

Lumos Technical Information Summary

Appendix to Lumos GP Information Pack

Version 3.1 - March 2021



Lumos

Introduction

This document aims to answer the following questions for General Practices that are participating or considering participating in Lumos:

1. What are the privacy and security controls in place for Lumos?
2. What data is extracted from my general practice and why?
3. Under what ethics approval does Lumos operate?
4. What data governance controls are in place?
5. What other data sets is my data linked to?
6. Who can I contact for further information?

Privacy and security controls in the Lumos program

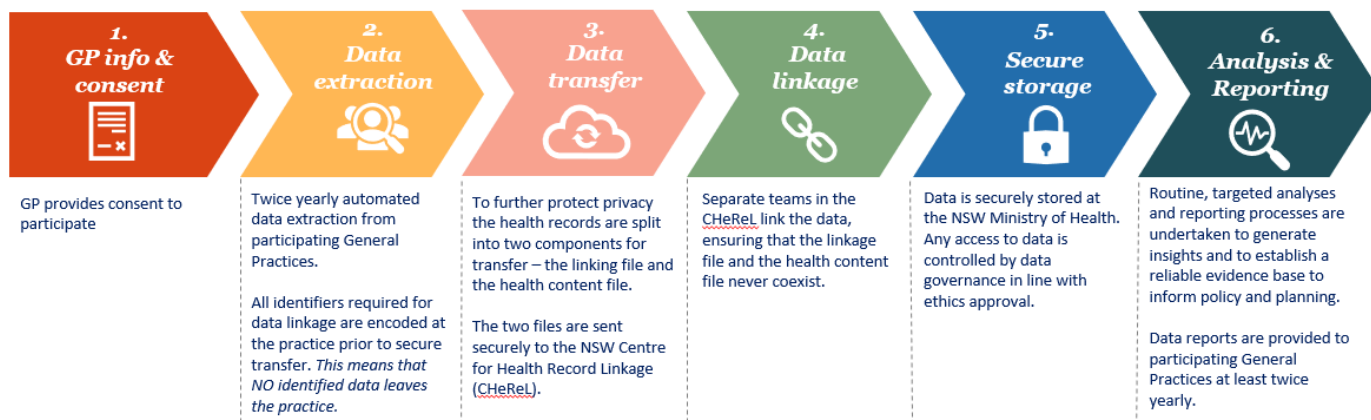
Privacy and security measures are embedded in the Lumos program, and stringent controls have been implemented to minimize privacy risks for patients and General Practices. These are explained below:

Independent Privacy Impact Assessment (PIA)

In 2020, an independent PIA was conducted by former NSW Deputy Privacy Commissioner, Anna Johnston, Principal at Salinger Privacy. The PIA investigated the privacy and security measures in the Lumos program, and the potential impact on participating patients and practices. The PIA reported: "In our view, the Lumos Program has been well designed to protect patient privacy to a very high degree and does not give rise to any likely negative impacts on individuals during the data extraction, data linkage or data analysis stages." (8 September 2020).

Privacy Preserving Record Linkage (PPRL)

The Lumos program uses technology which has been developed by Curtin University to protect patient privacy during record linkage. The data linkage is conducted in partnership with the NSW Centre for Health Record Linkage (CHeReL). Personal details that identify individual patients, such as names, addresses and dates of birth are encoded at the general practice before any data is transferred from the system, therefore minimizing the risk of identifying an individual person in the Lumos data asset. Further information on the full linkage process is outlined below.



Please refer to page 5 for further information on this process.

General Practice data extracted

In addition to the encoded identifiers required for linkage (the linking file), the following health content data is extracted for Lumos in line with ethical approval:

General Practice Variable	Ethical Justification
Unique record ID	To merge linked records
Clinical information system of source data	To improve interpretation of data and understand variation attributable to source system.
Practice ID	To identify the practice the patient attended, and so that practice specific analyses can be produced and reported.
Active patient flag	To investigate patient activity in relation to other characteristics and outcomes. Also to validate other information in this dataset.
Patient status	To investigate patient activity status in relation to other characteristics and outcomes.
Age in years at date of extract	To analyse and adjust for demographic characteristics.
Sex	To analyse and adjust for demographic characteristics.
Aboriginality	To adjust for this demographic characteristic.
Ethnicity	To analyse and adjust for demographic characteristics.
Postcode of residence	To allocate area based socio-economic and remoteness categories.
Department of Veteran Affairs status	To analyse and adjust for demographic characteristics.
Marital Status	To analyse and adjust for demographic characteristics.
Encounter count	For analysis of the number of GP encounters in relation to other health factors, service utilisation and outcomes. Also to validate other information in this dataset.
Date of first encounter	To provide an index date for duration of attendance at the practice as a basis for chronological analyses.
Encounter dates	For chronological analyses of GP encounters in relation to other health factors, service utilisation and outcomes.
Provider type (GP, nurse, etc.)	For analyses of the characteristics of GP encounters.
MBS Item Number	For analyses of the characteristics of GP encounters.
MBS Item date	For chronological analyses of the characteristics of GP encounters in relation other health factors, service utilisation and outcomes.
Chronic disease flags and dates	For analyses of chronic health conditions.
Disease flags and dates for COVID-19 related encounters and diagnoses	For analyses of the impact of COVID-19 on health Service Delivery
Chronic disease diagnosis date	For chronological analyses of chronic health conditions and duration in relation to other health factors, service utilisation and outcomes.
Medications prescribed during the data collection period	For analysis of pharmaceutical treatments and their duration in relation to other health factors, service utilisation and outcomes.
Current medication category flags	To analyse patterns of use of flagged medication categories of interest.
Current medication category commencement dates	To chronologically analyse flagged medication categories and adjust for duration of use in relation to other health factors, service utilisation and outcomes.
Last current medication category dates	To chronologically analyse flagged medication categories and adjust for duration of use in relation to other health factors, service utilisation and outcomes.
Lifestyle health risk factors	For analyses of risk factors in relation to other health factors, service utilisation and outcomes.
Lifestyle risk factor date	For chronological analyses of risk factors
Physical parameters	For analyses of physical parameters in relation to other health factors, service utilisation and outcomes.
Physical parameter date	For chronological analyses of risk factors
Biomedical measurements	For analyses of biomedical measurements in relation to other health factors, service utilisation and outcomes.
Biomedical measurement date	For chronological analyses of risk factors
Health screening	For analyses of health screening in relation to other health factors, service utilisation and outcomes.
Health screen date	For chronological analyses of risk factors
Immunisation	For analyses of immunisations in relation to other health factors, service utilisation and outcomes.
Immunisation date	For chronological analyses of immunisations in relation to other health factors, service utilisation and outcomes
My Health Record flag	For analyses to evaluate the impact of My Health Record (MyHR) in relation to other health factors, service utilisation and outcomes.
Dates of shared health summary uploads	For chronological analyses of MyHR use in relation to other health factors, service utilisation and outcomes.

Lumos Ethical approval

In addition to the technical mechanisms to preserve privacy, Lumos operates under ethical approval which further reinforces adherence to privacy standards.

This project has been approved by NSW Population and Health Services Research Ethics Committee. Project number 2019/ETHoo660/2019.48. If you have concerns about the conduct of this project, you can contact the ethics secretariat at: Ethics@cancerinstitute.org.au.

Program Governance

The Lumos program operates within stringent governance structures and in collaboration with a wide range of stakeholders. There are three key committees that oversee the governance of Lumos data and program implementation – the Data Governance Committee, Stakeholder Reference Group, and Implementation Reference Group. Across these committees we have representation from Primary Health Networks (PHNs), Local Health Districts (LHDs), Consumer Representatives, the Aboriginal Health and Medical Research Council (AH&MRC), the Centre for Aboriginal Health (CAH), the Royal Australian College of General Practitioners (RACGP), the Australian Medical Association (AMA), General Practitioners and Health Consumers NSW (HCNSW).

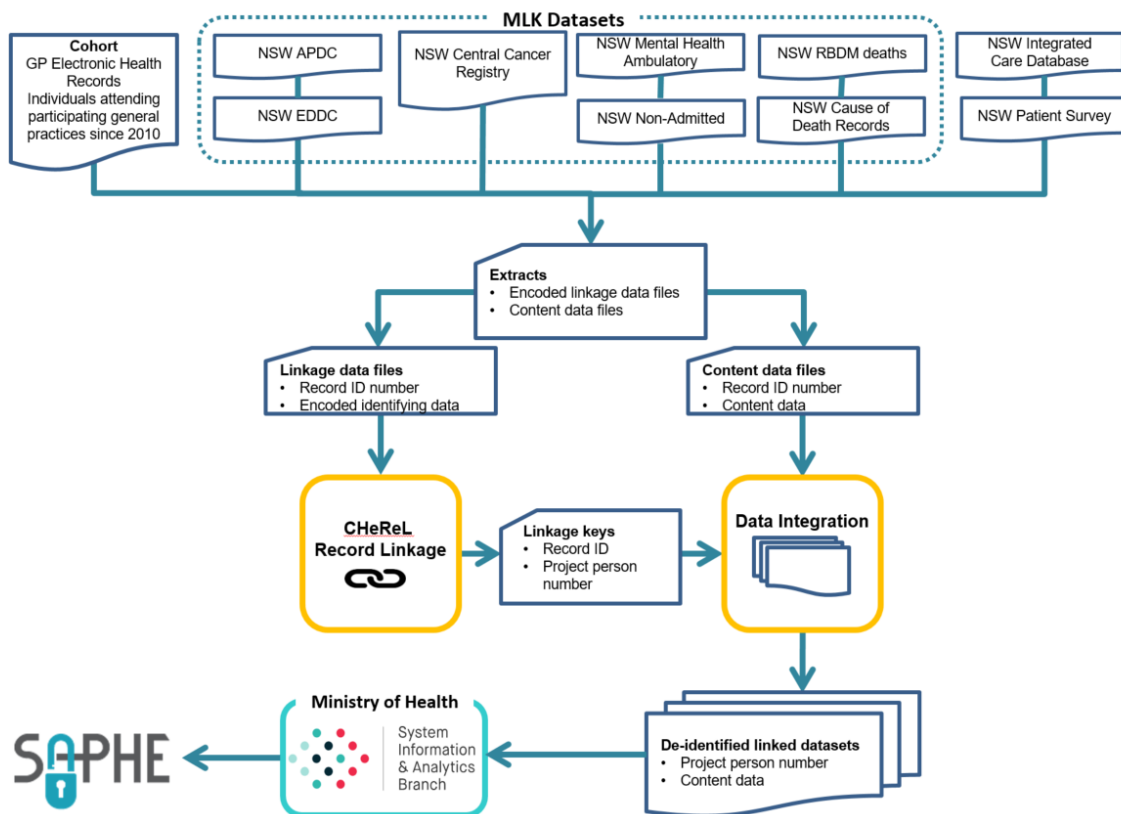
Lumos also operates within a strict data governance framework (DGF) which complies with the following legislation, and a summary of this DGF is presented in the GP Information Pack:

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)

Lumos data flow and PPRL diagram

Lumos links to a variety of other records which are outlined below:

Lumos data flow diagram - October 2019



Further Information

For further information about Lumos, please visit <https://www.health.nsw.gov.au/lumos/Pages/default.aspx> or contact your Primary Health Network.