# Lumos - Information for General Practitioners

Thank you for your interest in participating in Lumos, an initiative of your Primary Health Network (Healthy North Coast) and NSW Ministry of Health.

## What is Lumos?

**Lumos is an ethically approved program that securely links de-identified data from general practices to other health data in NSW, including hospital, emergency department, mortality, and others, to shine a light on the patient journey in NSW.** This is done under strict data governance processes and in partnership between Primary Health Networks (PHNs) and the NSW Ministry of Health. Currently nearly 700 General Practices in NSW are participating in Lumos which represents over 5 million patients, and this continues to grow. For further information about Lumos please visit www.health.nsw.gov.au/lumos.

## Participation benefits

In return for your consent to allow de-identified patient demographics and health information to be extracted, Lumos provides you with a custom report after each linkage, anticipated to be twice per annum. **The report includes new insights about your patients and the NSW Health services they have accessed**. This unique and valuable information can be used to inform your practice operations.

## Program aims

We have worked closely with GPs to develop relevant information including the following:

- 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 integration in health, including through monitoring and evaluating collaborative programs, to ensure the right care in the right place at the right time.

## How to participate

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

**If you would like to participate:**

1. Complete the consent form on page 3 and return to your PHN.
2. Review the technical requirements (further details and assistance is available from your PHN).
3. Provide your feedback to us via your PHN. We welcome feedback from all participating General Practices and use it to continue to meet your needs now and into the future.

## Protecting patient privacy

**Privacy and security measures are embedded throughout the Lumos program with appropriate controls to minimize risk to patient privacy**. Every precaution has been taken to de-identify data before it leaves practices through Privacy Preserving Record Linkage (PPRL), developed by Curtin University. This means that no patient identifiers leave the practice. During extraction, two files are extracted from your clinical software:

**File 1: Linking file -** computer encoded patient information, 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 sharing 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, MBS Item Numbers and dates,
- Chronic disease flags and diagnosis dates, diagnoses and dates,
- Generic names of medications and prescription dates, immunisations and dates,
- Lifestyle risk factors and dates, biomedical measurements and dates, health screens and dates,
- My Health Record flags and Shared Health Summary upload dates
- Participation in collaborative healthcare programs.

A key component of the linkage protocol is the use of de-identified records along with the "separation principle". This means that the 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 that 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 nor 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 kept confidential?

All data collected through Lumos will be used and disclosed in strict accordance relevant 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.

### What about patient consent?

The Lumos program is ethically approved to operate without individual patient consent as we do not extract named data. This is in accordance with state and federal privacy principles and law.

### 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 provide a unique overview of your patients' journey across the health system in NSW and can support the development of evidence-based resources to assist clinicians.

### Who can access Lumos data?

As well as practice reports provided to participating practices and PHNs, Lumos data can be accessed through the Secure Analytics Primary Health Environment (SAPHE) by limited users. The SAPHE is a custom-build platform that stores and facilitates analysis of the Lumos data asset for authorised users across PHNs, LHDs, the Ministry of Health and other relevant organisations. Access to the SAPHE is closely regulated and overseen by the Lumos Data Governance Committee which has membership from RACGP, PHNs, AH&MRC, LHDs and consumer representatives. Users of the SAPHE can only view practice identifiers in special circumstances, and patients are not able to be identified.

### How will Lumos data be used?

Lumos data is confined to the scope of ethics approval, which is for the planning, management, funding and evaluation of health services. Data may be used by practices to inform local quality improvement activities, or by PHNs to guide region-wide improvements. Additionally, Lumos data is used at a state-wide level to inform value-based healthcare improvements such as through Collaborative Commissioning.

### Does my medical indemnity cover me to participate in Lumos?

Any questions related to medical indemnity should be directed to your indemnity provider.

### 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. This assignment of 'data custodianship' to the PHN is to streamline the approval process for routine updates to the ethical approval under which the Lumos Program operates. It does not provide PHNs with any additional authority over GP's health data under federal and NSW privacy laws, beyond the specific sign-offs for the Lumos program.

### 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. Lumos links the GP data of approximately 4 million patients across nearly 700 NSW 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. Please contact your PHN.

### I have more questions or feedback

Your feedback helps us continually improve, please contact **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

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# Lumos Consent Form

| Practice Details | | | |
|---|---|---|---|
| **Practice Name** | | | |
| **Address** | | | |
| | | | |
| | | **Post Code** | |
| **Does this practice share a database with any other practice?** | | | Yes / No |
| **Is this practice an Aboriginal Medical Service?** | | | Yes / No |
| **Are the technical requirements met, as per the information pack?** | | | Yes / No |
| **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 Javier Gomez, Associate Director, Planning and Data Analytics to:

1. act as data custodian for General Practice Patient Electronic Health Record data used in the Lumos program, as a mechanism to streamline the processes for routine updates to the ethical approval of the Lumos Program; and
2. 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 Healthy North Coast:

_____ _____

Name GP Principal/Partner/Owner Name of authorised PHN executive team member

_____ _____

Signature (required) Signature (required)

_____ _____

Date Date

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# Optional - Lumos Consent Form Additional Signatures

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: _____

| | General Practitioner Name | Signature | Date |
|---|---|---|---|
| 1 | | | |
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