

Lumos - Information for General Practitioners

Thank you for your interest in participating in Lumos; an initiative of your Primary Health Network and NSW Ministry of Health.

How often do your patients use services in other parts of the health system? What types of patients are most likely to run into health problems that need significant unplanned care? How can you be more effective in planning services and improving your patients' outcomes? Lumos sheds light on the patient journey through the NSW health system by "Linking Up and Mapping Of Systems" across NSW. This can provide you with new insights that will benefit your services.

Lumos is an ethically approved program that securely links encoded data from general practices to other health data in NSW, including hospital, emergency department, mortality, and others. This is done under strict data governance processes and in partnership between Primary Health Networks (PHNs) and the NSW Ministry of Health.

Lumos has arisen from a four year pilot project which linked the GP data of approximately 1 million patients across over 100 NSW practices. It has shown that we can securely extract patient information from GPs, link it with other data collections and generate new insights while ensuring patient confidentiality.

In return for your consent to allow de-identified patient details and health information to be extracted, Lumos provides you with unique and valuable information that you can use to plan and deliver your health care services. We have worked closely with GPs to develop information and tools that are relevant. Lumos' aims include:

- Generating information and insights around the patient journey across healthcare services.
- Providing GPs with meaningful information about their patients that can help to improve care.
- Supporting data driven quality improvement in general practice.
- Providing an evidence base to support areas of future investment in primary care.
- Supporting greater collaboration in health to ensure the right care in the right place at the right time.

Your practice's participation in Lumos is entirely voluntary. No financial outlay will be incurred for your participation and your practice can decide to discontinue at any time.

What do I need to do to participate?

1. Complete the consent form
2. Review the technical requirements (**details and assistance available from your PHN**)
3. Provide your feedback to **help us meet your needs now and into the future.**

Only de-identified data leaves the general practice. We adhere to a rigorous set of protocols to ensure data linkage is conducted in a secure, privacy preserving manner.

Two files are extracted from your clinical software:

File 1. Linking file: a computer encoded patient ID, derived from your patient's personal particulars, which can be used to link the NSW Health data sets with your patient records – this allows record linkage without divulging your patients' identity to ensure the privacy of their health information is protected.

File 2. Health and service related variables: non-identifying patient health-related data including – dates of GP encounters, demographic details, provider type, chronic disease flags and diagnosis dates, dates with each of: generic names of medications, lifestyle risk factors, biomedical measurements, health screens, immunisations, MBS Item Numbers and also My Health Record flags and Shared Health Summary upload dates.

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). These two files will always be kept separate to ensure maximum privacy protection.

Frequently asked questions

How is the data extracted?

Your practice will be asked to allow the installation of updates, free of charge, to existing software in order to extract and transfer the data. We have worked hard to minimise the impact on the operation of your practice so that it will not interfere with the usual running of the software or cause any slowing of your systems.

What reports will I receive?

We provide you with aggregated reports about the patients at your practice and the range of health services they use. You will be able to use these reports to see where there are opportunities to add value to the care you deliver. The identity of your practice will never be revealed to any other practice or government agency beyond the NSW Ministry of Health and your local Primary Health Network and you will not be able to see the identity of any of the other practices.

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, the Privacy Act (national), related legislation and the 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.

Will I be able to directly follow up patients from these reports?

Due to the de-identified nature of the data it is not possible to identify any individual patients or providers from the reports. The reports will give you a unique overview of your patients' journey across the health system in NSW. We will also use the data to develop evidence based resources to assist clinicians, such as tools that will help you identify which patients may be at greatest risk of poor outcomes.

Does my medical indemnity cover me to participate in Lumos?

Any questions related to medical indemnity should be directed to your indemnity provider. Lumos uses only de-identified data and has ethics approval. Individual patient consent is not required.

Who is the custodian of the general practice data?

For the purposes of Lumos, you are asked to authorise a named data custodian in your Primary Health Network to be signatory for participation in Lumos. The governance of the resulting linked data set is strictly managed and involves multiple stakeholders that must adhere to the agreed data governance framework.

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

What about patient consent?

The Lumos program has been given permission to operate without individual patient consent as we do not extract named data 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.

Hasn't something like this already been done?

There have been primary care data linkages and data collections in the past, but not to the scale of Lumos. The Lumos pilot to date has linked data of approximately 1 million patients across 100 NSW general practices.

How is Lumos related to MY Health Record?

MY Health Record is a national online summary of key health information which is identified. Lumos is a linked data program that provides a de-identified view of patient journeys across the health system in NSW (including private hospitals).

How can I get more involved?

We have GP representation in the program governance structures and always welcome GP input to the project – if you'd like to know more, email lumos@health.nsw.gov.au

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

Your feedback helps us continually improve our reports. For any additional information or questions please email lumos@health.nsw.gov.au

This project has been approved by NSW Population and Health Services Ethics Committee. Project number 2019/ETH00660/2019.48. If you have concerns about the conduct of this project, you can contact the ethics secretariat at: ethics@cancerinstitute.org.au

Version 2 December 2019



Lumos Consent form

PRACTICE DETAILS			
Practice Name			
Address			
		Post Code:	
NOMINATED PRIMARY CONTACT PERSON			
Full Name			
Position			
Contact Number			
E-mail			

I have read the information provided about this project and have been able to resolve any questions or requests for further information.

I authorise:

John Baillie to:

- act as data custodian for General Practice Patient Electronic Health Record data used in the Lumos program.
- access the above premises and its technology infrastructure to update software for this project.

I confirm agreement of all current general practitioners at this practice (Page(s) attached for individual practitioners to sign if required)

On behalf of the general practice	On behalf of HNECCPHN
_____	_____
Name GP Principal/Partner/Owner	John Baillie
_____	_____
Signature (required)	Signature (required)
_____	_____
Date	Date

Confirmation that technical requirements are met ([as per information pack](#))

Lumos Consent form - additional signatures

Optional if practice requires

For most practices, the data custodian is the owner or principal GP. However some practices will have other arrangements with multiple data custodians.

This page is provided to include additional data custodian sign-offs from the practice's general practitioners if required.

This is **optional** and is decided by the practice based on their individual structure and preferences.

Practice Name: _____

	Name of General Practitioner	Signature	Date
1			
2			
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10			

Please print out more copies of this page if needed to include all practitioners at this general practice.