



Ethics and Privacy Workshop

Patricia Correll

Principal Epidemiologist

**System Integration and Analytics
Branch**

NSW Ministry of Health

22 July 2022

Lumos | www.health.nsw.gov.au/Lumos



Overview

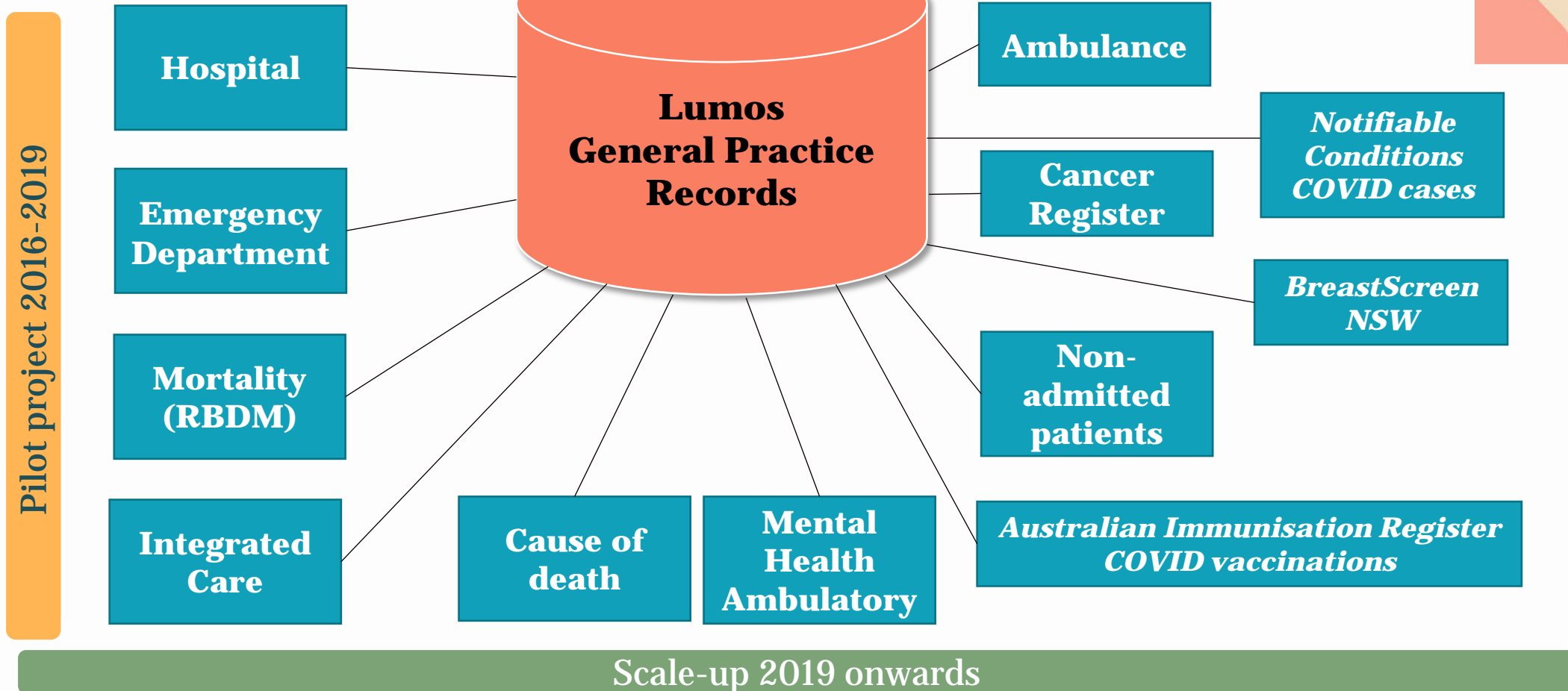
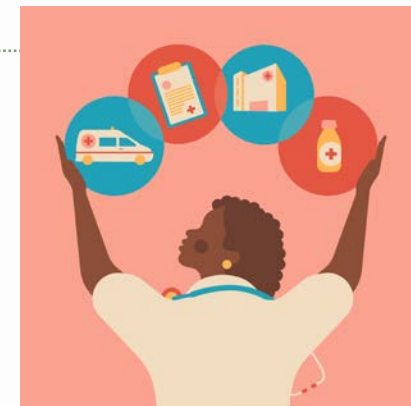
- About Lumos ethics and privacy
- Workshopping future directions
- Discussion and further information



Data in Lumos

Cohort: patients who have visited participating general practices from 2010 onwards

Linkages: twice per year



Elements of ethics and privacy in Lumos

1. Ethics approval

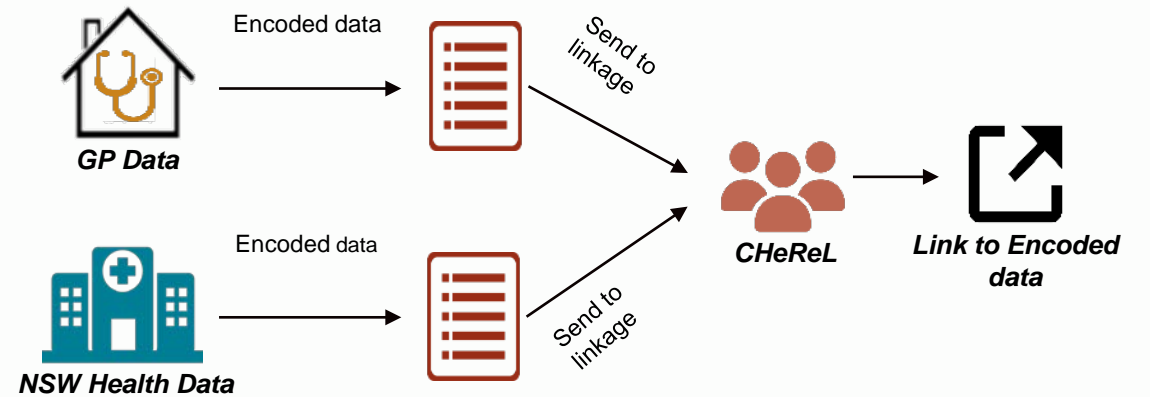
*Waiver of individual consent granted under guidelines for the **Management of Health Services**.*

3. Secure data storage



Data securely stored using cloud solution externally vetted by eHealth.

2. Privacy Preserving Record Linkage



4. Data Access



Access to de-identified data by strict protocol.



Ethics approval

Privacy Law

NSW Health: Health Records Information and Privacy Act 2002

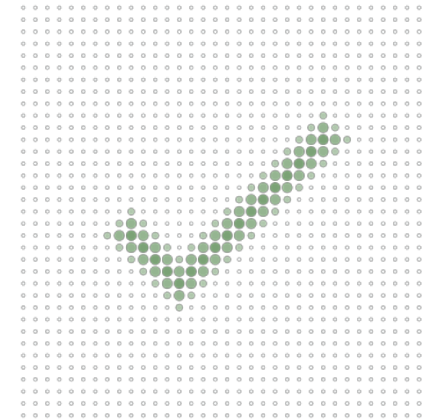
- 15 Health Privacy Principles (HPPs)

General practices: Australian Privacy Act 1988

- 13 Australian Privacy Principles (APPs)

Privacy Principles cover our standards, rights and obligations for holding, use, accessing and correction of personal information.

- NSW Act is specific to Health Information
- Privacy Act, this relates to all personal information.



Ethics approval

Conditions of use and disclosure of personal information

APP 6 and HPPs 10&11 provide conditions for the use or disclosure of personal information (APP 6 and HPPs 10&11).

- Use or disclosure must **only be for the primary purpose for which the data was collected.**
- It must not be used for a secondary purpose (such as GP data linkage) without the **person's consent**
 - *unless* it meets criteria for +an exemption
 - This is known as **a waiver of consent**

Ethics committee evaluate if the criteria are met

Ethics approval

Exemption or waiver

Privacy Act, must comply with: Guidelines under Section 95A of the Privacy Act 1988

Note: this covers private organisations, i.e. GPs.

<https://www.nhmrc.gov.au/about-us/publications/guidelines-approved-under-section-95a-privacy-act-1988>

HRIP Act, this is the **management of a health service exemption** in HPP 10(1)(d) or 11(1)(d) that must comply with the Statutory Guidelines on the management of health services

Note: This does not cover research.

https://www.ipc.nsw.gov.au/sites/default/files/file_manager/statutory_guidelines_health_issue_management.pdf

Ethics approval

Ethical review

Proposals must be reviewed and approved by an ethics committee who will assess the proposal against criteria and ensure the public interest in the research activities substantially outweighs the public interest in the protection of privacy.

Lumos program reviewed by the NSW Health Population and Health Systems Research Ethics Committee based at the Cancer Institute NSW.

Approval for Lumos October 2019.

Data access

Application pack

Part 1 Application Form

Applicant details

- PHN /NSW Health (collaborators) or other

Purpose of the work

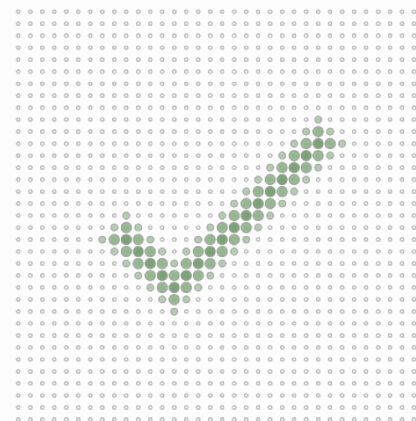
- Alignment to planning, funding management and evaluation of health services

Access region

- Individual PHN(s) or statewide?

Sign-offs

- Includes option for sponsorship of third parties



Data access

Application pack

Part 2 Conditions

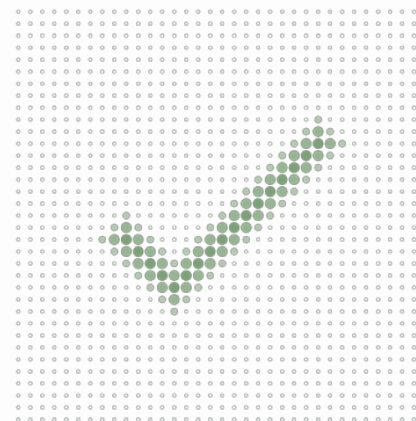
Conditions of data release

Terms of use

Confidentiality undertaking

Part 3 Data governance review

Authorisation of release if approved



Future directions for Lumos privacy and ethics

Discuss in your group (1 per group)

1. Lumos should become more available for research
2. PHNs should be able to see data from other regions
3. GPs should have access to Lumos recOrd level data
 - Do you agree?
 - What are the pros and cons?
 - What is your final position statement?
 - Give your reasons



Group discussion



Working collaboratively



State of the art record linkage to many data sources



Expand reach



Safeguarding patient privacy



Descriptive statistics



State of the art data analytics



Automated processes



Cloud based data integration platform



Following patient journeys



Better population health