
Lumos

Data Governance Framework

February 2024

Version 3.3



Lumos

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Glossary

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

Term	Definition
CHeReL	Centre for Health Record Linkage
GP	General Practice
LHD	Local Health District
MoH	NSW Ministry of Health
NSW	New South Wales
PHN	Primary Health Network
PHSREC	Population and Health Service Research Ethics Committee
PPRL	Privacy Preserving Record Linkage
SAPHE	Secure Analytics Primary Health Environment
SIA	System Information and Analytics
SMI	System Monitoring and Insights

1. Introduction

Achieving value-based care in NSW is a strategic direction for the NSW Ministry of Health (MoH) that requires understanding the patient journey through the health system, including the services patients need, and where, when and how those needs are met. Health information spanning the various services, settings and systems is a critical enabler for this understanding. However, Australian patient data is stored across different levels of government and by private organisations, each holding a piece of the patient journey puzzle.

The Lumos Program seeks to analyse entire patient pathways and journeys through the health system in NSW by linking de-identified data from a variety of sources, enabling the generation of new insights, improvements to patient care, and ultimately improvements in patient experiences and outcomes.

1.1. The Lumos program

Lumos is an ethically approved program that securely links encoded data from general practices to other health data in NSW, including hospital, ambulance, emergency department and mortality data. Lumos is delivered through a partnership between NSW Primary Health Networks (PHNs), general practices (GPs) and the NSW MoH, and operates under strict data governance processes.

The Lumos program creates a linked data asset comprising de-identified records for patients of health services in NSW. It is Australia's first such state-wide and regularly updated data asset, and can be used to map and analyse patient journeys to support the planning, funding, management and evaluation of the health system. The data linkage is Undertaken by the MoH's Centre for Health Record Linkage

(CHeReL), and the resulting linked dataset is analysed by officers working for the Lumos Program. Reports using aggregated data are provided back to participating GPs via their PHN.

The program is the result of a four-year pilot project which linked the records of approximately 400,000 patients across 40 NSW GPs. The pilot demonstrated that it is possible to securely extract patient records from general practice systems and link them to data about patients in the public health system, in order to yield actionable insights for both primary care and acute care sectors.

1.2. Need for data governance

Australians overwhelmingly want their de-identified data to be used for authorised health purposes, but hold substantial concerns about its protection and the impact of data breaches on their lives:

- Most (91%) Australians support the use of their de-identified data for advancing medical research, improving patient care and tracking disease, disability and their causes (Research Australia, 2019);
- Seventy percent (70%) of Australians consider the protection of their personal information to be a major concern in their life (Australian Government, 2020).

2. About Data Governance

Data governance is *"... a system of decision rights and accountabilities for information-related processes, executed according to agreed-upon models which describe who can take what actions, with what information, and when, under what circumstances, using what methods."* (Data Governance Institute, n.d.). Data governance reflects the practice of bringing direction and control over data-related aspects of a project. It ensures that data access is provided to the right people, and that users can trust and rely on it.

Effective data governance strengthens overall governance structures, and ensures data is managed, used and protected in line with legal and community expectations. It ensures that:

- Data management and linkage meets the needs of relevant stakeholders. Stakeholders are meaningfully engaged to determine objectives and overall direction of data/information activities;
- A clear plan is made for data/information management, with effective prioritisation and decision making;
- Data/information resources are regularly monitored and evaluated in line with the overall direction and objectives.

Data governance differs from data management. To quote the NSW Health Data Governance Framework:

"Data governance designates the source of authority for making decisions about data; the roles/structures authorised to make decisions; and the basis upon which decisions are made. Data management is the planning, execution and oversight of policies and processes that acquire, store, protect, and deliver data and information assets."

In other words, **data governance sets expectations. Data management fulfils them.**

3. The Lumos Data Governance Framework

Data governance frameworks typically encompass both data governance and data management, as depicted in Figure 1.

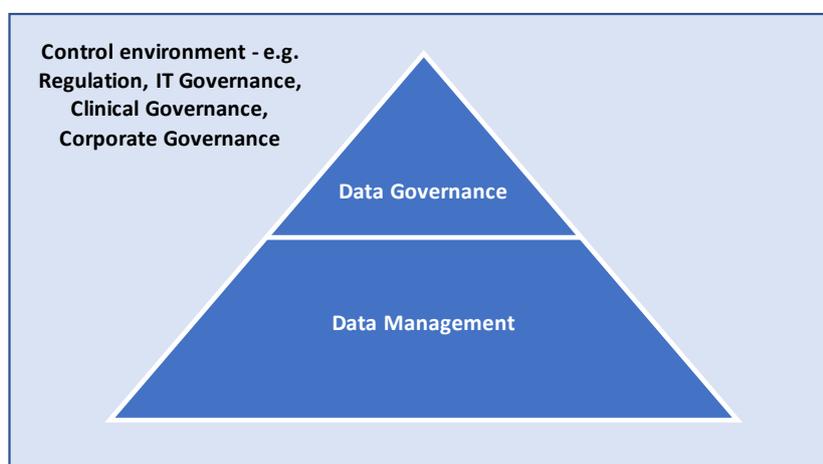


Figure 1 – Typical Data Governance Framework

However, the data governance environment for the Lumos program is not 'typical'. Rather, it comprises a variety of organisations operating under different regulatory requirements, with different capabilities, purposes and roles. It is a partnership, controlled through relationships and negotiation rather than 'lines of command'. It is perhaps best described as a federation – an overarching entity formed by uniting smaller or more localised entities (Adapted from Merriam-Webster, n.d.)

Accordingly, this framework focuses on data *governance* only, setting common expectations for the entities involved. Data *management* – how these expectations are fulfilled – is recognised to differ between entities and is regarded as the responsibility of each and every such entity, as depicted in Figure 2.

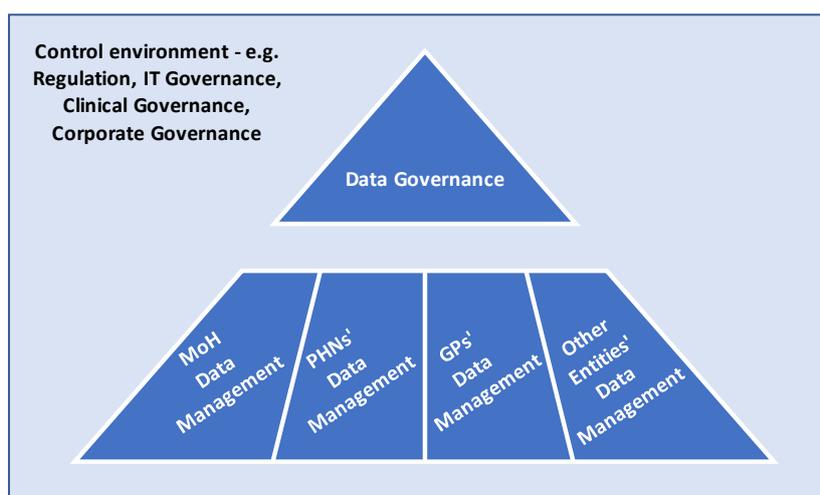


Figure 2 – Lumos Data Governance Framework

The Lumos Data Governance Framework has been designed for compatibility and coherence with the:

- NSW Health Data Governance Framework (NSW Health, 2019);
- Primary Health Networks Data Governance Framework (PHN Cooperative, 2020);
- Australian Institute of Health and Welfare Data Governance Framework (AIHW, 2021).

However, it most closely follows the approach of the NSW Health Data Governance Framework.

3.1. Purposes

The purposes of the Lumos Data Governance Framework (the Framework) are to:

- Ensure that data management across the Lumos program is aligned with the aims of Lumos, complies with relevant requirements, and achieve the common aims articulated in this Framework;
 - Build social license and public trust in Lumos, by showing that data assets are appropriately managed and generate high value results;
 - Promote alignment between data governance and information technology governance across the program;
 - Guide Lumos stakeholders in their data-related decision making;
 - Establish responsibilities and accountabilities for relevant decision makers.
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3.2. Structure of the framework

The Framework:

1. Contains a set of guiding principles that apply at three levels:
 - Accountability;
 - Critical enablers – including People, Processes and Technology; and
 - Central components – including Quality, Access, Security and Standards.

These principles are applied at all stages of the data lifecycle and depicted at Figure 3.

2. Embraces a set of policies that articulate common expectations at the three levels described above and across the data lifecycle, and associated procedures that reflect the differing environments within which Lumos entities operate.



Figure 3 – Lumos Data Governance Framework

3.3. Scope

The Framework applies:

- To all data in the linked Lumos data asset and any data sets or information derived from this.
- To all staff, contractors and other persons who contribute data, use, or have access to the Lumos data asset. This includes the staff and agents of NSW Health, the MoH, the CHeReL, PHNs, GPs and other participating health services.
- For the duration of the Lumos ethics approval, after which it will be reviewed to ensure its relevance and validity.

3.4. Benefits

The Framework clarifies roles, responsibilities, accountabilities, behaviours, processes and structures, enabling:

- Lumos data and information assets to be created that are high quality, standardised, well understood and well utilised;
- Access to the right information in the right formats, by the right people and at the right time, to support best practice, integrated, and value-based care, and
- Appropriate, efficient and effective data management across the health system in NSW, leading ultimately to:
 - Better care and value;
 - More effective and satisfied health workforces;
 - Better health outcomes for NSW citizens.

3.5. Definitions

The following definitions apply in this document:

Data	generally refers to facts and figures that can be represented as numbers, text, graphics, sound or video, as well as how these are interpreted. Data can also take different forms e.g. digital, and can pertain to a range of topics or areas e.g. people, systems and the environment. Data can further be broken down by type or purpose, for example transactional and operational data.
Data Governance	implementation of a set of policies, processes, structures, roles and responsibilities to ensure that an agency's data is managed effectively and that it can meet its current and future business requirements. NSW Data governance Toolkit https://data.nsw.gov.au/data-governance-toolkit-0/module-1-introduction-to-data-governance
Data Governance Framework	a logical structure for organising and communicating relevant Data Governance concepts. Data Governance Institute (http://www.datagovernance.com/glossary-governance/)
Data Management	refers to the activities involved with managing data across the full lifecycle so that it is protected from unauthorised use and inappropriate deletion. Data needs to be appropriately managed from procurement or service design through to creation and final disposal. This includes protection of personal, health and sensitive information, and the prevention of deletion until enabled by legal authorisation. NSW Data governance Toolkit https://data.nsw.gov.au/data-governance-toolkit-0/module-1-introduction-to-data-governance
Data Quality	generally accepted as meaning "fitness for purpose". The Australian Bureau of Statistics (ABS) Data Quality Framework contains seven characteristics of quality: <ul style="list-style-type: none"> • Institutional environment • Relevance • Timeliness • Accuracy • Coherence • Interpretability

	<ul style="list-style-type: none"> • Accessibility <p>NSW Government Standard for Data Quality Reporting https://www.digital.nsw.gov.au/sites/default/files/NSW%20Standard%20for%20Data%20Quality%20Reporting%20v1.2%20FINAL.pdf</p>
Data asset	a structured collection of data developed for a broad purpose. An enduring data asset (or enduring linked data asset) is a subset of this category, denoting the linkage of a larger range of data that is designed for potentially many purposes and users. An example of this is the NSW Human Services Data Set. A data asset could also include models, methodologies and algorithms..
Duration	a period defined by a 'from' and a 'to' time point.
General practice	<p>a) a unique discipline of largely relationship-based specialist medical care providing person-centred, continuing, comprehensive and coordinated whole person healthcare to individuals and families in their community.</p> <p>RACGP https://www.racgp.org.au/FSDEDEV/media/documents/Education/Students/A%20career%20in%20general%20practice/RACGP-General-practice-career-guide.PDF)</p> <p>b) an establishment providing general practice services.</p>
General Practitioner	a medical practitioner authorised to practice general medicine in a primary care setting and to provide referral for additional health services as needed.
Health Care System	<p>a system (a regularly interacting or interdependent group of items forming a unified whole) via which health care is made available to a defined population. The elements of a health care system typically embrace:</p> <ol style="list-style-type: none"> personal health care services for individuals and families, available at hospitals, clinics, neighbourhood centres, and similar agencies, in physicians' offices, and in clients' own homes; the public health services needed to maintain a healthy environment, such as control of water and food supplies, regulation of drugs, and safety regulations intended to protect a given population; teaching and research activities related to the prevention, detection, and treatment of disease; and third party (health insurance) coverage of system services. <p>Farlex Medical Dictionary https://medicaldictionary.thefreedictionary.com/health+care+system)</p> <p>Note – May be abbreviated to 'health system'.</p>
Health Event	a single interaction of the patient and the health system. Each health event occurs at some time point and is usually of a particular health event type (see below). Health events occurring outside the health system are usually not considered, with the most notable exception of 'death events', which are considered as health events irrespectively of where they occur.

Health Event Type	a way of abstracting and grouping health events into categories where conceptually the same kind of health service is being delivered in a health system. The declaration of the types of health events of a health care system depends on how the health system is conceptualised and how data represents health events. For example, someone presenting to ED then admitted may be conceptualised as one or two events, or even many events as the patient interacts with many clinicians.
Indicator	a statistic whose value can be a surrogate or predictor of measurements of an individual or population.
Lumos data asset	the main dataset created by the Lumos Program, consisting of the combined data content derived from extracts of the included data collections linked to the GP record extracts.
Lumos information asset	knowledge gained through study, communication, research, instruction, in relation to the Lumos program. The Lumos program may release information in the form of reports based on analysis of Lumos data.
NSW Health System	the health system under the state government of New South Wales, including NSW Ministry of Health, the Pillars, and Local Health Districts. The NSW Health System delivers publicly available health care and other services to the citizens of New South Wales and visitors.
Patient	a person who is suffering from any disease or behavioural disorder and is under treatment for it. Farlex Medical Dictionary (https://medicaldictionary.thefreedictionary.com/patient)
Patient Journey	the collection of health events of a patient over a duration.
Patient pathway	a defined series of health interactions for a patient to treat their disease or behavioural disorder
Primary Care	the usual point at which an individual enters the health care system. Its major task is the early detection and prevention of disease and the maintenance of health. This level of care also encompasses the routine care of individuals with common health problems and chronic illnesses that can be managed in the home or through periodic visits to an outpatient facility. Providers of care at the primary level include family members as well as the professionals and paraprofessionals who staff community and neighbourhood health centres, hospital outpatient departments, physicians' offices, industrial health units, and school and college health units. Farlex Medical Dictionary (https://medicaldictionary.thefreedictionary.com/health+care+system)

4. Guiding Principles

The following principles underpin the Framework and guide the development, implementation and review of Lumos data governance and management practices. They are applied to each central component of the Framework – Quality, Access, Security and Standards.

1. Federation	
Description:	Decision-making is shared across and negotiated between the entities comprising the Lumos program
Supports:	Accountability
Rationale:	Lumos comprises a large number of independent organisations which collectively enable a purpose-driven program.
Implications:	<ul style="list-style-type: none"> • Data governance expectations can be common across participating entities, but data management processes will differ between entities. • Data governance expectations are negotiated between the entities comprising the federation.

2. Data governance complements existing governance bodies and structures	
Description:	Lumos data governance supports the devolved responsibilities inherent in the health system (decision-making as close to the patient and those working on the ground as possible)
Supports:	Accountability
Rationale:	Health service planning may be system-wide but health service delivery takes place at local levels via local decision making. Accordingly, Lumos must support better decision -making at all levels.
Implications:	<ul style="list-style-type: none"> • Relevant, authorised stakeholder organisations all at levels have secure access to Lumos data in sufficient detail, and supported by effective and efficient tools and sufficiently capable staff to undertake the analyses they require.

3. Transparency	
Description:	It must be clear to everyone how, when and by whom data-related decisions and controls were introduced into the processes.
Supports:	Accountability
Rationale:	Transparency constitutes good practice and is essential in building the level of trust demanded by stakeholders and the NSW public.

Implications:	<ul style="list-style-type: none"> • Data Governance Committee Meeting minutes document all decisions related to data governance. These minutes are available to all participating organisations. • The Lumos team maintains a log of all data access requests, and provides a report of access requests, outcomes, and current SAPHE users which is reviewed at each Data Governance Committee Meeting. • A data governance annual report is prepared.
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4. Appropriate application of Lumos data and information assets

Description:	Governance and management of Lumos data and information assets align with the defined aims and purposes of the Lumos program.
Supports:	Accountability
Rationale:	Lumos has ethics approval for a defined set of purposes, stakeholders and processes which reflect the program's aims (see Section 5.3). The use of data for other aims would be unethical.
Implications:	<ul style="list-style-type: none"> • Requests for Lumos data that are not clearly associated with these aims are denied. • Data management practices that do not clearly align with these aims are not applied. • Decisions or actions that do not align with the aims of the Lumos program are identified and mitigation and / or remediation steps taken

5. Indigenous data sovereignty

Description:	To be developed
Supports:	Accountability
Rationale:	To be developed
Implications:	To be developed

6. Currency and fitness for purpose

Description:	The Framework is reviewed on a regular basis to ensure its ongoing currency and fitness for purpose.
Supports:	Accountability
Rationale:	The Lumos program is likely to evolve over time, as may community or stakeholder expectations, the regulatory environment, and best practice in data management. The Framework should evolve accordingly.

Implications:	<ul style="list-style-type: none"> • The Framework is reviewed at least annually and its currency and fitness for purpose re-endorsed by the Data Governance Committee. • Alignment of the Framework with other relevant frameworks and controls is maintained. • Changes are managed to embed relevant data management practices across the Lumos program. • Lumos data assets are managed efficiently and effectively in light of contemporary data management practice and principles
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7. Data management is everybody's business

Description:	All participating organisations contribute to data management decisions needed to accomplish the program's aims.
Supports:	Accountability People
Rationale:	Lumos's stakeholders are spread across a variety of organisations with different characteristics, capabilities and interests. However, they each have a shared interest in the aims and success of Lumos. The actions of each may affect all others, and therefore all must 'play by the same rules'.
Implications:	<ul style="list-style-type: none"> • Every stakeholder adheres to the Framework. • Commitment of resources is required to implement this principle.

8. Risk management

Description:	Data governance and management risks, and residual risks, are continually identified and mitigated. Data governance and management risks are incorporated in the Lumos risk and issues register.
Supports:	Accountability
Rationale:	No program can be undertaken without risk, but risk can be managed. Data governance sets an obligation to actively manage risks.
Implications:	<ul style="list-style-type: none"> • The risk tolerance(s) associated with Lumos data and information assets are identified and communicated to participants. • Risk management is included in every stage of the Lumos data lifecycle, and in every role, responsibility and accountability statement. Risk management is everybody's business.

9. Compliance

Description:	Management of Lumos data and information assets is compliant with relevant legislation, regulations, policies and contractual obligations.
Supports:	Accountability

Rationale:	Lumos operates within a regulatory environment and aligns with community expectations regarding compliance.
Implications:	<ul style="list-style-type: none"> • All relevant laws, regulations, and policies are identified and accessible to the stakeholders who may need them. • Any inconsistencies between these are identified and the preferred authority identified. • Compliance is monitored.

10. Auditability

Description:	Data-related decisions, processes, and controls related to data governance must be auditable.
Supports:	Accountability
Rationale:	Data governance establishes data management controls but must itself be examinable. The reasons for and nature of data-related decisions, processes, and controls must be clear, reviewable and contribute to a learning organisation.
Implications:	<ul style="list-style-type: none"> • Data-related decisions, processes, and controls within the Lumos program must be accompanied by documentation to support compliance-based and operational auditing requirements.

11. Roles, responsibilities and accountabilities

Description:	The data management roles, responsibilities and accountabilities of all organisations, entities, positions and individuals relevant to Lumos must be articulated, understood and accepted by all.
Supports:	People
Rationale:	Lumos operates across a range of organisations which gives it a complex data governance environment. Data governance can only be effective if the roles, responsibilities and accountabilities of all stakeholders are agreed, clear and adopted in practice.
Implications:	<ul style="list-style-type: none"> • All relevant roles, responsibilities and accountabilities are articulated. • These are communicated to all relevant stakeholders, with ongoing awareness raising and training as required. • Adherence to roles, responsibilities and accountabilities are linked to performance management systems. • Checks and balances exist between those who create information, those who manage it, those who use it, and those who introduce standards and compliance requirements.

12. Data and information quality

Description:	The quality of Lumos data and information assets is known, and continuous improvement is performed to meet defined quality benchmarks.
Supports:	Quality
Rationale:	The value and usability of Lumos data and information assets are directly associated with their quality.
Implications:	<ul style="list-style-type: none"> • Lumos has and uses an industry-standard data and information quality framework. • A quality monitoring and improvement program is in place.

13. Standardisation

Description:	Data is defined and described consistently throughout the project, and clear definitions are available to all users. Where possible, existing and shared standards are applied by Lumos.
Supports:	Standards
Rationale:	Standards provide for efficient and effective linkage, data cleansing, comparison and re-use. They also provide for safe interpretation.
Implications:	<ul style="list-style-type: none"> • Lumos has and uses an appropriate metadata management framework. • Lumos metadata is current, fit for purpose and accessible to those who need it, including the establishment and maintenance of a data dictionary. • Lumos data management is supported by and exploits the benefits of existing appropriate standards

14. Privacy and confidentiality

Description:	The Lumos program and all its participants understand and protect the privacy and confidentiality regulatory requirements, and the expectations consumers and health services.
Supports:	Accountability Access Security
Rationale:	Privacy and confidentiality are not simply regulated requirements. Rather, they reflect community expectations and the levels of trust given to organisations and entities, including the Lumos program. Meeting these benchmarks is critical to the success and sustainability of the program.

Implications:	<ul style="list-style-type: none"> • Lumos privacy and confidentiality requirements are articulated, sourced and provided to all participating organisations, their staff and agents. • Lumos privacy and confidentiality requirements are accessible to NSW citizens. • Controls to meet these requirements are implemented and monitored.
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15. Data security

Description:	Lumos data and information assets are protected from unauthorised access, use and disclosure.
Supports:	Access Security
Rationale:	Lumos data and information assets include highly sensitive personal and practice-related information. Although de-identified, Lumos linked unit records could potentially be associated with other (non-Lumos) data to identify individuals. The NSW community has strong expectations concerning health data security.
Implications:	<ul style="list-style-type: none"> • The security of Lumos data and information assets is architected. • The entire Lumos technology architecture, across all participating organisations, meets defined security benchmarks. • All staff participating in the Lumos program are aware of and understand relevant security requirements and protocols. • Ongoing awareness raising and training is provided as required. • Data breaches are notified and investigated.

16. Utility

Description:	The Lumos Data Governance Framework adds demonstrable value.
Supports:	Accountability
Rationale:	The Framework is a means to an end, not an end in itself. It must not be so burdensome that the ends are not achieved. Rather, it must effectively balance risks and benefits; goal and practice.
Implications:	<ul style="list-style-type: none"> • Performance measures exist for the Framework

5. Accountability

The Accountability component of the Framework deals with who is responsible for what, and the major controls that support these accountabilities. Accountability policies for Lumos data governance include organisational structures and relationships, roles, responsibilities and accountabilities, aims and ethical approval, and compliance with legal, regulatory and policy environments.

5.1. Organisational structures and relationships

The Lumos program comprises a wide variety of participating entities including the MoH, PHNs, General Practices, the Commonwealth, the CHeReL and Local Health Districts (LHDs).

These are independent organisations, but in terms of Lumos data governance:

- **Each participating General Practice is contracted to a single PHN. This contract requires compliance with the Framework**, which is developed and maintained in collaboration with the participants. **Once data is extracted from a GP and encoded, custodianship of the encoded data transfers from the practice to the PHN.**
- **Each participating PHN is contracted to the NSW MoH**, with the contracts administered by the Lumos Implementation Team. **This contract also requires compliance with the Framework.**
- **The CHeReL is contracted to the NSW MoH to perform Privacy Preserving Record Linkage (PPRL) for the Lumos program**, with the contract administered by the Lumos Team. **This contract also requires compliance with the Framework.**
- **All end users of the Lumos linked data asset are required to complete an access request form. Once approval is granted, access and use require compliance with the Framework.**
- The Stakeholder Reference Group is responsible for sharing perspectives of the organisations and constituents they represent on matters that relate to patient consent, privacy and security safeguards, data sharing arrangements, social license and public trust.
- The Data Governance Committee provides the overall strategic direction and advises the Lumos Executive Sponsor on the use, access and disclosure of data that drive data sharing and connection and better-informed health policy.
- These two groups work in close collaboration.

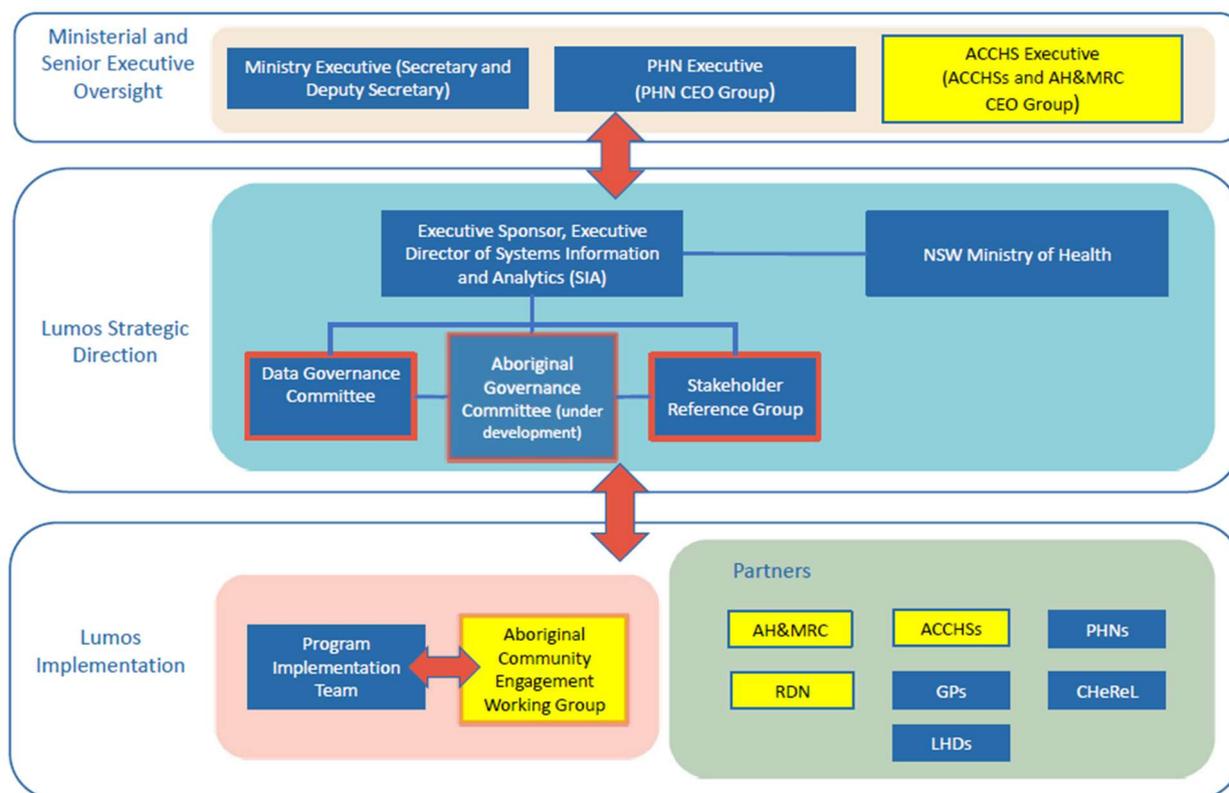


Figure 4 – Organisational structures and relationships

5.2. Roles, responsibilities and accountabilities

The following roles contribute to the effective governance and management of Lumos data and information assets.

1. Lumos Executive Sponsor

The Lumos Data Sponsor:

- Controls the strategic direction of the Lumos program.
- Has legal rights and control over all Lumos data and information assets captured, stored, generated and used by the NSW MoH.
- Is responsible for data governance of the entire Lumos program. This is achieved through operating alongside the most senior executives of other organisations participating in Lumos.

The Lumos Data Sponsor role is undertaken by the Executive Director of the Systems Information and Analytics (SIA) branch within the MoH.

The key accountabilities of the Lumos Data Sponsor are to:

- Establish the strategic direction for creating and maintaining all Lumos data and information assets.
- Establish, maintain and implement a data governance framework for the Lumos program
- Enable strategic management, governance and operation of all Lumos data and information assets.

- Provide direction and guidance, and authorise appropriate resources, for management of all Lumos data and information assets.
- Authorise any public release of information, except where this authority is delegated by the Combined NSW Health Delegations Manual.
- Ensure compliance with all relevant legislation, policies and standards.
- Appoint a Data Custodian and ensure the Data Custodian's duties are fulfilled.

2. Lumos Data Governance Committee

The primary responsibilities of the Lumos Data Governance Committee (the Committee) are to:

- Establish the Data Governance Framework
- Recommend the Framework to the Lumos Data Sponsor for adoption
- Oversee compliance with, and performance of, the Framework
- Perform specific roles on behalf of the Lumos Data Sponsor as required. These are incorporated in the Committee's terms of reference.

Committee membership is voluntary and aligns with the stakeholders described in the terms of reference (see Attachment 2).

3. Lumos Data Custodians

Data Custodians are responsible for day to day management and oversight of the Lumos data and information assets, including overall quality and security. The key accountabilities of Data Custodians are to:

- Establish the basis for the Lumos Data Asset – i.e. ensure that any use of the Lumos linked data asset aligns with the purpose it was collected for.
- Control access to Lumos data and information assets in compliance with all relevant legislation, policies and standards, and any additional conditions specified by the Data Sponsor.
- Ensure that up-to-date technical documents are available for the supply and storage of the Lumos data assets.
- Establish a data quality framework that ensures the integrity, accuracy, completeness, timeliness, relevance, consistency and reliability of the data.
- Ensure processes are in place to provide feedback to data suppliers about data quality, including any issues that require fixing.
- Establish and maintain an acceptable level of data protection to ensure privacy, security and confidentiality.
- Ensure there is a documented process for responding to breaches and potential breaches of data security.
- Ensure there is a documented process for responding to breaches and potential breaches of Lumos policies and procedures.
- Ensure ongoing development, maintenance and review of Lumos data assets to ensure they remains relevant to system and business needs.

- Appropriately escalate risks and issues to Data Sponsor and/or other Data Custodians.
- Authorise Ethics amendments

Data custodianship occurs at several points across the Lumos program.

Prior to data linkage, data is extracted and collected from a variety of health organisations including General Practices and LHDs. As the data moves through the processes from source to storage as a linked data asset, data custodianship moves accordingly:

- Each **contributing health agency** provides custodianship for their own patient source data.
- For General Practices, consenting to Lumos includes consenting to their **PHN** becoming the Data Custodian on their behalf once their data is extracted and encoded, before it is linked.
- The **Director of the System Monitoring and Insights (SMI) unit**, within the NSW MoH, provides custodianship of the Lumos linked data asset. This director oversees the Lumos program. The Lumos Data Custodian in MoH has two additional accountabilities:
 - Control access to the Lumos linked data asset in line with all relevant legislation, policies and standards, and any additional conditions specified by the Data Sponsor.
 - Sign off applications to access to the Lumos linked data asset as recommended by the Data Governance Committee.

The various stages of data custodianship are depicted in Figure 5.



Figure 5 – Stages of Data Custodianship

Custodians of source data are responsible for day to day management and oversight of their data assets, including their overall quality and security. Data Custodians for consented pre-linked source datasets (other than GPs) are also responsible for:

- Compliance with all relevant legislation, policies and standards relating to data collection and supply
- Liaising as appropriate with their partnering health agencies to drive improvements to data quality of the source data.

4. General Practices

General Practices (GPs) are key in maintaining quality data that is provided from their practices to the Lumos Program. The responsibilities of GPs participating in the Lumos Program are to:

- Review the program information and raise any questions or concerns with their PHN and/or the NSW MoH to ensure a clear understanding of their ongoing participation.
- Provide documented consent to participate in Lumos and have their PHN act as data custodian, authorised by the Practice Owner or Principal.
- Provide the required information to participate including practice name, practice email address and practice address.
- Ensure that the minimum required technology platforms for participation in Lumos are kept up-to-date. Provide reasonable access to the practice premises and technology for installation or configuration of any software required for the project.
- Apply recommendations from the Lumos Data Governance Committee and their PHN for improvements to data quality issues.
- Report any breach or suspected breach of data security or privacy related to Lumos to their PHN or the central Lumos Data Custodian.
- Provide feedback via their PHN on the conduct of the Lumos Program and the utility of the various information products created.
- Ensure data privacy is maintained whenever data is collected, accessed and used in accordance with Australian privacy law.

5. Lumos Data Stewards

Data Stewards are responsible for the day to day management and operation of Lumos data and information assets, including their completeness and quality. The key accountabilities of Data Stewards are to:

- Manage Lumos data assets in line with relevant legislation, policies and standards, and any conditions specified by the data sponsor.
- Co-ordinate stakeholder engagement and input into the business requirements for Lumos data and information assets.
- Provide advice to the Data Custodian and Data Sponsor on the management of Lumos data and information assets as required.
- Provide feedback to data suppliers in relation to data quality issues as appropriate.

- Coordinate data access requests, providing a report on pending applications at each Lumos Data Governance Committee meeting.
- Review, assess and sign off applications to access the Lumos data asset, following recommendations from the Data Governance Committee.
- Participate in regular reviews of current users of the Lumos data and information assets to identify any that are no longer appropriate for access. This is performed in collaboration with the Lumos Data Governance Committee
- Escalate significant risks and issues to a Lumos Data Custodian.

Data Stewards requiring access to the Lumos data asset are reviewed by the Lumos Data Governance Committee.

6. Centre for Health Record Linkage (CHeReL) staff

The key responsibilities for the Centre for Health Record Linkage staff supporting the Lumos Program are to:

- Implement PPRL. This will encode patient identifying information from the general practice systems, other source datasets, and the Master Linkage Key
- Receive records of patient information from the individual participating general practices and other data sources
- Link general practice patient records to other data collections included in the Lumos Program using probabilistic linkage of encoded patient identifiers
- Manage the integration and distribution of linked content data sets (with no personal identifying information)
- Assess the performance of different linkage approaches used and raise any issues with the MoH

7. Lumos program Implementation Team in NSW Ministry of Health

The key responsibilities of the NSW MoH staff within the Lumos program are to:

- Oversee and manage the state-wide Lumos Program including budget management, coordination, liaison, and feedback between Lumos partners
- Provide support to PHNs to enable participation in the Lumos program
- Commission technology infrastructure for secure data collection, storage, access, use and reporting
- Commission expertise as required to continue to meet the Lumos objectives
- Securely store, access and analyse the Lumos linked data asset to meet its aims and objectives

- Produce confidential practice reports and distribute to the relevant PHNs
- Provide PHNs with a copy of any publication or information arising from the Lumos linked data asset at least two weeks before public release
- Provide a timely response to any issue raised by the Data Custodians of the source data
- Prepare reports and publications on the Lumos Program as appropriate
- Support GPs to ensure that patients are provided information on secondary uses of their health data in accordance with the Royal Australian College of General Practitioners (RACGP) Principles on secondary use of GP data by third parties.
- Ensure that GP Advisors are involved in data analysis and interpretation

8. Primary Health Network and Local Health District staff

The key responsibilities of LHDs/PHNs within the Lumos Program are to:

- Provide a timely response to any issue raised by the Lumos Data Custodian or Data Governance Committee
- Attend information and training sessions provided by the Lumos team
- Inform the Lumos Data Governance Committee of any local issues that will have an impact on data quality and integrity
- Provide data governance advice, review recommendations from the Committee, and resolve data quality issues
- Designate a primary contact to liaise with the Data Steward or Lumos Data Governance Committee in relation to the linked data
- Provide the Lumos team with a copy of any publication or information arising from the Lumos linked data asset at least two weeks before public release
- Establish local data governance processes, in compliance with relevant legislation, policies, standards and the Lumos Data Governance Framework

9. Lumos Data Asset Users

All personnel who gain access to the Lumos linked data asset have a responsibility to ensure security and appropriate use of the data. It is the responsibility of all data users to:

- Ensure login details are kept confidential and are only used by the designated user
- Report data errors and quality issues in a timely manner
- Ensure security and privacy of the data is maintained at all times
- Report any breach or suspected breach of data security or privacy
- Sign a legally binding Confidentiality Undertaking before accessing the Lumos linked data asset

- Follow all terms and conditions of access as issued at the time access is granted, and any updates that follow
- Obtain approval from a delegated authority for public release of data if the user is a NSW Health personnel
- Provide the Lumos team with a copy of any publication or information arising from the Lumos linked data asset at least two weeks before public release
- If any data quality issues are identified from the data, the Lumos team will refer them to the relevant PHN or LHD. The issues will then be addressed directly with relevant data providers

5.3. Aims and ethical approval

Data governance and management must be aligned to the aims and ethical approval of the Lumos program. These aims are to:

1. Provide information that will support public health programs in NSW in areas like chronic condition management, smoking, obesity, risky alcohol use, youth suicide and early intervention.
2. Improve the ability to target high risk groups in the population by determining reliable and modifiable predictors of poor health outcomes.
3. Discover the most effective leverage points to refine health service processes and to improve quality in patient care while reducing waste for a more cost-effective health system with better patient outcomes.
4. Improve identification of, and reductions in, preventable emergency department demand, unplanned hospital presentations and readmission rates.
5. Implement data-informed and evidence driven quality improvement, and system re-design to deliver better patient care.
6. Proactively monitor new service models to address emerging population health issues.
7. Foster greater collaboration between Local Health Districts (LHDs), PHNs and GPs to ensure the right care in the right place at the right time.

Uses of Lumos data are restricted to purposes for the planning, funding, management and evaluation of health services. Any external users must also work in partnership with the directly collaborating organisations of the Lumos program. This is because the Lumos program has been granted a waiver of the usual requirement to obtain individual patient consent for the secondary use of personal health information, under the 'exemption for the Management of Health Services'. Details about this exemption are provided in the Statutory Guidelines for the Management of Health Services under the Health Records Information and Privacy (HRIP) Act 2002. In these guidelines, the purpose of this exemption is defined as:

“Activities which fall within the ‘funding, management, planning or evaluation of health services’ include activities for the purpose of undertaking, monitoring, assessing, or improving clinical practices and health service delivery. For example, the activity may involve a clinically significant departure from the routine clinical care provided to patients. It may involve developing a systematic investigation of possible innovations in technique, process or intervention. Sometimes such activities are difficult to distinguish from research and may form a continuum with it.”

This differs from a waiver under the 'Research exemption', which is the more commonly used exemption granted by ethics committees and has its own statutory guidelines for implementation. While the conceptual boundary between research and health service management analytics are sometimes blurred, for practical implementation, Lumos establishes its boundaries **to deliver benefits to the community through informing data driven improvements to health service delivery.**

This choice of exemption underlies processes for Lumos data use and access. While research typically addresses defined questions with a named team of investigators, Lumos is an ongoing, multi-user, multi-purpose data asset to be used within its defined purposes. The use of the Management of Health Services exemption permits the Lumos program to operate without additional ethical approval for each analytical activity, project and user, provided these have been approved through the established authorisation processes.

5.4. Compliance with legal, regulatory and policy environments

Data governance and management must comply with all relevant laws, regulations and policies relating to any of the participants.

A register with current copies of all documents describing relevant laws, regulations and policies relating to the Lumos program is maintained by the Lumos Data Custodian. It is available to members of the Data Governance Committee and all participating organisations.

If any participant finds an inconsistency between any of these documents, it is reported to the Data Custodian and submitted to the Data Governance Committee for review, with external expert input as required.

6. Critical Enablers

People, processes and technology are critical enablers for data governance. The accountabilities above cannot be exercised unless attention is paid to these enablers. Critical enabler policies for Lumos data governance refer to people, processes and technology.

6.1. People

People, skills and competencies are required for good decisions, execution of change and successful completion of all data governance and management activities.

Data governance controls in respect of Lumos program team members include:

- The **identification and clear articulation of requisite competencies** for Lumos program staff including NSW Health data analytical competencies. These are described consistently, included in the recruitment, development of Lumos program position descriptions and reviewed in performance management discussions.
- **Access to ongoing professional development to ensure up-to-date data governance and management skills.**
- **Awareness raising about the data governance framework and data management requirements**, including the ethics requirements.

- **Communication of changes to the Framework.**
- **Supportive workplace culture.**

6.2. Processes

Data governance controls on processes entail:

- **Having it documented and made available wherever it is needed** to assure appropriate, coherent and consistent treatment of the Lumos data and information assets; and
- Knowing where and when the process fails, so that it can be improved or replaced.

Critical Lumos processes include:

1. Data Extraction and Transfer
2. Data Linkage
3. Data cleansing and processing
4. Storage and Security of Linked Data Assets
5. Accessing the Lumos Linked Data Asset
6. Applying conditions of use and public disclosure
7. GPs withdrawing from Lumos
8. Data retention and disposal
9. Responses to data breaches
10. Lumos program completion

COBIT® 2019 recommends the use of a maturity assessment scale for processes, as depicted in Figure 6.

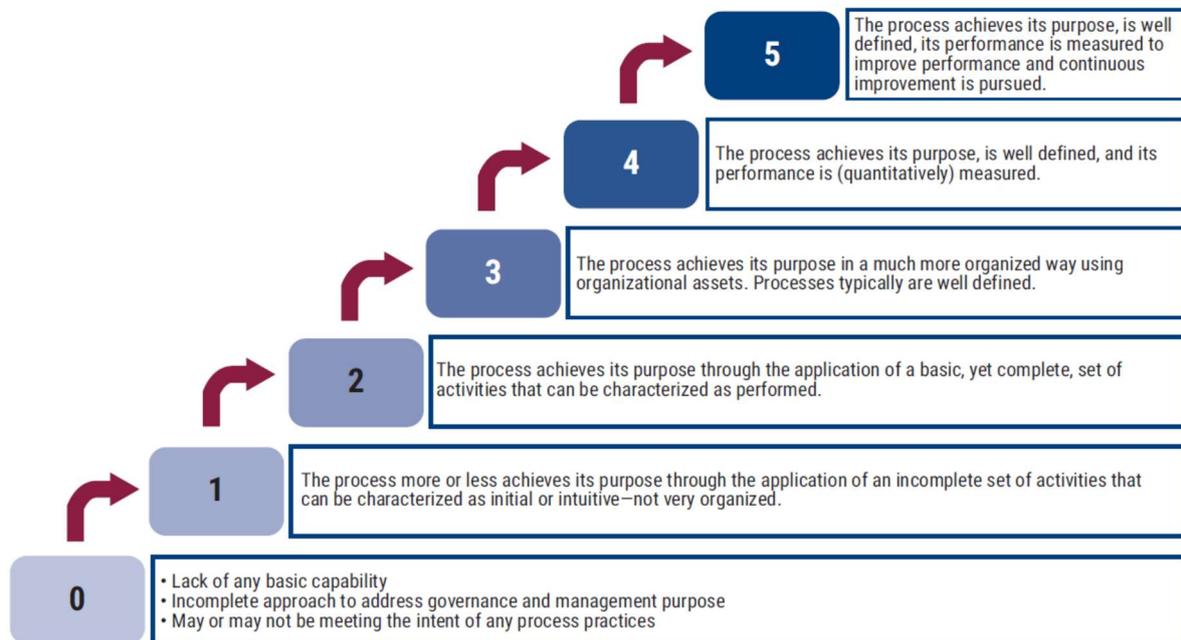


Figure 6 - Process Maturity Scale (ISACA, 2019)

6.3. Technology

Appropriate analytic tools, technologies and services must support access to data and information for management, monitoring and improving NSW Health services. Each ICT upgrade or new system must maintain data asset integrity and quality and consider opportunities to improve data assets and governance.

The technology enabler provides detailed guidance on third-party services, types of infrastructure and categories of applications that can be applied to support the achievement of a data governance or management objective.

Privacy preserving record linkage (PPRL):

Patient names or other directly identifying particulars are not extracted from General Practice systems in the Lumos program. This information is automatically encoded in the source systems in general practices using Linxsmart software prior to extraction. All data to be linked to the GP records are also encoded prior to the linkage using this technology for the purposes of PPRL.

Authentigate Portal

In order for automated data extraction and transfer, files must be credentialled in order to pass into NSW Ministry of Health. Participating GPs are registered with the Authentigate Portal in the Centre for Health Record Linkage. This technology has been developed to provide automated credentialing of incoming files to enable the secure transfer of GP record extracts into the NSW Health system en masse.

The Secure Analytics Primary Health Environment (SAPHE)

The SAPHE is a remote-access computing environment that provides highly secure storage and analytic tools to access the Lumos linked data asset. The SAPHE does not hold any personal data that identifies individuals within the Lumos linked data asset and has controls that restrict access and outputs to optimise patient privacy. The SAPHE has been custom built for Lumos and developed in line with the eHealth NSW's stringent Privacy and Security Assurance Framework (PSAF). This ensures that it meets the health system's security and functional requirements for storage of sensitive data. Access is strictly controlled by the SAPHE administration team and overseen by the Lumos Data Governance Committee. The SAPHE architecture has also been designed to incorporate encryption.

7. Central Components

Each central component of data governance and management requires ways of evaluating their performance. Central component policies for Lumos data governance refer to quality, access, security and standards.

7.1. Quality

A quality framework applies to the Lumos program to provide the standards for assessing and reporting on the quality of Lumos data. This will facilitate high quality outputs.

Purposes of the Lumos data quality framework include:

- Identification of areas for improvement in the Lumos program; and
- Measurement in quality using tangible outcomes.

The quality framework will encompass set standards that can be measured through indicators of quality. These indicators will include:

- Data and the degree to which it is fit for purpose
- Interpretations that arise from the data
- Representativeness of the Lumos program
- Ability of Lumos to provide value to the health system
- Impact that result from Lumos

7.2. Access

Lumos data is for purposes relevant to the funding, management, planning or evaluation of health services. Examples include health system performance monitoring, planning public health programs, evaluation of health service models, quality improvement and health services re-design, co-commissioning and other collaborative initiatives across health services. Access to Lumos is only provided for those purposes.

Health and non-health personnel can apply for access to Lumos via the Secure Analytics Primary Health Environment (the SAPHE) by following the established access process.

All access to Lumos is subject to conditions for its use and release, including in any publication or report of information arising from the Lumos Data Asset. Such requirements are set in law by the *NSW Health Administration Act 1982* and the *Health Administration Regulation 2015* and align to the ethics approval under which the Lumos program operates. Further, Unauthorised access to information stored in the Lumos Data Asset may constitute an offence under section 308H of the *Crimes Act 1900*.

7.3. Security

Security is robustly addressed within the Lumos program, and several measures exist to protect general practice records including:

- General practice data custodian(s) are required to provide informed consent to participate in Lumos.
- Patient identifiers are encoded before being securely transferred to the CHeReL.
- General Practice Data are transferred by Extraction Vendors to the CHeReL through secure channels in an encrypted form.
- A Project Person Number (PPN) is assigned to each individual at each linkage, ensuring that no records can be linked retrospectively across linkages.
- Linked data is securely transferred to the System Information and Analytics branch (SIA), where it is stored on the Secure Analytics Primary Health Environment (SAPHE). This platform has been developed specifically to house the Lumos data (see 5.3 Technology for further information on the SAPHE).

7.4. Standards

Creating and applying data standards is necessary for ensuring data quality and interoperability (the ability to exchange information between different systems).

Having data standards is essential for Lumos due to the compilation of similar information from a wide range of sources. Data standards will ensure that the meaning of data does not change between sources.

Important data that are applicable to Lumos include:

- **International Classification of Primary Care version 2 (ICPC-2)**
- **International Classification of Diseases Version 10, Australian Modification (ICD-10-AM)**
- **Systematic Nomenclature in Medicine (SNOMED)**

Mapping the data extracted from Lumos to standardised systems will have long-term benefits for ensuring validity and is a key piece of work under this Framework.

8. The Data Lifecycle

The table below outlines the 6 stages of the data lifecycle, and the key policies and processes relevant to each stage.

Data lifecycle stage	Policies and processes
Plan/design	Lumos Analysis Plan Lumos Ethics Protocol
Build/acquire	Lumos Data Dictionary Lumos Ethics Protocol
Store	Reference sections 6.3 & 6.4 of this Data Governance Framework Lumos SAPHE Solution Design
Use	Lumos Ethics Protocol, including the Lumos access packs referred to in the Ethics Protocol Appendices C & D. Lumos Analysis Plan
Share	Lumos Ethics Protocol Lumos Communications Plan
Archive/destroy	Lumos Ethics Protocol Lumos Data Retention and Disposal Protocol

9. Performance Measurement – *In Development*

10. Review

The Lumos Data Governance Framework is reviewed yearly, in consultation with the Data Governance Committee and other relevant stakeholders.

References

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Document Management

The following tables cover the documentation management of this Data Governance Framework

Version History

Version	Date	Author(s)	Description
0.1 – 1.8	26/7/2019 – 12/6/2020	EY, Lumos Team Members & David Rowlands	Internal first draft iterations progressed with internal team members
1.9	15/06/2020	Megan Steele	Draft version provided to Data Governance Committee members for review
2.4	10/08/2020	Megan Steele	Incorporates updates from Data Governance Committee members and internal review to incorporate more plain English into the document.
3.0	30/05/2021	David Rowlands	One year review, including comparison with Health Networks: Data Governance Framework. Version 1.0.
3.1	06/06/2021	David Rowlands	Incorporating feedback from Patricia Correll
3.2	07/09/2021	David Rowlands	Updates to section 5.3
3.3	19/01/2024	Mandy Fung and Patricia Corell	Updates to sections: 3.5 Definitions have been updated 5.1 – Updates to organisation structures and relationships 5.2 – Updates to roles and structure per organisational changes DGC recommendation for incorporation of RACGP data principles

Approval List

Date	Approver	Role
25/08/2021	Data Governance Committee	
04/03/2024	Data Governance Committee	