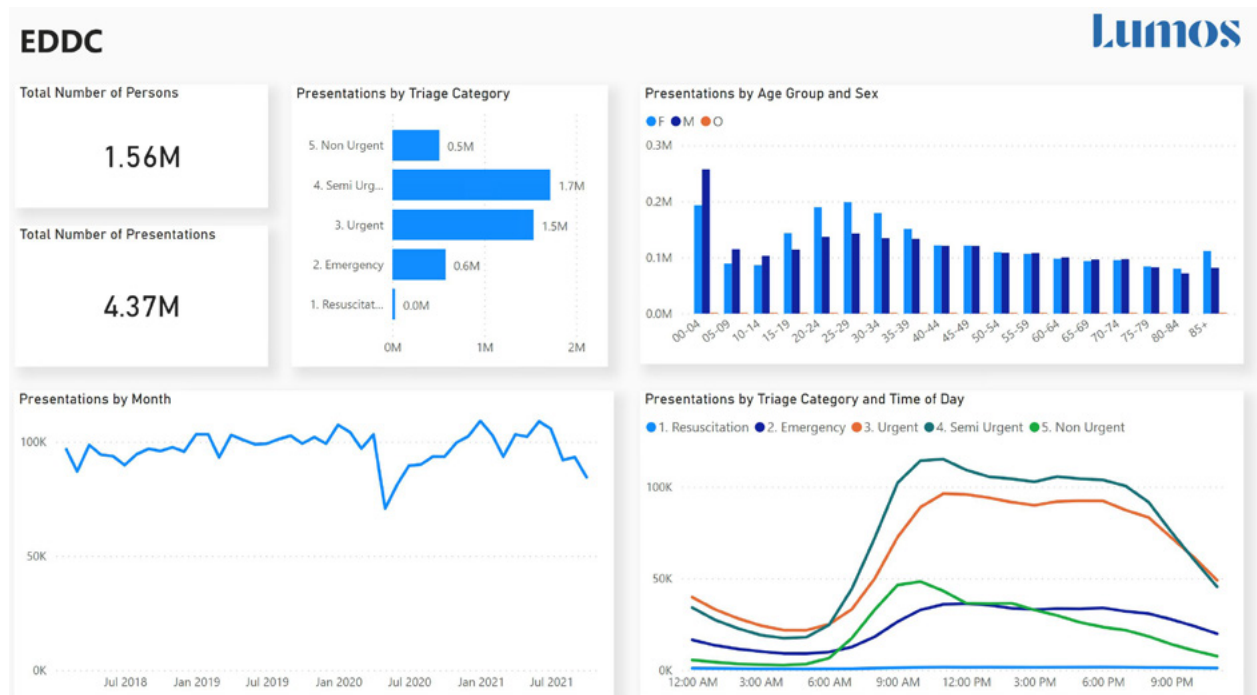
The majority of PHN stakeholders reported accessing the SAPHE to some degree,

however very few PHN stakeholders reported being proficient in using the SAPHE at this time. Others reporting as being new users of the SAPHE included the Agency for Clinical Innovation, Strategic Reform and Planning Branch, the Collaborative Commissioning team and the Integrated Care team.

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. The Community of Practice is well-attended (averaging 30 attendees from an invitation list of 100 stakeholders) and well-regarded by the community of SAPHE users. Recent direct feedback from an LHD user considered it an “excellent initiative This is something we should do more of in the data and analytics space within NSW Health”. Through the community of practice, experience and feedback underpins continuous improvement of the accessibility of the data and its insights to the broader health system.

Feedback from SAPHE users in 2021 indicated 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. This includes investment in the development of a range of business intelligence dashboards to help users navigate and explore the data in Lumos. The outputs of these dashboards can be used to inform needs assessments and other reporting. Users can also adapt the dashboards as their own to suit their organisational reporting requirements. The Community of Practice continues to be a well-regarded source of support. An example of the dashboard content is presented in Figure 8 below.

Figure 8: Example outputs of the Lumos dashboards



The exceptional quality of SAPHE guidance resources was highlighted by stakeholders.

Stakeholders new to using the SAPHE commented on the comprehensive nature of the guidance resources provided to assist users in navigating and understanding the data asset.

The development of summary dashboards in the SAPHE was viewed as a positive step.

However, some stakeholders reported that the dashboards in SAPHE were somewhat difficult to interpret without the assistance of an analyst. Additionally, as the dashboards are still housed within the SAPHE only those with access to the SAPHE are able to utilise them.

PHN stakeholders and the Integrated Care team were accessing the dashboards within the SAPHE.

The dashboards are a new tool that enable a visual representation and basic analysis of standard data elements in Lumos and were considered a useful tool for stakeholders to view the data. It was noted that as the dashboards are housed within the SAPHE only those with access to the SAPHE are able to utilise them.

Stakeholders indicated that further development of simplified dashboards for practice support staff and similar would be a welcomed addition to the current dashboards. It was also noted that more interactive and granular dashboards/ tools and easier to access dashboards would be useful.

The development of Lumos dashboards has been enthusiastically endorsed by stakeholders, allowing them to become increasingly familiar with Lumos data; challenges remain however with fully utilising access to the Lumos data

Many of the technical obstacles to the linked primary and acute care data becoming business-as-usual in terms of data acquisition, linkage and processing have been overcome. Challenges remain with the ambition to enable use of the data by stakeholders. A founding principle of the program has been enablement of stakeholders to use the data to drive system improvement. Close engagement with stakeholders around the maturing Lumos data asset over the last 12 months has allowed stakeholders to consider the technical solutions from their own perspective. The consultations revealed a range of new, continuing and changed perceptions of the Lumos technical solutions, alongside identification of several opportunities for improvement and future consideration.



Stakeholders indicate continuing challenges in accessing and using the Lumos data in the SAPHE

- Stakeholders acknowledged that the Lumos data asset is a large and complex data set that requires advanced data analytics skills to analyse; most PHNs do not have inhouse capability (or often the capacity) to undertake their own analysis using Lumos.
- Some LHDs noted challenges in gaining local authorisation to access the SAPHE, this was likely due to software or system challenges e.g. organisational firewalls. No LHD consultees interviewed had access to the SAPHE.
- NSW Health stakeholders noted the lengthy process required to gain permission to access the SAPHE and the requirement to apply for access for individual project uses.
- The quality of the data remains an ongoing and long term challenge with the potential for continued improvement in both the data extraction process and data entry and collection practices in primary care.

Technical enhancements

Technical enhancements continue to be driven by the program's aspirations to continue to operate at best practice both technically and in terms of data security. These include the need to continue to be aligned with evolutionary developments in the GP practice software and extraction tools.

There have been many improvements to the SAPHE, including increased computational resources to meet the demands of advanced user groups and growing user base, along with trialling collaborative workspaces for analytical teams. The SAPHE Firewall was also upgraded, improving security while also making it easier for end users, particularly in LHDs to access.

In August 2021, Deloitte were engaged to perform a technology and data review of the Lumos program. This review took the form of three parts:

- Mapping the end-to-end data lineage and understanding the current risk / control landscape
- Reviewing the current technology landscape
- High level review of the overall solution design

The findings and recommendations were developed through interviews and workshops with relevant Ministry of Health Subject Matter Experts (SMEs) and the review of Lumos documentation provided to Deloitte. No risks were identified through the review that threaten Lumos's short term ability to operate with the current control framework. The review found several opportunities to improve on the overall solution design.

Since that review, actions to appraise, review and address the opportunities outlined have taken place, however many of the issues are due to factors beyond the control of Lumos.

Lumos subsequently commissioned Deloitte in June 2022 to scope out what it would take in order to action the recommendation to improve the SAPHE. The output of that review was a four-phase roadmap which the Lumos team is in the process of actioning.



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 health-related data from patient GP records to be linked to health, service use, demographic and mortality data in other NSW Health data collections.

In line with best practice, the membership, functioning and documentation for the Lumos program governance is regularly reviewed. This includes an updated review of the PIA to ensure that evolution of the program has continued to satisfy the highest standards of practice and privacy protection.

The Lumos PIA update for 2022 was completed in September 2022.⁴ This PIA update examines the

program 'as is' (as at August 2022), as well as current proposals for expansion, and other fresh questions about the program's potential scope. It has involved examining the Lumos program in terms of compliance with relevant privacy laws, as well as considering community or stakeholder expectations.

Overall, the PIA update expresses confidence in the Lumos program:

"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."

The key factor for the Lumos program that emerged from the PIA update, the need to consider on, an on-going basis is the maintenance of controls around access to and use of the Lumos Data Asset, to maintain social licence and to ensure that the lawful authority for each 'data flow' is in place. With this in mind, 15 recommendations have been made with respect to:

- Ensuring the lawful authority is in place to enable PHNs to access unit-record level data, in appropriate circumstances.
- Ensuring the lawful authority is in place to enable program evaluations to link with Lumos data, in appropriate circumstances.
- Providing a path forward to broaden out use of the Lumos Data Asset for research purposes, in appropriate circumstances.
- Ensuring the lawful authority is in place to enable new NSW and Commonwealth datasets to be ingested into the Lumos Data Asset.
- Ensuring the appropriate contractual provisions are in place in the event that a third party is required to perform encoding work on behalf of the Ministry.
- Updating a minor matter in the data retention and disposal policy.

The updated assessment concludes that any potential negative privacy impacts are outweighed by the potential public interest benefits to be realised through utilisation of the Lumos Data Asset, to better manage health services and deliver better health outcomes to the people of NSW.



As highlighted by some stakeholders described the inability to download data from the SAPHE as a barrier to its use.

However most understood that this related to the governance and privacy requirements of Lumos.

Some of the challenges highlighted include:

- The ability to undertake analytics in SAPHE but the inability to take data out of SAPHE and link this with other local data analyses, needs analysis, and quality improvement programs.
- The inability to link Lumos with “Primary Health Insight”, a platform commonly used by PHNs to analyse and share data.

At the same time, there is improved understanding of ethics and privacy constraints from stakeholders compared to the first evaluation period, suggesting recognition of the enhanced value to the data asset of strong ethical and privacy provisions.

Extending the use of Lumos for research was a theme raised by stakeholders.

- The primary purpose under which Lumos has been granted a waiver of consent, and with which the program has engaged with the primary care sector, is its focus on health services improvement directly involving the key service delivery and commissioning partners.
- Professional researchers could provide a unique opportunity to grow the value of the data set, more fully engaging with professional researchers is limited due to the Lumos governance arrangements.
- Solutions to address this barrier were discussed:
 - Creation of a ‘matchmaking service’ - where academics are linked with relevant project sponsors (eg MoH Branch, PHN) to assist in the conduct of quality improvement and health-service-improvement-oriented research activities.
 - The development of synthetic Lumos data is considered worth exploring. Synthetic data could provide an opportunity to engage more broadly with researchers and enable them to use the data asset while minimising risk. Synthetic data could be used to test data applicant capabilities and hypotheses without the need to provide access to sensitive information.

Domain 3

Analytics and Reporting Relevant, reliable, and actionable insights

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?

As participation and engagement ramps up, so too has production of Lumos outputs to underpin stakeholders' strategic endeavours. Delivery of actionable insights across the range of stakeholders has been an active focus of the program.

More broadly, enhancing use of the data remains a priority. Working collaboratively with end users is supporting meaningful use of the data through activities such as a data community of practice, and the development of interactive dashboards.



In development



Maturing



Mature

KEY FINDINGS

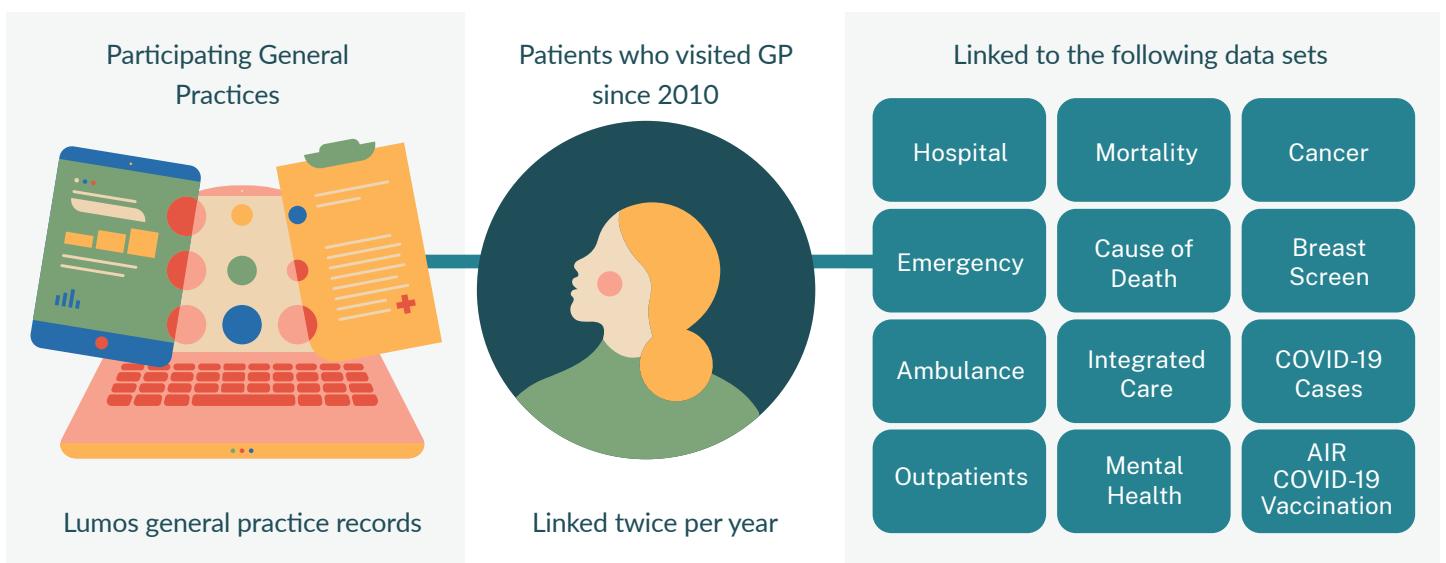
Lumos reliably links a substantial range of data sets to produce a high value data asset

The ambition of the Lumos program is to link the most relevant health data sets, as they emerge over time. A key example of this is recent ethical approval for inclusion of data sets that will allow assessment of a range of influences of COVID-19 on care and health outcomes.

- The majority of stakeholders were aware of the intention to link Lumos with Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) data and welcomed this as an important addition to the data asset.
- Several additional data sets were suggested for potential inclusion in future Lumos linkages:
 - Allied Health data (with a focus on the large professions: speech pathology, physiotherapy, podiatry, psychology, then smaller professions such as exercise physiology)
 - Aboriginal Medical Services (AMS) data
 - More timely private hospital data
 - Social care and other government data sets, such as education and justice.

At the time of reporting, the Lumos data asset currently links 12 data sets to general practice records (Figure 9).

Figure 9: Lumos data asset linkages



Stakeholders acknowledged the ongoing challenge of data quality at its source. They highlighted the need to continue endeavours to improve data quality.

Efforts to improve data quality may be addressed through the implementation of updated data loading or cleaning scripts with embedded logic to improve data quality. It was suggested that 'data cleaning time' may be a useful KPI for the Lumos program and highlighting data quality with GPs (already reported in Practice Reports) might also contribute to improvement in data input quality (e.g. smoking field 70% missing).

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. 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 an Indigenous Data Sovereignty Plan together with strong Aboriginal leadership and capacity building. Engagement with the Aboriginal health community is being progressed through active collaboration with NSW ACCHSs, the Aboriginal Health and Medical Research Council (AHMRC) and the NSW Health Centre for Aboriginal Health (CAH). Virtual and face to face workshops and other information sharing activities are being progressed to share the opportunities for insights from the Lumos program.

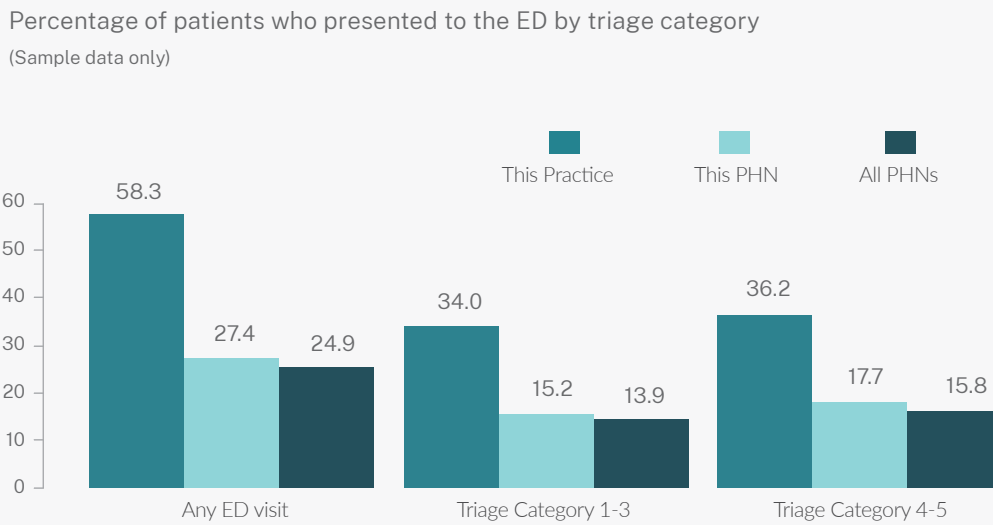
The inclusion of Medicare Benefits Schedule (MBS) data is a priority. Addition of MBS data would provide a substantial enhancement of Lumos. These data capture all service events paid for by the Australian Government. This data would allow almost complete capture of primary care service episodes by patients 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.

A working group has been established with collaborators from the DOHAC, and MoH to work through the processes needed to authorise release of GP items in the MBS data for linkage to Lumos.

Lumos data has potential to reliably inform improvement strategies

Custom practice reports continue to be produced for each participating practice after each linkage, twice per annum, and provide a range of data comparing the journeys of patients of the practice with those of the PHN and state level (Figure 10). The reports explore how patients of the practice interact with different health services and include a unique condition in focus each linkage. The sample data below indicates that the patients from the hypothetical practice were more frequent attenders at the Emergency Department (ED) overall and in all triage categories, than was the case in their PHN and at state level.

Figure 10: Percentage of patients who presented to the ED by triage category



GPs and PHN stakeholders indicate that the reports are high quality with valuable content about patients in the region and in individual practices. Consultations suggested increased understanding of the data (compared with the first monitoring report), and how the Lumos reports might support quality improvement processes. As understanding of the constraints and uses of Lumos reports in particular, and the Lumos data in general, increase, not surprisingly most stakeholders described a desire for increased analytics outputs from the Lumos data asset. The delivery options for supporting broader analysis of Lumos data can be described under the following three categories:

- **Centralised support and analysis** – the Lumos team conducting novel and/or priority analysis ‘in-house’, e.g. further ‘insights’; ‘conditions in focus’; priority queries support.
- **In partnership with priority initiatives** – utilisation of the Lumos data asset to support priority projects and initiatives through a combination of ‘in-house’ support and initiative team resources (e.g. LBVC, Collaborative Commissioning, Urgent Care Centres, Integrated Care etc).
- **Analytics support for local priorities** – the Lumos expert team providing training, coaching and mentoring style support for capable analysts to utilise the Lumos asset for local analytics (e.g. support for PHNs priorities, LHDs, Ministry and Pillar teams and researchers).



Unique and actionable insights are being revealed and disseminated

As the data asset has matured, it has enabled an active program of fact sheets which was initiated in the second half of 2021. Below a brief snapshot of insights is provided, with a link to the full fact sheet alongside.

1. Confirming and quantifying the benefits to patients and to the system of continuity of care

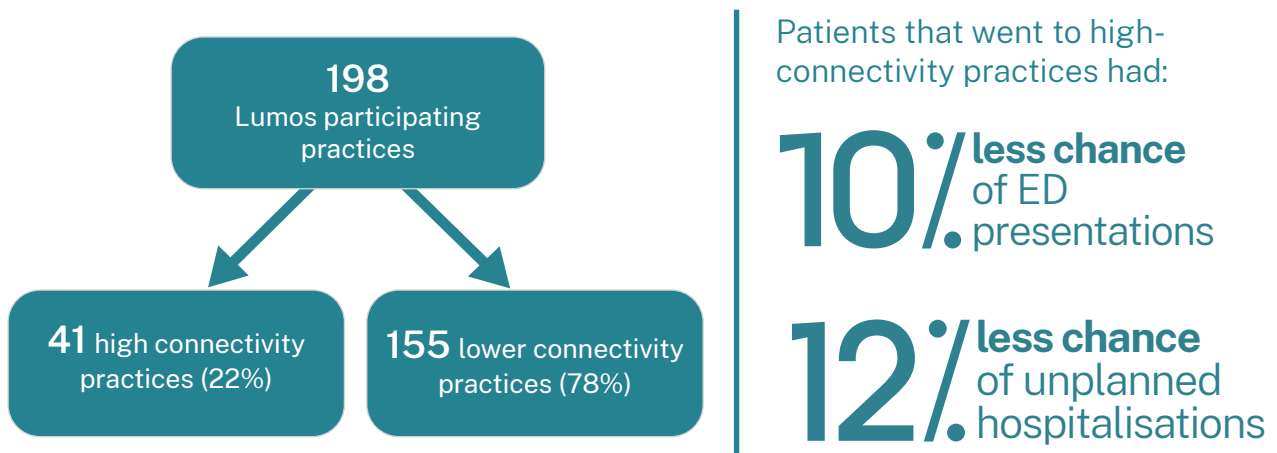
INSIGHT: There is a clear benefit for patients who attended high connectivity practices ([see fact sheet](#)).

The value of continuity of care for patients and the system is well-documented⁴. The Lumos data asset offers a proxy for continuity of care based on practice behaviour. Specifically, high connectivity practices were defined as those practices where >30% of patients visited at least 12 times in 2 years. The threshold for defining high connectivity aligns with the national average of 6 GP visits per person per year.

Practices (N=198) providing data for visits by patients (N=1,066,203 patients) between 2018 and 2019 could be divided into high and low connectivity practices. Of these, 22% met the criteria for being a high connectivity practice, and 78% of practices were considered lower connectivity practices.

After accounting for differences in practices and patients (e.g. socio-demographics), patients who attended high connectivity practices were less likely to present to emergency departments and less likely to be admitted to hospital figure 11. Moreover, the benefit was seen in both patients who attended frequently and those who attended less frequently.

Figure 11: Benefits to patients of attending a high connectivity practice

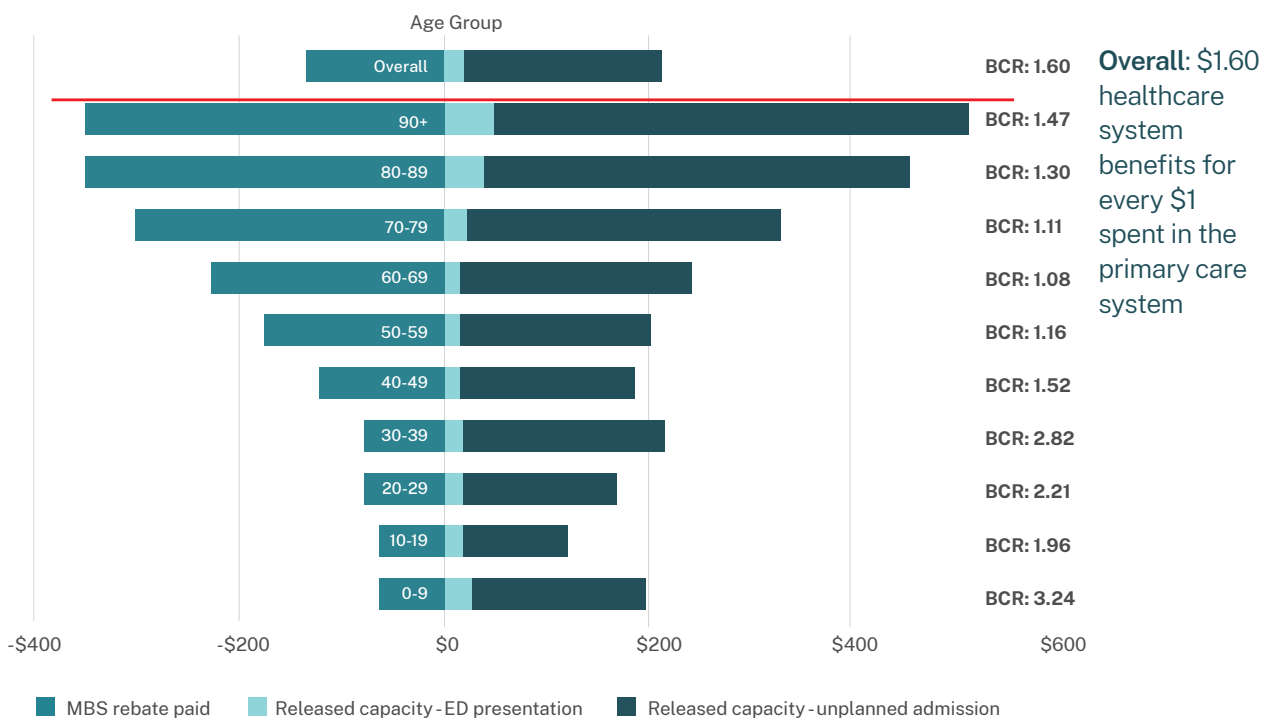


INSIGHT: There was a clear benefit to the health care system of patients attending a high connectivity practice.

The benefit cost ratio (BCR) of a patient being serviced by a high connectivity practice compared to a lower connectivity practice was evident for all age groups (Figure 12). Overall, the analysis showed that there was a \$1.60 healthcare system benefit for every \$1 spent in the primary care system.

Figure 12: Benefit cost ration of a patient being serviced by a high connectivity practice.

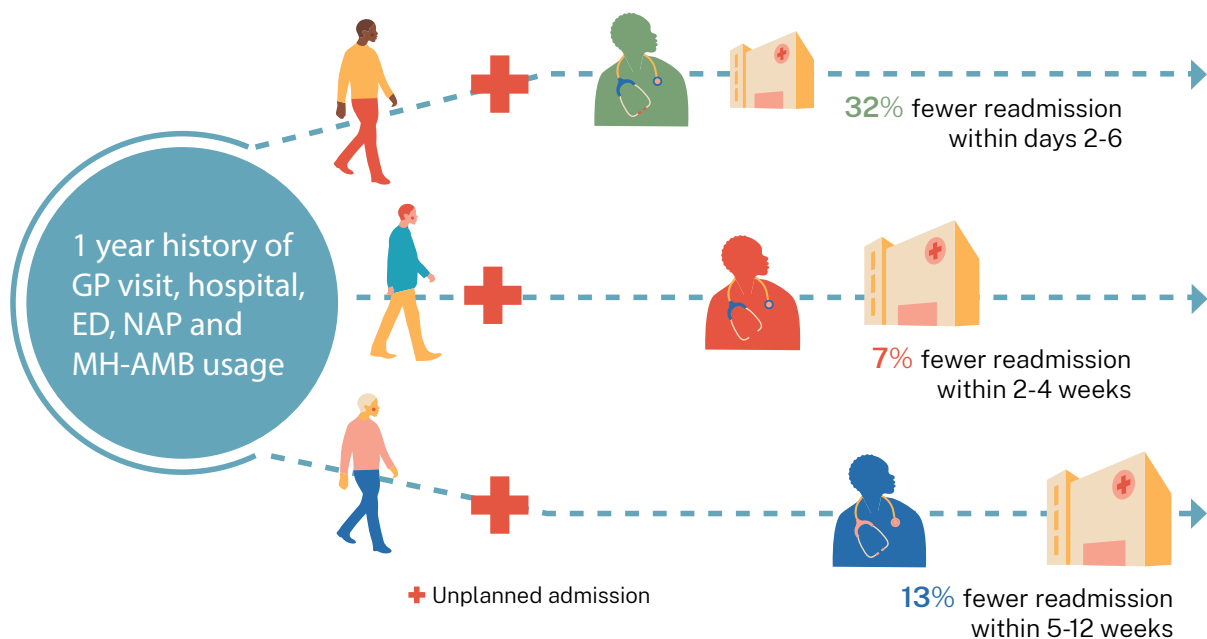
Prompt general practice follow-up after being discharged from hospital demonstrates the benefits of intergrated care.



INSIGHT: A visit to the GP following discharge from an unplanned stay in hospital reduces the risk of being readmitted immediately and down the track (see fact sheet).

Patient records from practices (N=344) that provided data for their patients (N=2,852,691) between 2017 and 2019 allowed identification of unplanned admissions (N=542,936) among these patients, and their experience of unplanned readmissions (180,143). After accounting for differences between patients (eg socio-demographics), a visit within two days was followed by 32% fewer readmissions within the first week. A visit in the first week was followed by 7% fewer readmissions within 28 days. A visit in the first 4 weeks was followed by 13% fewer readmissions down the track (1-3 months). While more difficult to directly attribute reduced readmissions to the presence/ absence of a GP visit in the first month post discharge, the finding would seem to align with thinking about the benefits of continuity of care (Figure 13).

Figure 13: The impact on readmission of a visit to the GP following discharge from hospital.



2. Diabetes care in the community – A NSW Health Priority

Diabetes is a burdensome condition for patients in NSW and management of diabetes is compounded by fragmentation in the current health system, particularly at primary and acute care system interfaces.

The NSW Ministry of Health, the Agency for Clinical Innovation (ACI) and NSW Primary Health Networks are working with Local Health Districts, Aboriginal Community Controlled Health Services, Diabetes NSW & ACT and other partners on a statewide initiative. The document [Integrating care for people with diabetes: A Statewide Initiative for Diabetes Management](#) released in early 2022 outlines the approach to improve the coordination of diabetes care across NSW and keep people well and out of hospital. NSW partners will work together in a 'one health system' approach⁵.

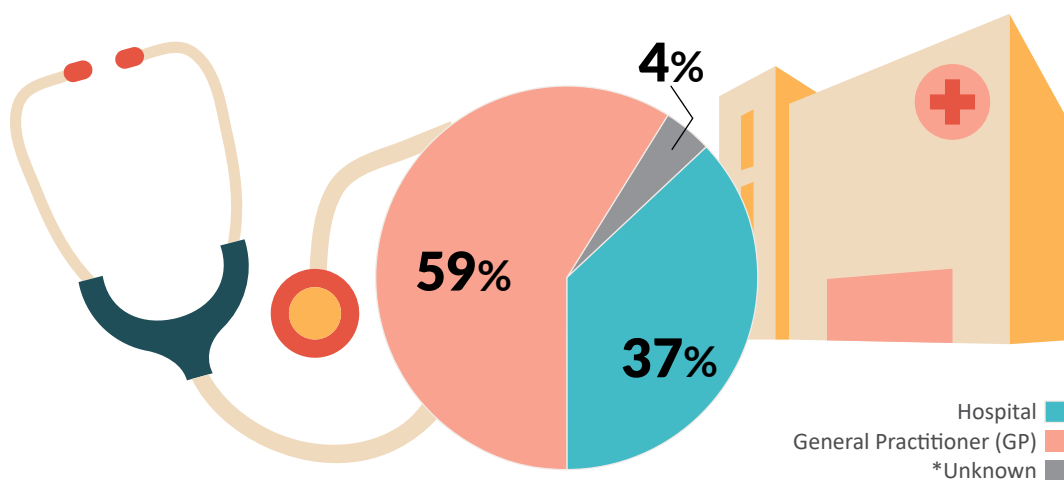
A key focus area of the statewide initiative is shared information and data across the one-system approach. There have long been aspirations to understand the impact of primary care and its interactions with other health services. However, up until recently, attempts to assemble this information have been small scale. The Lumos data asset has been able to provide information about diabetes care in primary and acute care settings at scale, and to provide measurable indicators in primary care of the initiative as it rolls out.

INSIGHT: Outcomes are improved when diabetes is managed early in general practice ([see fact sheet](#)).

Patient records (N=3,965,041 patients, representing 48.5% of the NSW population) from Lumos participating practices (470 practices, representing 17.9% of all NSW general practices) that contributed data to Lumos in October 2021 were analysed to identify adults (>=18 yrs) who had a diabetes diagnosis recorded in their GP or hospital record. In all, 8.2% of adults included in the Lumos data had a recorded diagnosis of diabetes, compared with an estimated 11% of the NSW adult population and 6.1% reported by the Australian Bureau of Statistics.

Using Lumos data, dates of diabetes diagnoses were compared in GP and hospital records to determine which of these settings held the earliest record of diabetes diagnosis.

Figure 14: Service setting where patient received diabetes diagnosis

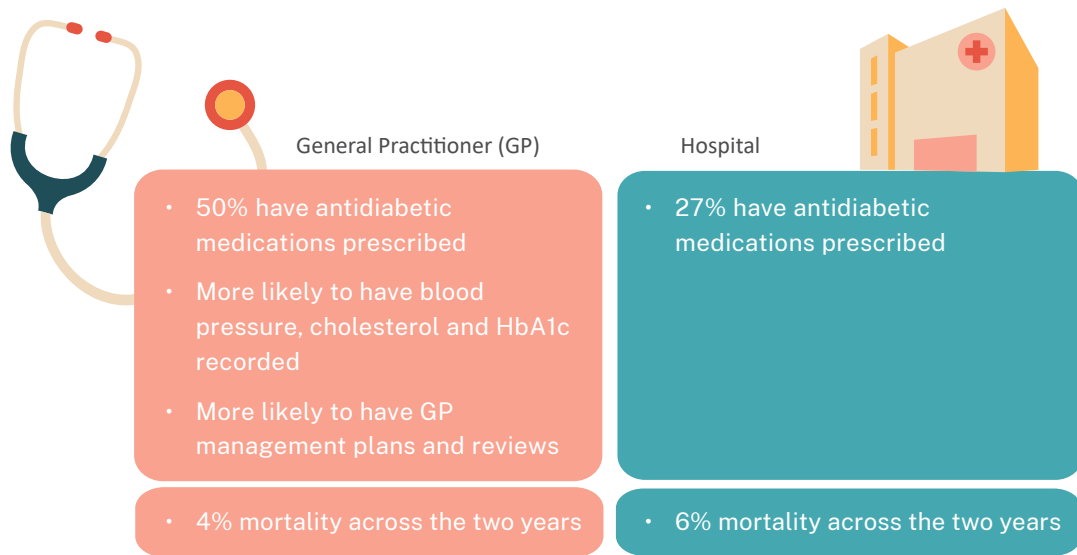


* First diabetes diagnosis is unknown among people whose diagnosis dates are missing in the Lumos data

INSIGHT: First recorded diagnosis in the GP record is associated with important benefits for patients and for the system ([see fact sheet](#)).

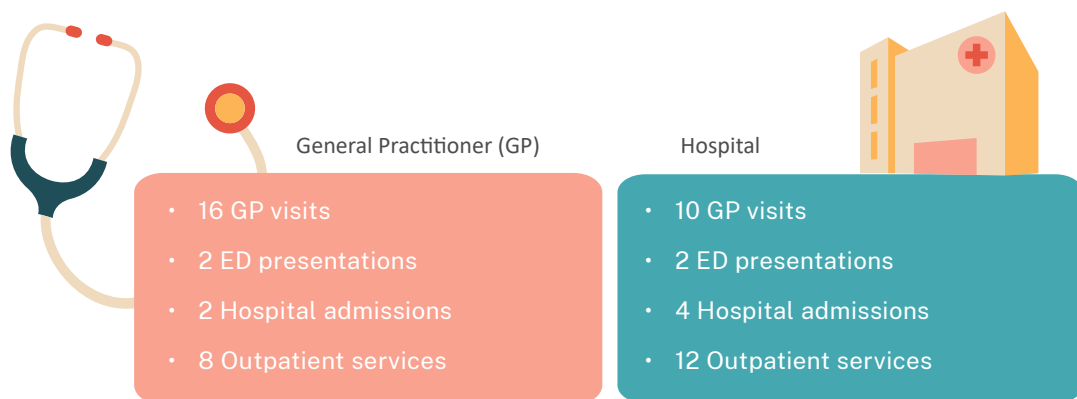
For patients – Over the previous two years (between 1 October 2019 to 30 September 2021) proactive care in the community was more common for people who had their first recorded diabetes diagnosis in the GP record. Mortality was lower for those with their first recorded diagnosis in primary care (Figure 15).

Figure 15: Service setting where patient received diabetes diagnosis – benefits for patients



For the system – Presentation to hospital over the previous two years was less common among people who had their first recorded diabetes diagnosis in the GP record (Figure 16).

Figure 16: Service setting where patient received diabetes diagnosis – benefits for patients



INSIGHT: Where people with diabetes live has an impact on access to primary care and outcomes ([see fact sheet](#)).

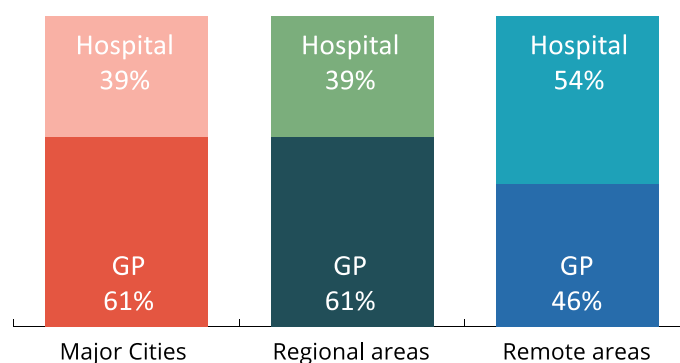
Access to healthcare in regional and remote areas has been identified as a priority area in NSW Health. Given the reach and representativeness of the distribution of participating practices across NSW, the Lumos data asset provides an opportunity to examine the impact of where people live on their diabetes care and patient journey.

Again, the patient records from Lumos participating practices (470 practices, representing 17.9% of all NSW general practices) that contributed data to Lumos in October 2021 were analysed to identify adults (>=18 yrs) who had a diabetes diagnosis recorded in their GP or hospital record. Using the Accessibility and Remoteness Index of Australia (ARIA+), the analysis explored the impacts of where people live on diabetes care and patient journeys (Figure 17).

Figure 17: Where people with diabetes live has an impact on access to primary care and outcomes

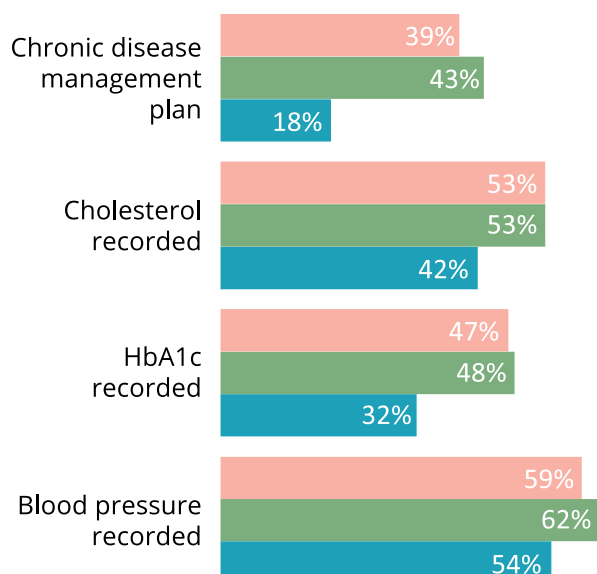
For most people who live in remote areas, diabetes is first recorded in the hospital setting.

Most people with diabetes who live in major cities and regional localities have diabetes first recorded in the GP setting.



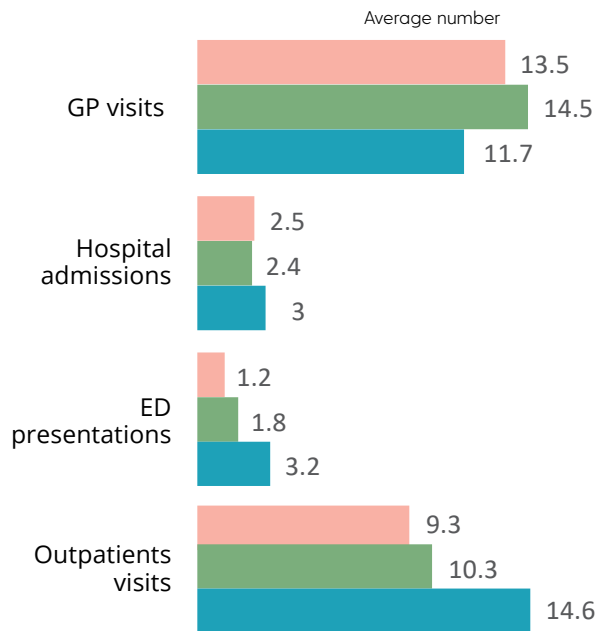
Over a 2-year period, people with diabetes who live in remote areas were less likely to have chronic disease management plans with their GP and less likely to have their cholesterol, HbA1c or blood pressure recorded in their GP data than those living in major cities or regional areas.

- Major cities
- Regional areas
- Remote areas



Over the 2-year period, people with diabetes who live in remote areas had fewer GP visits, but more need for acute care, than those living in major cities or regional areas.

- Major cities
- Regional areas
- Remote areas



Older people: case for change analysis

Among people aged 65 years and over, GP attendance and ambulance utilisation increased with age. Residents of aged care facilities had particularly high rates of GP attendance, ambulance utilisation, ED presentation and hospitalisation. Nearly all people who lived in residential aged care facilities had at least one unplanned hospitalisation over 5 years, and 40% had at least five. Among community-based adults aged 65 and over, people who had higher GP use also had higher ambulance and hospital use. People aged 65-74 had a larger proportion of priority 1 (emergency) ambulance use than people aged 85 years and over.

The Inaugural Lumos Symposium successfully brought together stakeholders

In June 2022, the inaugural Lumos Symposium was held, with approximately 100 in-person attendees and approximately 50 virtual attendees. Its purpose was to share insights, case studies, perspectives and opportunities for data in general, and the Lumos data asset in particular, to drive health system reform.

The inaugural Lumos Symposium was highlighted by most stakeholders as a valuable forum to actively raise awareness, share insights, and discuss the current and future application of Lumos.

A number of stakeholders suggested the potential value of sharing the contributions of Lumos to health system change with GPs who are contributing their data. This would deliver a different value to GPs than the direct value of Practice Reports, highlighting the contributions of practices to system level change.

Stakeholders perceive Lumos Analytics and Reporting to be high quality, relevant and actionable

The Lumos data asset has matured over the last 12 months, providing increased range of linked data and more extensive NSW population coverage. This has enabled the program to focus more intensively on the provision of relevant, reliable, and actionable insights that can be used to measure value across the system and support continuous improvement. Stakeholders reported a range of new, continuing and changed perceptions reflecting the increased program focus on the analysis and dissemination of high quality and relevant insights, as well as suggested improvements for the future.

- There was consistent positive feedback from stakeholders regarding the quality and ongoing improvement of the GP Practice Report, the Condition in Focus sections of the Practice Reports were highlighted as being of particular value.
- Most stakeholders were aware of the continued development of Lumos insights and the most often cited analysis and insights were those focused on GP visits following hospital admission and impact on related hospital readmissions. Other analysis and insights referred to during consultations included:
 - Frequency of general practice visits in the management of chronic disease
 - Diabetes management
 - GP encounters around the time of hospital admission
 - Frequency of hospital admissions for GP patients
 - Conditions of focus section of the GP Report
 - Analysis supporting policy changes to the provision of medication on discharge from hospital
- Stakeholders continued to highlight the primary challenges to the value of Lumos reports was: a) the frequency of reporting; and b) the currency of data contained in the reports.
- All PHNs were aware of the newly developed summary reports for each PHN and were positive about their potential value, however as these were only recently provided stakeholders did not provide examples of how these reports had been used.



Domain 4

Delivery of Value

High quality, policy relevant and system reform focused insight

Overarching goal: delivery of support to Value Based Healthcare is demonstrated.

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?



..... In development



..... Maturing



..... Mature

KEY FINDINGS

Both federal and NSW governments are committed to an ambitious reform agenda focused on more care in the community, addressing crisis levels of presentation to emergency departments and reformed funding models that drive value not volume, outcomes not inputs. This environment has presented the opportunity for the Lumos data asset to inform policy in very direct ways.

- All stakeholders acknowledged the inherent value in linking data across primary and acute health care. While this sentiment was evident in the first evaluation, there appeared to be a more consistent or strengthened understanding from stakeholders during the current consultations. Similarly, the ‘untapped’ potential of Lumos was highlighted and stakeholders saw a wide range of future applications for the linked data in the Lumos data asset.
- At the same time it was recognised that Lumos must continue to evolve to become a system asset and align and support strategic health system priorities: E.g. Integration of Lumos with other Ministry data assets, dashboards or platforms such as [HealthStats NSW](#)).



Lumos is delivering value to NSW Health's VBHC initiatives

Improved Lumos use to inform state-wide initiatives –during the first evaluation period there were limited examples of the Lumos data asset being used to support state-wide initiatives, however during this evaluation period there were numerous examples provided such as support for the:

- Leading Better Value Care (LBVC) diabetes initiative (case for change refresh)
- State-wide initiative for diabetes management
- Geriatric outreach case for change
- Analysis of the impact of virtual care
- Integrated Care program
- Collaborative Commissioning program
- Trial of the COPD interactive tool

Integrated Care – Lumos allowed better identification of care needs of patients with chronic conditions

48 Follow-up program design

As previously reported Lumos analyses found that people who visit their GP within 48 hours of discharge from an unplanned hospital admission are a third less likely to have a readmission within a week. This finding is now being used to develop a program to ensure people enrolled in the NSW Health Integrated Care program have prompt GP follow-up within 48 hours of discharge.

Hunter New England Diabetes Alliance Program

The Hunter New England Local Health District is working with primary care services in their region to develop the Diabetes-Alliance program under Integrated Care. The program recruits general practices that participate in the Lumos program to actively promote connected care for people with diabetes. The Lumos team will support monitoring and evaluation of this initiative using Lumos data including through the use of propensity score matched comparison cohorts.

Lumos is a core part of the Collaborative Commissioning program

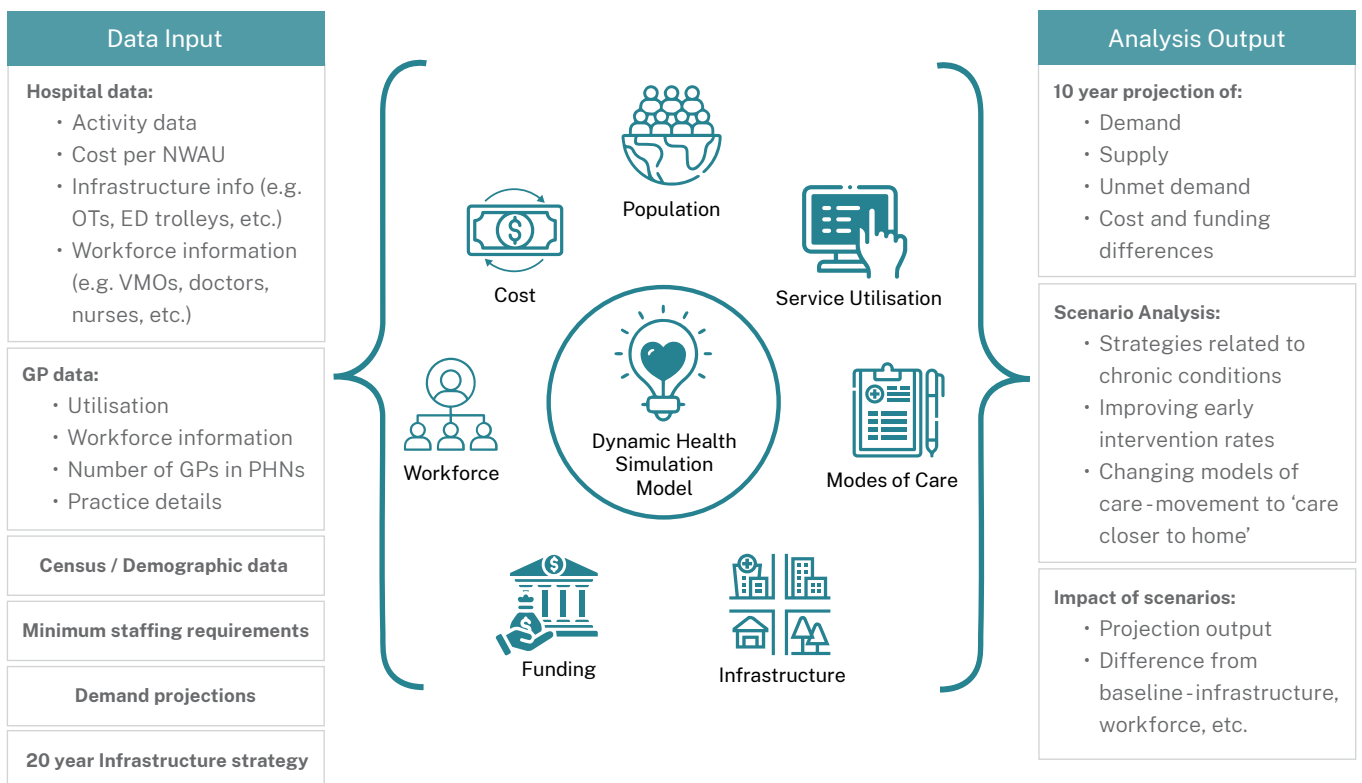
Collaborative Commissioning supports partnerships between LHDs and PHNs in Patient Centred Co-commissioning Groups (PCCGs). PCCGs focus on local health needs and develop interventions to improve patient and community outcomes. At the time of reporting, there were four partnerships in the process of operationalising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

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 healthcare (Figure 18).

The Lumos data allows a dynamic simulation model (DSM) approach to provide end-to-end care pathway modelling, across settings to support joint planning, design and monitoring. 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 DSM based on the Lumos data asset has the capability for one-system modelling to provide a patient centric view of demand, supply and implications to models of care, workforce and infrastructure. (Figure 18)

Figure 18: One-system modeling using Lumos



Value to the Commonwealth

The potential value for reform of better health data across the continuum of care has long been recognised and, accordingly, has been an aspiration of national and state reform agendas⁶. Increasingly, the Commonwealth is using Lumos as a successful proof of concept that secure and reliable linkage across settings can be achieved. For example, the Productivity Commission (PC) included Lumos as a case study in their Innovations in Care for Chronic Conditions report⁷. The PC reported that Lumos provides a successful case study of the benefits of using data and information more effectively. They further noted that the flow of information, such as that envisaged through the Lumos program, is a key part of facilitating a comprehensive understanding of people's journeys through the health system, enable people to self-manage, and assist healthcare workers to collaborate.

The recent Commonwealth Primary Health Care 10 Year Plan specifically highlights the value of Lumos⁸. The Plan recognised the critical importance of capturing better health data and using it well, to underpin quality primary care 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”⁹

2022 saw the mobilisation of the “Strengthening Medicare” reform program of the incoming Labour government.¹⁰ Together with the implementation of the Primary Health Care 10 year Plan, the proposition that Lumos becomes an enduring data asset is well accepted. Using the Lumos experience in NSW, there is appetite to support the evolution of similar locally driven initiatives in other jurisdictions. Recent findings from the Lumos program relating to the positive cost benefits of high-connectivity practices were presented to the Strengthening Medicare Taskforce¹⁰ in October 2022 prompting active discussion about the evidence for general practice reform including the role of patient registration in general practices.

Stakeholders consistently recognise the value of Lumos to deliver system reform focused insight

As scale has been achieved in the Lumos program, there has been a focus on delivering the program's aspiration to influence change at a policy and system level through the provision of a unique evidence base. The focus has been multi-faceted: supporting the VBHC initiatives of NSW Health, informing reform discussions at state and national levels, and delivering value through insights and data to a range of stakeholders. Consultations suggested that the active strategic focus on delivery of value has been recognised (and well-received) across a varied spectrum of interests.

- Lumos Practice Reports were typically described as being 'one part of a quality improvement program' provided to practices by PHNs, with Lumos reports being considered alongside PHN data reports.
- An improved understanding of the strengths and limitations of the Lumos Practice Reports, which included:
 - The strengths of linked data in providing insights across the health system to support a 'case for change'.
 - The frequency of reports and currency of the data limiting the role of Lumos Practice Reports in monitoring the implementation of change programs.
 - The nature of the de-identified data limiting the potential to identify patients to target specific interventions.



The range of examples of Lumos analyses being used to support state-wide and local initiatives and programs has increased substantially since the first evaluation report. In particular, stakeholders increasingly reported the value of Lumos data in their local quality improvement programs including:

- Western Sydney Service Delivery Reform, which provides a vision for healthy, resilient and thriving communities and families across the region (see [Data and Analysis – a catalyst to health system reform](#)); and
- evaluation of the ‘My Care Partners’ program for chronic disease management in South Western Sydney).

Stakeholders noted continued interest and engagement from Commonwealth and interstate health agencies in the progress of Lumos with a focus on learnings and potential for application of integrated primary and acute care data assets across the nation. At the same time, stakeholders were aware of the time limited funding for Lumos and were emphatic that the Lumos program be sustained into the future:

“don’t let it go away!”... “you can’t take it away now!”.

Stakeholders were clear in expressing the opportunities for using the Lumos asset in the future. These opportunities extend from developing a case for change, informing service design and projections of costs and outcomes, to informing evaluation of active programs. Stakeholders identified the importance of further opportunities for Lumos to support current Ministry of Health system priorities and contribute to system level change (e.g. areas aligned to Future Health). This was also highlighted as valuable in securing Lumos’s place as a sustainable system asset within the Ministry. A “Lumos Strategy” or “Roadmap” are seen as key developments for the program as it moves from establishment to business as usual.



Appendices

Appendix 1: Stakeholder consultation list

Organisation

Centre for Health Record Linkage, NSW Ministry of Health

Strategic Reform Branch, NSW Ministry of Health

Integrated Care team, NSW Ministry of Health

Royal Australian College of General Practitioners (RACGP)

NSW Australian Medical Association (AMA) and GP representative

Agency for Clinical Innovation (ACI)

Information for Mental Health (InforMH), NSW Ministry of Health

Digital Health Cooperative Research Centre (DHCRC)

Consumer representatives

Northern Sydney Local Health District (NSLHD)

Western NSW Local Health District (WNSWLHD)

Murrumbidgee Local Health District (MLHD)

Northern Sydney Primary Health Network (NSPHN)

Western Sydney Primary Health Network (WSPHN)

South Western Sydney Primary Health Network (SWSPHN)

North Coast Primary Health Network (NCPHN)

Hunter New England and Central Coast Primary Health Network (HNECCPHN)

Nepean Blue Mountains Primary Health Network (NBMPHN)

South Eastern NSW Primary Health Network (SENSWPHN)

Western NSW Primary Health Network (WNSWPHN)

Appendix 2: GP survey

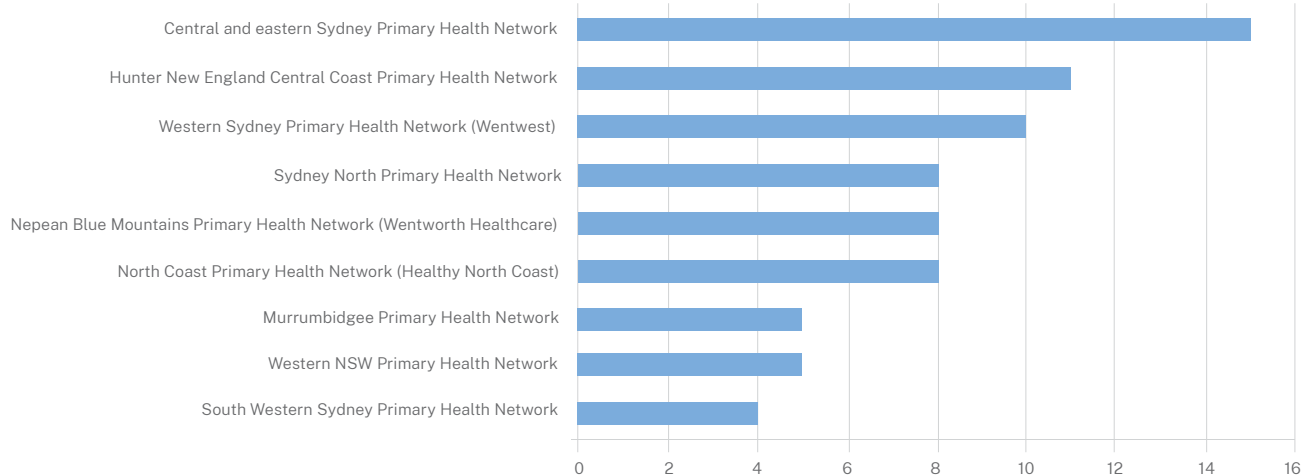
Question 1) What is your Primary Health Network?

Region*

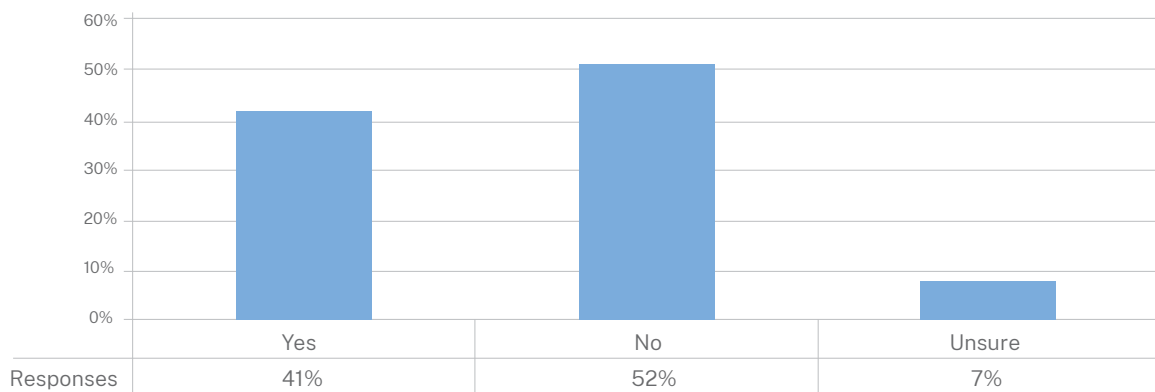
Central and Eastern Sydney Primary Health Network	15
Hunter New England Central Coast Primary Health Network	11
Western Sydney Primary Health Network (Wentwest)	10
Sydney North Primary Health Network	8
Nepean Blue Mountains Primary Health Network (Wentworth Healthcare)	8
North Coast Primary Health Network (Healthy North Coast)	8
Murrumbidgee Primary Health Network	5
Western NSW Primary Health Network	5
South Western Sydney Primary Health Network	4
Total	74

*Note: A survey was received from a practice in the the South Eastern NSW Primary Health Network (Coordinare) but was excluded from analysis because all responses were blank. A total of 74 responses were received. There were no mandatory questions for the survey and response numbers may differ for each question. The maximum responses for any question is 74.

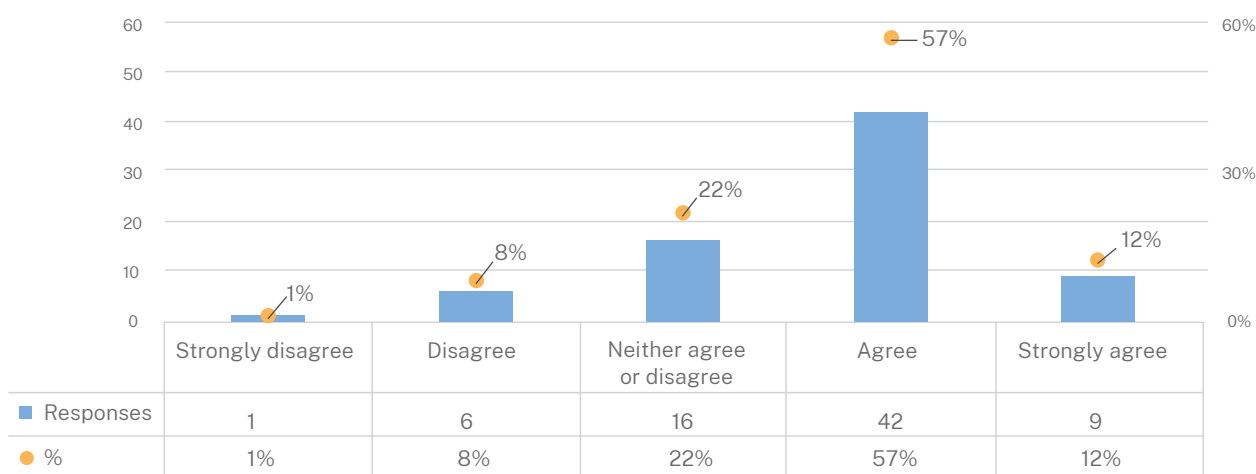
There were 37 responses from 'METRO' PHNs and 37 responses from REGIONAL PHNs



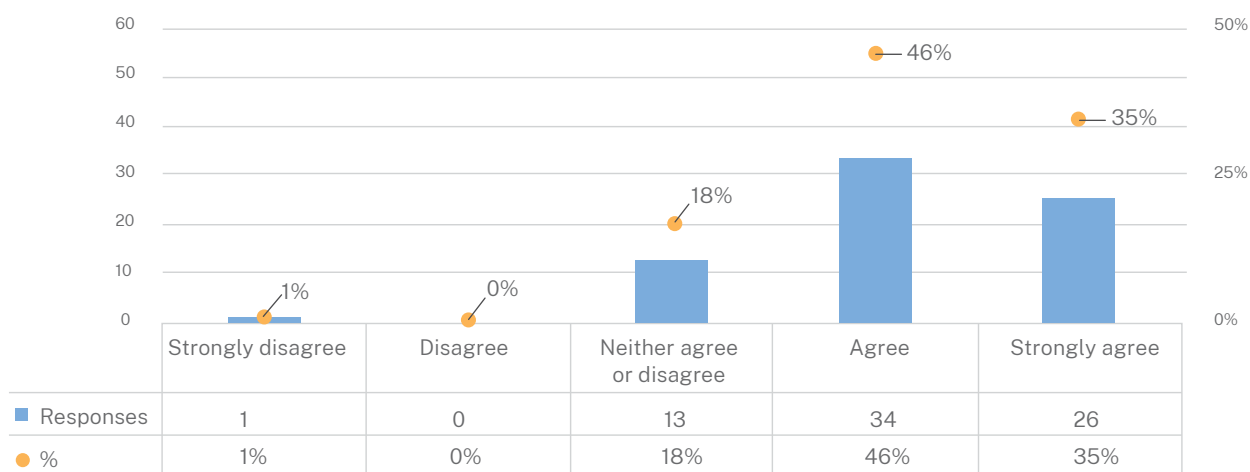
Question 2) Is this the first time you are receiving a Lumos Practice Report (sample pictured below)?



Question 3) The information in the report is easy to digest.



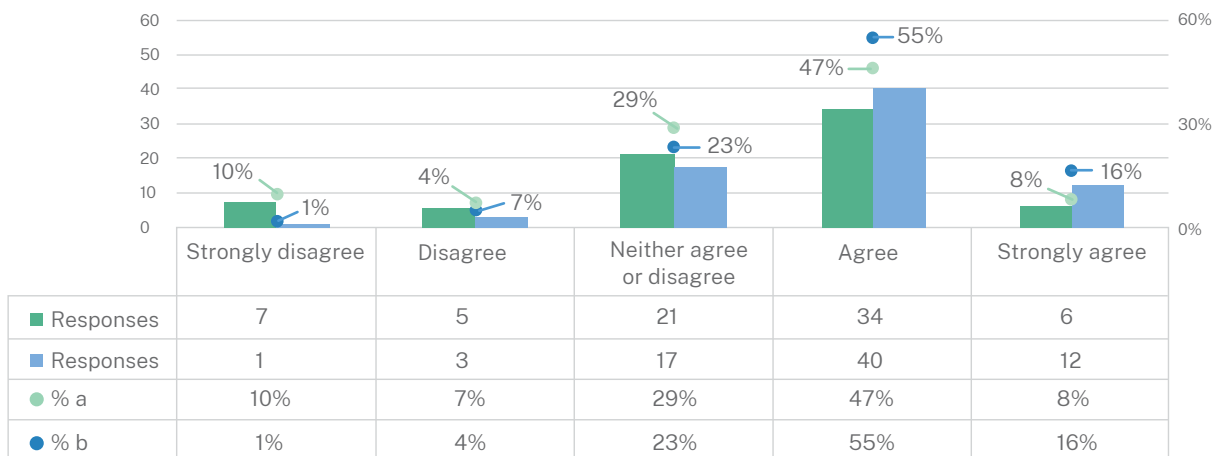
Question 4) The report should be distributed electronically to practices.



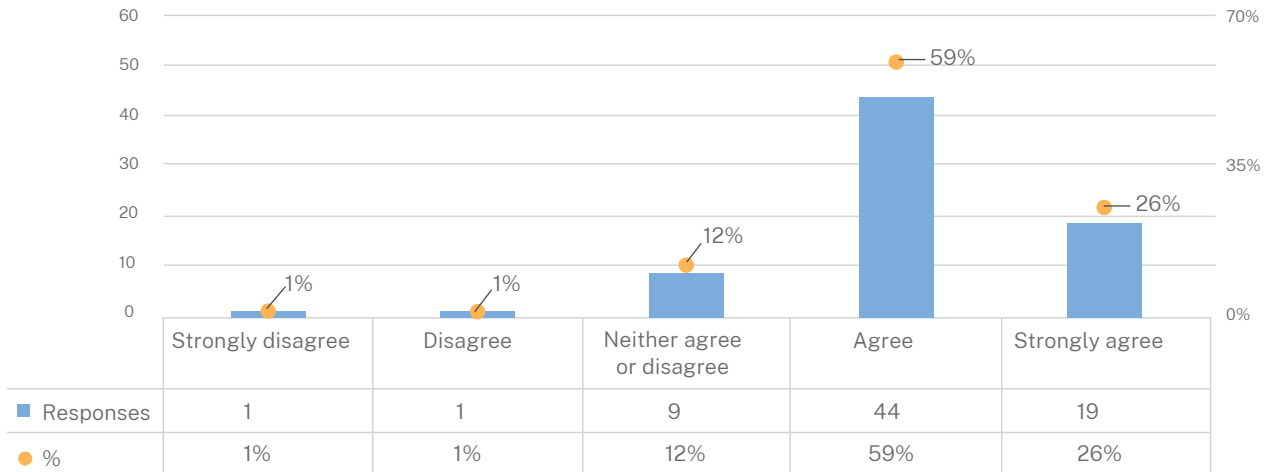
Question 5) The information in the report is relevant to my practice in terms of:

a) timeliness ■

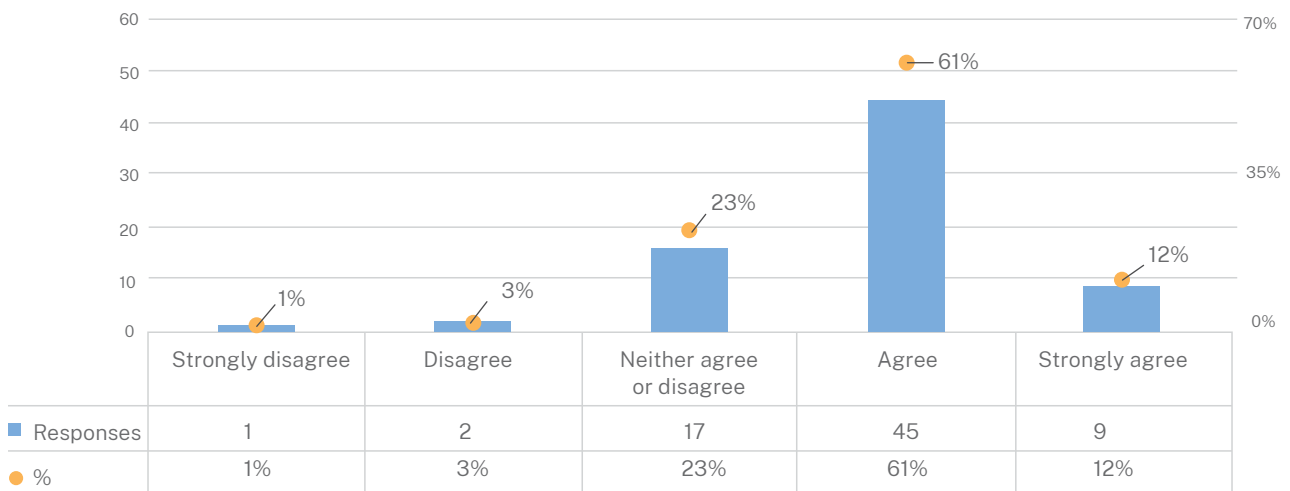
b) the information included ■



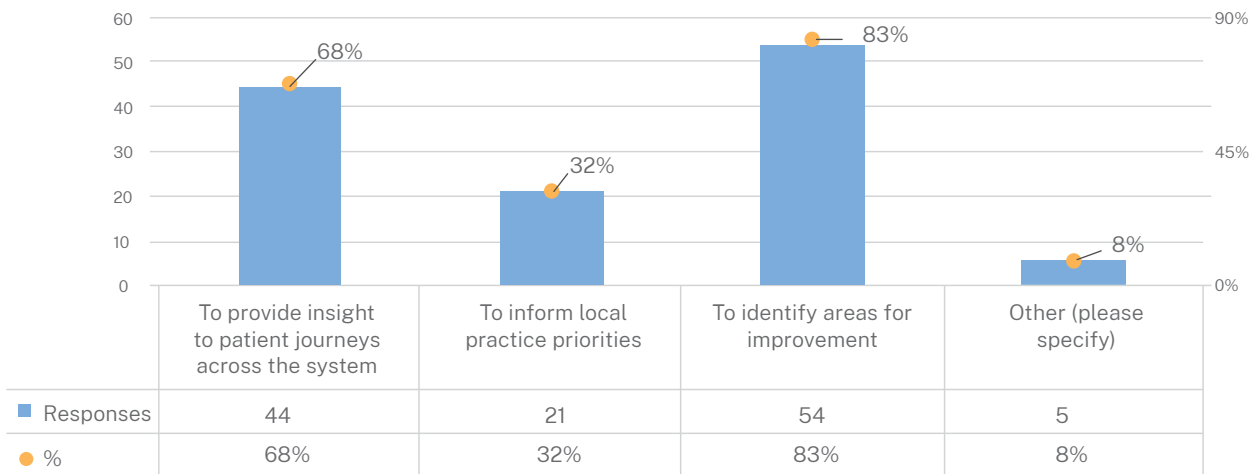
Question 6) Data about hospital attendance, general practice attendance, and clinical information in the report is valuable.



Question 7) The information in the practice report has changed -or has the potential to inform changes - to improve my Practice.



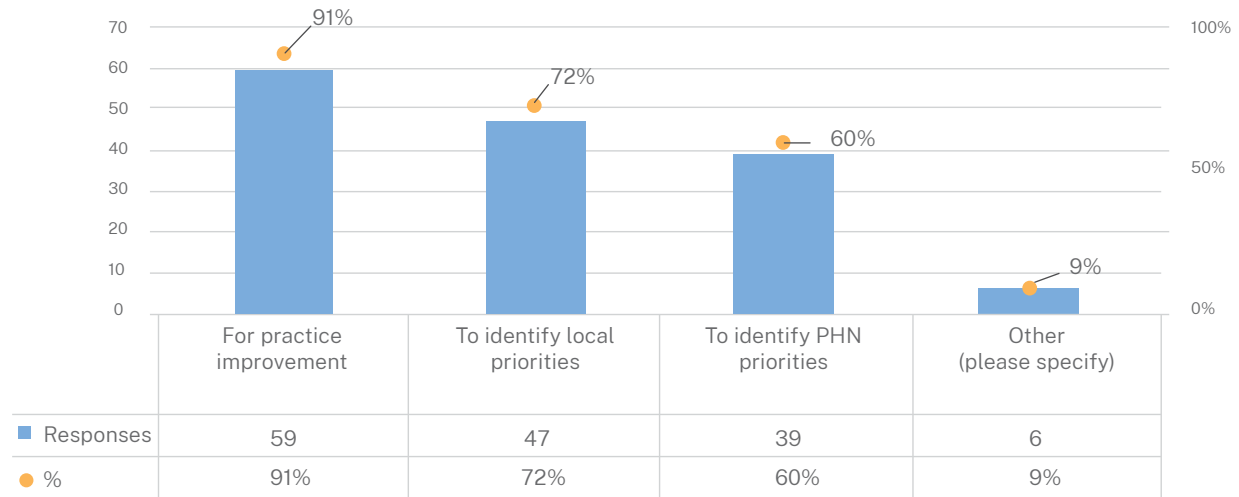
Question 8) What was the motivation for you to engage your practice in the Lumos program? (select as many answers as relevant)



Other responses

- Better understanding of the wider health system dynamics
- Never seen the report
- To get better understanding of whatr other health services my patients were accessing
- Hopefully the govt will get wind of the importance of General paractice in reducing hospital admissions and stop making things harder for them
- To see the difference good GP care makes at a systematic level

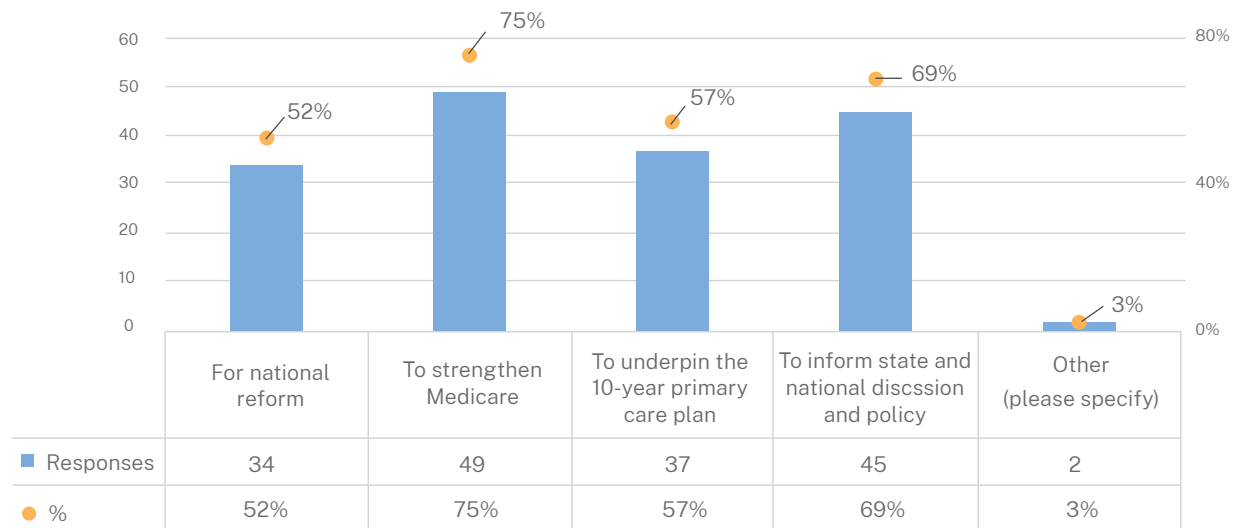
Question 9) How would you like to see the Lumos data being used across the profession
(Select as many answers as relevant)



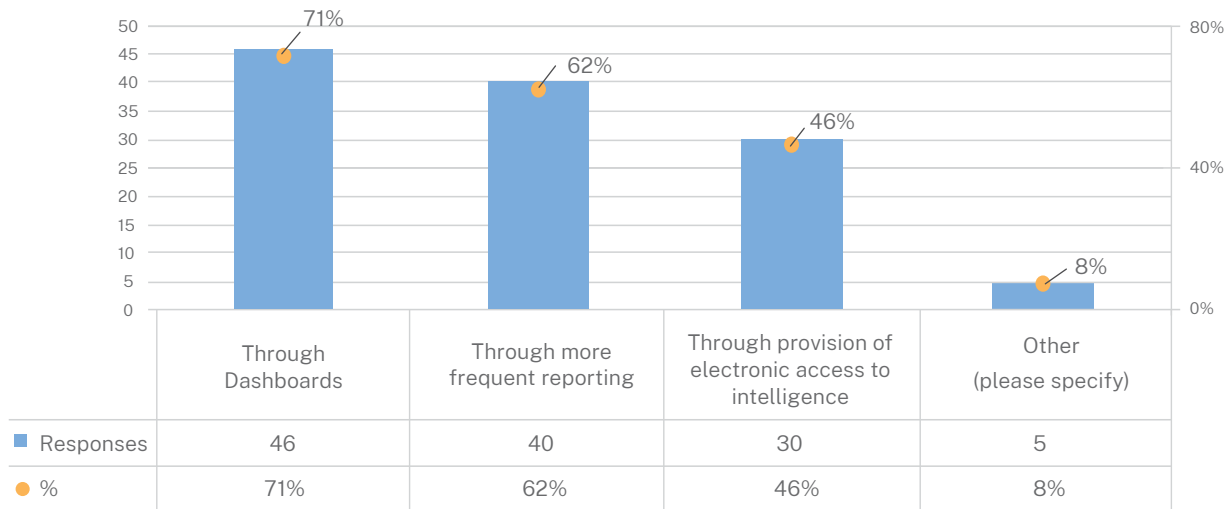
Other responses

- For LHD priorities
- Never seen the report
- For Local Health Districts to provide better support for primary care
- To assist LHD to understand the immense pressure we are under in General Practice
- Private Hospital data
- To advocate for general practice

Question 10) How would you like to see the Lumos data being used at the system level
(Select as many answers as relevant)



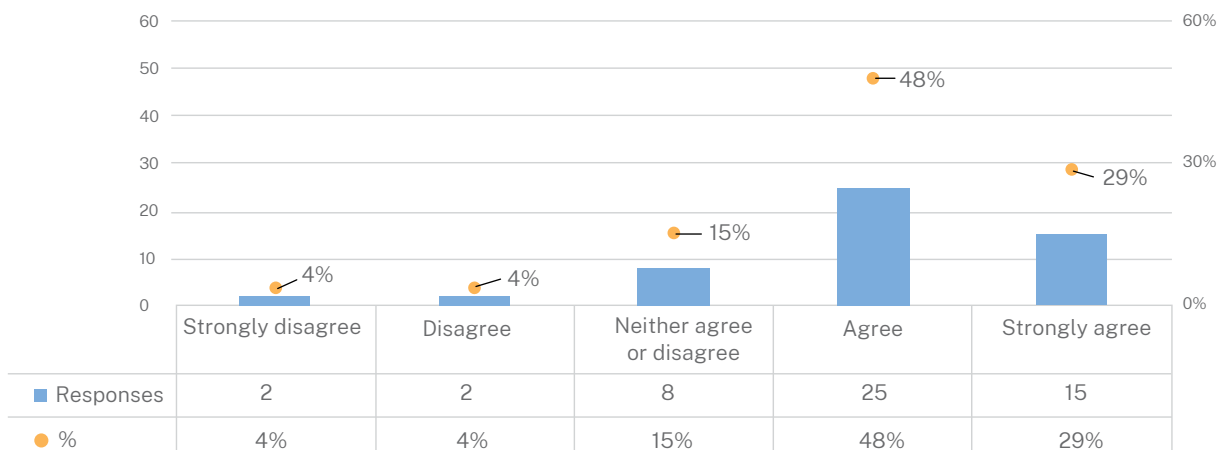
Question 11) How do we make the unique insights from Lumos more accessible?
(select as many answers as relevant)



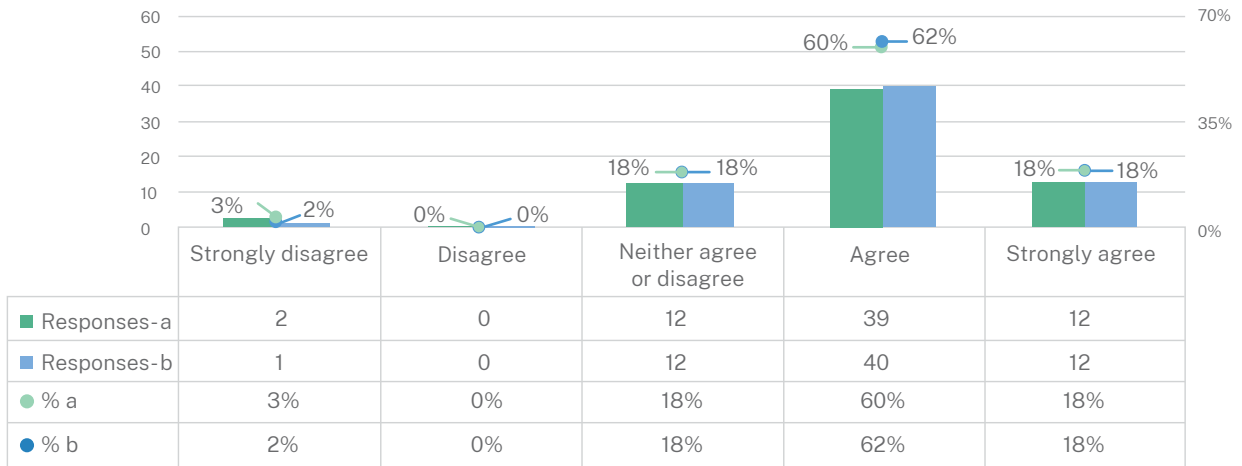
Other responses

- I find the reports interesting but the date of the reports are so delayed and with gps changing and patients moving around it makes it hard for my practice to do anything meaningful with the report.
- Reporting that is not so far behind, ie 2yrs prior to the date received.
- More timely reports. Data from more than a year ago has little usefulness to current operations when our GP workforce and patient cohort has significantly changed in that time
- Get all hospitals to participate. I believe our local hospital Northern Beaches Hospital does not participate which makes this data unhelpful for us
- Never seen the report

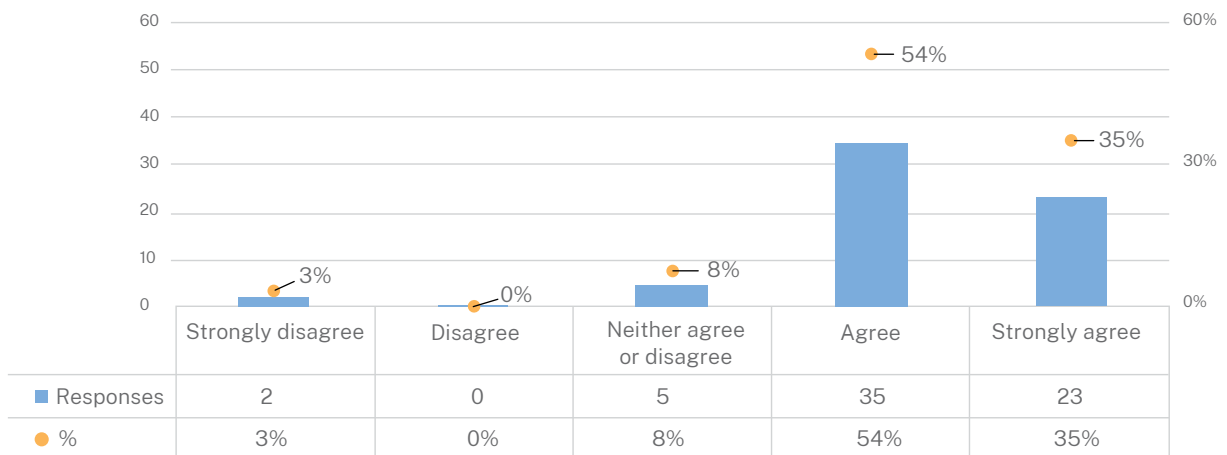
Question 12) The information sessions about the report are helpful (either one-on-one with the PHN or as part of a group information session).



Question 13) I am confident in the program's
 a) privacy measures (i.e., patient confidentiality) ■
 b) security measures (i.e., storage and use of the data) ■



Question 14) Access to comprehensive information about the patient journey is important for health care delivery.



Question 15) Do you have any other comments or feedback about the Lumos program?

Responses

- The data is 12 months old when I get to see the report
- Never seen the report so very hard to give any feedback :)
- It must be interpreted in line with local resources especially GP availability
- Far too slow to come out
- As stayed, timeliness of reports is crucial for this to be a useable data set
- Report can be made brief with identifying areas need to improve
- We're glad to be part of the LUMOS program. I wonder whether engaging a GP champion within each PHN region (and having them drive region-wide interest) would be more successful than the current method of engagement by PHN staff. This could include GP champions talking to the LUMOS insights at around the same time that practice reports are released each 6 months. Otherwise, keep up the good work!
- Please include Private hospital visits/data for ED. Would make a big difference in our Q.I.
- The focus on diabetes has identified an area for improvement in our practice.
- I believe our local publicly funded hospital -Northern Beaches Hospital -does not participate in Lumos. Means we cannot interpret the data provided to us.
- Number of diabetes patients in the practice
- I would like to know what exactly is done with the information gathered. And yes I would like fed back sessions on our practice e and how it compares to others
- I am so happy to see this program running, as a way to link the system data together. I would like to see data from other states included especially for cross border communities
- The concept is good. It would be a useful tool to drive practice improvements if the reports were more timely and more frequent (in order to monitor impact of change on reported parameters).
- Thanks it's a bit hard to understand the blue lines and the colour coding some more words may help
- I'm not sure we code hyperlipidaemia we code usually high chol or high triglycerides whats the coding used in this analysis what cut points are used its hard to know what is being discussed otherwise
- Looks like our practice is saving the LDH some money
- Look at the numbers of ED presentations per hour of the day -are the numbers high enough to consider expanding your services? -Who pays to expand services its hard to justify on the MBS rebate with overtime for staff etc
- Better handover at discharge may save money for the LDH if you want early review perhaps that needs to be planned and negotiated

Appendix 3:

Representativeness of Lumos Practices

Lumos Data - Measure of representativeness (histogram intersection) for April 2022

PHN	PHN Name	Practices (Oct 2022)	Total Practices (NHSD)	% Practices	Persons (Oct 2022)	Population (ABS)	% Pop.	5 year age groups Female	5 year age groups Males	RSAD	ARIA	Avg
101	CESPHN	94	541	17.4%	1,103,601	1,670,312	66.1%	92.9%	92.8%	88.4%	97.7%	93.0%
102	NSPHN	37	278	13.3%	468,560	954,462	49.1%	91.1%	93.7%	80.3%	98.8%	90.9%
103	WSPHN	61	318	19.2%	555,903	1,045,146	53.2%	95.3%	95.1%	89.7%	98.9%	94.7%
104	NBMPHN	16	124	12.9%	132,788	384,136	34.6%	94.4%	95.8%	87.3%	97.2%	93.7%
105	SWSPHN	109	376	29.0%	768,954	1,040,813	73.9%	94.8%	95.4%	89.9%	99.2%	94.8%
106	SENSWPHN	20	201	10.0%	183,540	639,854	28.7%	93.5%	93.5%	88.8%	93.8%	92.9%
107	WNSWPHN	14	122	11.5%	135,613	312,621	43.4%	90.2%	92.1%	74.7%	84.6%	85.4%
108	HNECCPHN	92	394	23.4%	676,464	1,288,568	52.5%	93.6%	95.0%	91.7%	95.7%	94.0%
109	NCPHN	14	180	7.8%	149,437	533,558	28.0%	86.5%	90.3%	62.1%	83.4%	80.6%
110	MPHN	13	85	15.3%	80,100	244,649	32.7%	91.6%	94.3%	75.1%	83.8%	86.2%
NSW TOTAL		470	2,619	17.9%	3,965,041	8,167,893	48.5%	93.7%	95.7%	96.0%	92.5%	94.4%

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