

# Frequently Asked Questions: Lumos and Data Sharing



## Lumos

Lumos is a new partnership initiative between Central and Eastern Sydney PHN (CESPHN) and the NSW Ministry of Health (MoH) to assist practices gain a stronger understanding of their patients' journey across the health system. This is an ethically approved program that securely links data across primary, ambulatory and acute care and will launch in February 2020 within the CESPHN region.

Once consent has been received from practices to allow de-identified data about your patients to be extracted, Lumos presents a unique opportunity to improve patient care through actionable knowledge.

It can:

- Generate insights into patient journeys across the healthcare system
- Identify current and emerging population health issues
- Improve patient experience and quality of care
- Inform data driven quality improvement and system redesign responses

This FAQ factsheet on Lumos privacy and security aims to address questions you may have around data extraction and linkage.

### ***What does 'de-identified data' mean?***

Data extracted from your practice is de-identified – meaning that personal, identifiable information such as a person's name, address, email address, telephone number and date of birth is removed to prevent an individual's personal identity being revealed – no identified information leaves the practice.

### ***What data is extracted?***

2 files are extracted from your clinical software:

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

- A de-identified computer encoded patient ID which can be used to link the NSW Health data sets with your patient records
- Enables record linkage without disclosing your patients' identity

#### **File 2: Health content file**

- Non-identifying patient health-related data including; dates of GP encounters, demographic details, chronic disease flags, dates and generic names of medications, health risk factors, MBS item numbers, My Health Record flags and Shared Health Summary upload dates.

### ***How is the data extracted?***

Your practice will be asked to allow the installation of updates to existing software (free of charge) in order to extract and transfer the data. There should be minimal impact on the operation of the practice.

Pen CS will install a software update to the existing Pen CAT software in participating general practices, which can be used to create patient-record level data extracts in a form that can be securely transferred and used for data linkage and analysis in conjunction with other data collections. Pen CS do not access or receive GP data. The software defines the file content and extracts it from the practice database into a file that can be sent to CHeReL and MoH.

### ***How is the data linked?***

Linkage will be carried out by the Centre for Health Record Linkage (CHeReL), whose linkage system and expertise have become core infrastructure for research, population health surveillance and health system performance monitoring since 2006. A key component of the linkage protocol is the use of de-identified records along with the 'separation principle', which means that no one working with the data can view both the linking information (File 1) and the analysis data (File 2) as they will always be kept separate to ensure maximum privacy protection.

Further information is available at [www.cherel.org.au](http://www.cherel.org.au).  
 Linked data will be analysed by the investigator team in the NSW Ministry of Health.

**What data sets are currently linked?**

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

In future:

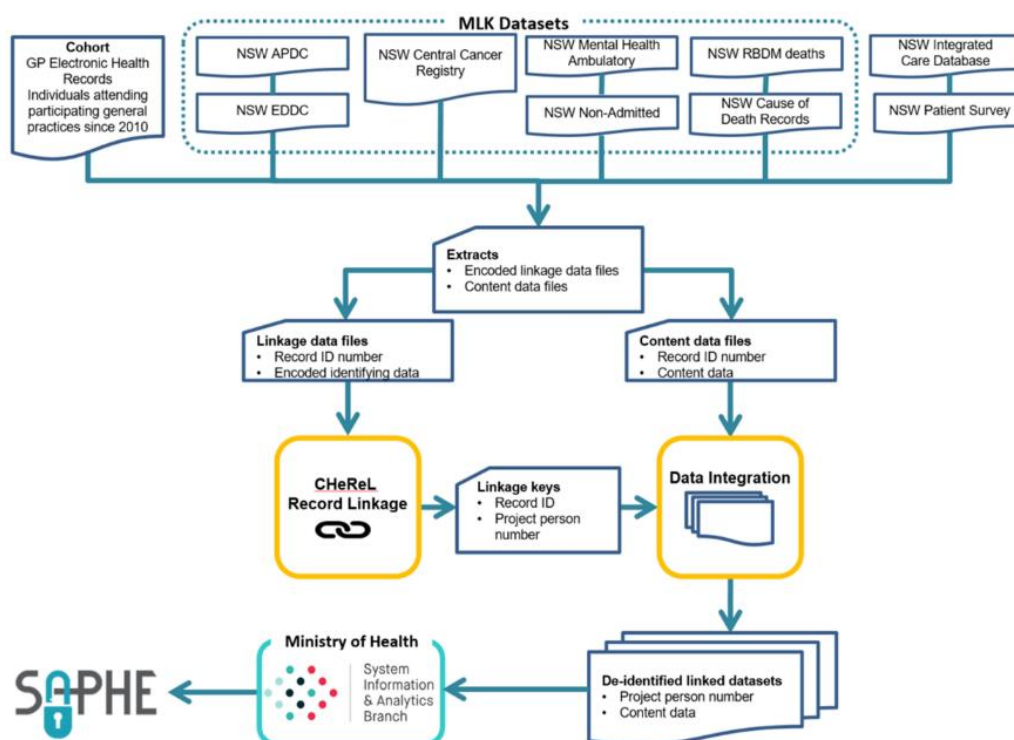
- NSW Mental Health Ambulatory
- NSW Central Cancer Registry
- NSW Ambulance
- Cause of Death

**How is the data stored?**

Upon completion of pre-processing of the linked data sets received from the CHeReL, the linked data asset will be securely transferred to and stored on the centralised cloud repository Secure Analytics Primary Health Environment (SAPHE), which has been developed specifically to house the Lumos data.

The SAPHE does not hold any personal data that directly identifies individuals within the Lumos linked data asset and implements controls that restrict access and outputs to further ensure privacy. The SAPHE is developed in line with the eHealth NSW’s stringent Privacy and Security Assurance Framework (PSAF) to ensure it meets the health system’s security and functional requirements for storage of sensitive data. Access will be strictly controlled by the SAPHE administration team and overseen by the Lumos Data Governance Committee.

**Lumos data flow diagram - October 2019**



Lumos Technical Information Summary • October 2019

**How is the data governed?**

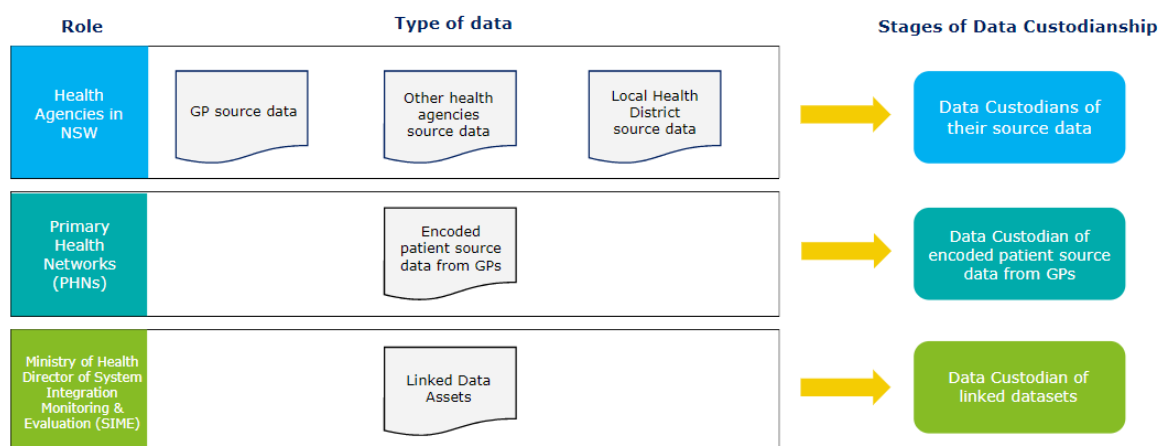
Lumos has full ethics approval from the NSW Population and Health Services Ethics Committee based at the Cancer Institute NSW and operates under a strong governance structure in partnership between CESPHN and NSW Ministry of Health. The ethics approval reference is detailed in the Lumos GP Consent form. A rigorous set of protocols is adhered to, to ensure data linkage is conducted in a secure, privacy-preserving manner.

In addition to the technical and ethical mechanisms to preserve privacy, Lumos operates within a strict data governance framework (DGF) which complies with the following legislation, and a summary of this DGF is presented in the GP Information Pack:

1. Crimes Act 1900 (Cth)
2. Government Information (Public Access) Act 2009
3. Health Administration Act 1982 (NSW)
4. Health Records and Information Privacy Act 2002 (NSW)
5. Higher Education Standards Framework (Threshold Standards) 2015 (Cth)
6. Higher Education Support Act 2003 (Cth)
7. Mental Health Act 2007 (NSW)
8. Privacy Act 1988 (Cth)
9. Privacy and Personal Information Protection Act 1998 (NSW)
10. Public Health Act 2010 (NSW)
11. State Records Act 1998 (NSW)

## Data Governance Custodianship

Throughout the process, the data custodians will shift through various stages of custodianship as the data is extracted and moved from one location to the next



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

All data collected through Lumos will be used and disclosed in strict accordance with the:

- Health Records Information Privacy Act 2002
- Australian Privacy Act 1988
- related legislation
- conditions of ethical approval.

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

### ***How will the Lumos data be used?***

The use of the data is strictly confined to the scope of the ethics approval and subject to the strong governance mechanisms in place.

For more information, contact: [lumos@health.nsw.gov.au](mailto:lumos@health.nsw.gov.au).

### ***How will patients know their de-identified data is being shared?***

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

***Will my practice identity/patient be shared?***

Identity of a practice will never be revealed to any other practice or government agency beyond the NSW Ministry of Health and CESPHN.

***How do I participate in the Lumos program?***

1. A visit can be arranged with your CESPHN Digital Health or Practice Support Officer.
2. Your practice will need to complete the consent form (attached), signed by all your current practitioners. The practice will not be eligible to participate otherwise.

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

For further clarification or support, please contact your dedicated CESPHN Digital Health or Practice Support Officer allocated to your practice. Alternatively email us at [digitalhealth@cesphn.com.au](mailto:digitalhealth@cesphn.com.au) or [practice.support@cesphn.com.au](mailto:practice.support@cesphn.com.au).

Additional information or questions can also be forwarded to: [lumos@health.nsw.gov.au](mailto:lumos@health.nsw.gov.au).