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**Publicly Available Health Data:
What it is, where it is, and how to use it**

Wednesday 1st May 2024, 3:00-4:00pm

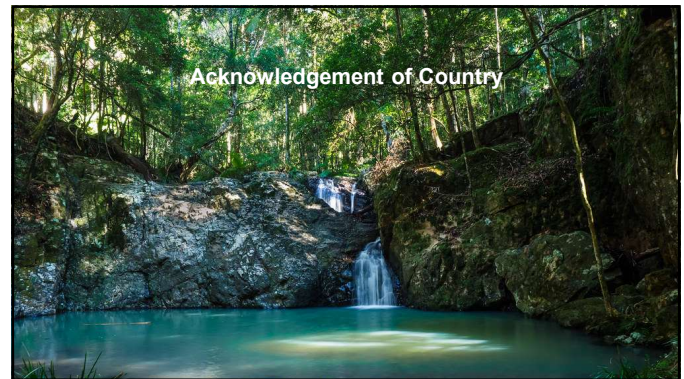
Seminar presented by:



Daniel Barry, Data Analyst, Northern NSW LHD



Dr Alex Stephens, Director of Research,
Northern NSW LHD



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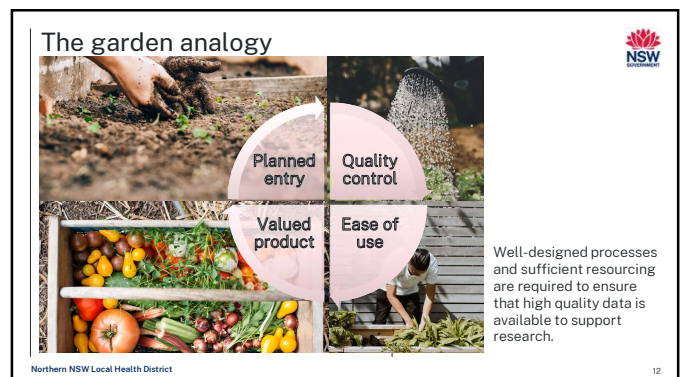
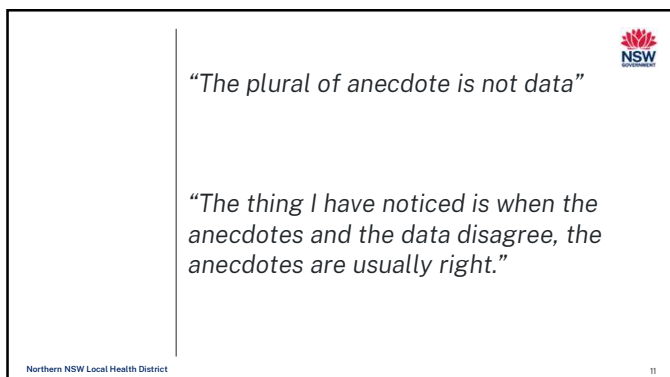
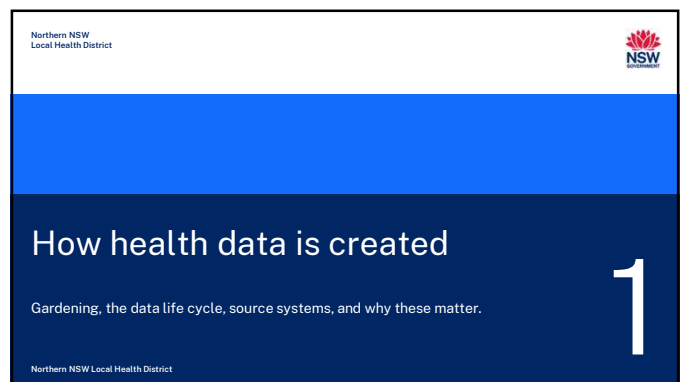
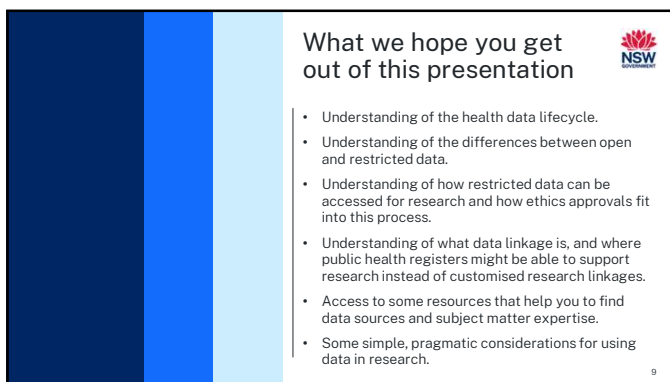
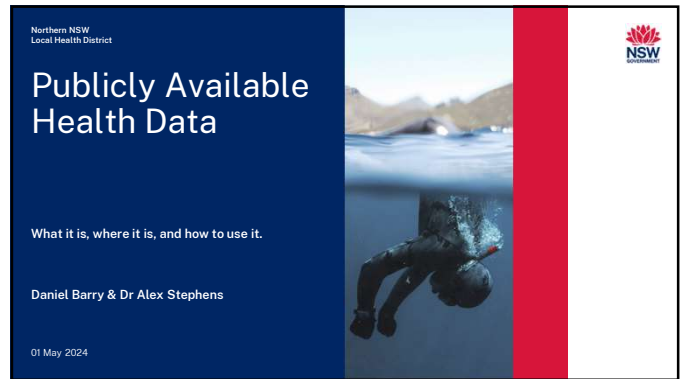
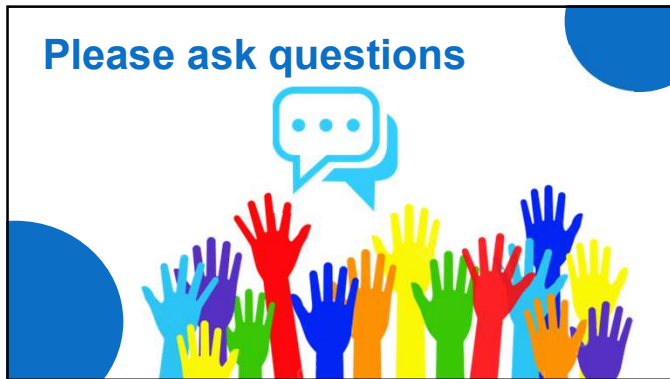
Housekeeping



RECORDING



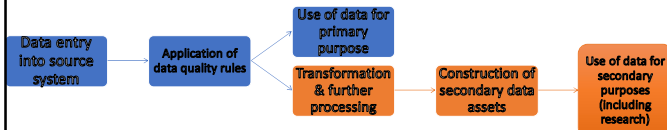
Keep your microphone on mute during the session



The clinical data lifecycle

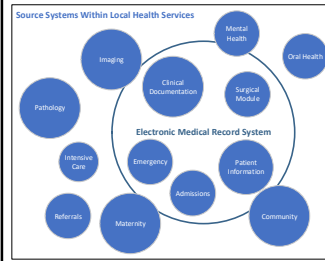


- Usually, some elements of a dataset used for health research will originate as clinical data.
- The system used to capture the data supports clinical management (primary use).
- Research, reporting and other uses of the data (secondary use) may or may not be considered in system design.
- Additional processing and restructuring of the data is generally needed for research.



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Source systems complexity



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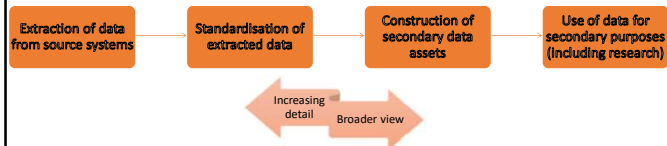
- Generally – one central eMR system for a facility/area, with a mix of uses supported by that system.
- Other clinical streams may be purchased/licensed under the eMR, or standalone products used for these purposes.
- Standalone products may have limited or no integration with eMR.
- Different implementation at different organisational levels (generally LHD in NSW)
- Different business rules at different sites.

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Processing clinical data for research

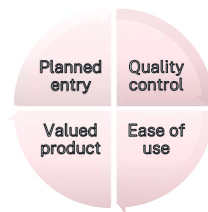


- Usage of health data for research tends to require additional processing due to:
 - Restrictions on which data can be supplied for use in research
 - The need for data from different systems to be supplied in a consistent format for analysis.
- Additional processing allows the incorporation of more data sources, at the cost of detail.



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What's the benefit of knowing this?



Research typically deals with the end product of these processes.

Knowing how the data in a research data asset was entered and processed provides:

- Understanding of the limitations of the data and the questions that data can answer.
- Ability to advocate pragmatically for improved processes.
- Avenues to investigate anomalies in the data.

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Open and restricted data.

It's almost self explanatory, and there's a lot of it out there.

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Open data – what is it?



Open data is data that anyone can use and share.

The only caveat around use of open data is generally citation / attribution / recognition.

It is typically aggregated data, and documentation quality can be mixed.

Australian governments generally have a commitment to supplying open data – e.g. in NSW (per the NSW Information & Privacy Commission):

“Agencies need to open their data in a format that can be readily used. Data will be made available to the people of NSW, while respecting the privacy and confidentiality of those to whom the data relates.”

There are a range of sources of open health data that can be used to support research.

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Sources of open data



- [QLD Health - Open Data Portal](#)
- [NSW Health - Open Data](#) – also (and confusingly),
- [NSW Government - Open Data](#)
- [AIHW – Data Downloads](#) – also (and confusingly),
- [AIHW – Reports & Data](#)
- [ABS – Free Data](#)
- [PBS Statistics](#)
- [MBS Statistics](#)

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How does open data support research?



Open data can be sufficient to support publication of research.

Where it isn't sufficient as a standalone data source to answer a research question, it can still be insightful. Some use cases are:

- Generation of ideas.
- Feasibility assessment.
- Results triangulation.
- Supporting information.
- Location of more detailed data sources & subject matter expertise.

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Restricted data – what is it?



In this context – restricted data is data sources / assets held by health organisations, but where access & use requires approval (especially for research).

Access is not always limited in terms of who can use, but rather by the reason for use.

This data may be made available by application, depending on use case.

- Certain data assets are available for use in research but only for certain types of research.
- Generally specific and stringent requirements around data usage, storage, analysis and publication. The data might be kept as unit record data, but also as aggregated data.
- The rules for use are often unique to the data source.
- Includes public health registers utilising linked data.

Data that is available and possibly easily accessible for clinical management will generally be restricted for research.

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Using and accessing restricted data for research



Rules for accessing and using data from restricted data assets can be difficult to interpret.

There are a few options for guidance:

- Research units.
- Data custodians / subject matter experts.
- Local users / communities of practice.

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Restricted data sources



SAPHaRI – Secure Analytics Platform for Population Health Research & Intelligence.

[Data assets accessible via SAPHaRI](#)

LUMOS – The Linking Up & Mapping Of Systems data asset.

[Lumos access information \(data accessible via secure portal\)](#)

QIDS – Quality Improvement Data System.

[QIDS - Clinical Excellence Commission](#)

Statewide Data Assets & Metadata

[Registry Link](#)

[Metadata via HIRD](#)

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Research Ethics & Data Access

How is access governed and approved, and where the ethics approval process fits.

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Purpose of access and use of personal health information

- Research
- Management of health services
- Training and education



How data are held and available



- Publicly available / open data
- Data held by health organisations (restricted data)
- Data held by other organisations (e.g. ABS, AIHW) – these organisations will likely have their own specific requirements around how to access and use data they hold or are the custodians of.

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Processes for accessing and using data held by health organisations

For data held by health organisations, the processes for accessing and using such data are governed by legislation, policy and other key guiding documentation. Notable ones include the:

- Health Records and Information Privacy Act (HRIPA) 2002 (NSW) and its statutory guidelines
- National Statement on Ethical Conduct in Human Research
- NSW Health Combined Delegations Manual
- NSW Health Privacy Manual
- NSW Health Policy Directive PD2018_001: Disclosure of unit record data by Local Health Districts for research or contractor services
- NSW Health Policy Directive PD2015_037: Data Collections – Disclosure of Unit Record Data for Research or Management of Health Services.

DELEGATIONS MANUAL

COMBINED
ADMINISTRATIVE
FINANCIAL
STAFF

Statutory Guidelines on Research

Health Records and Information Privacy Act 2002 (NSW)

PRIVACY MANUAL FOR HEALTH INFORMATION

NSW Health

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Permissions to access and use and authority to disclose personal health information

What provides the **permission** to use personal health information?

What provides the **authority** to disclose/access personal health information?

What are the **conditions** for using personal health information?

Step through the process through the lens of accessing unit record data?

We are not covering the special case of accessing and using aggregate data, noting that this data may be openly accessible or, if held by organisations, would follow similar processes to unit record data.

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Permissions to access and use personal health information

Following the guidance within the Statutory Guidelines for the HRIPA

- Can de-identified data be used?
- Has consent been obtained?
- Was the data collected for the primary purpose of the research?
- Is the proposed research directly related to the primary purpose for which the health information was collected?
- Is the use or disclosure for the research reasonably required by any applicable law?
- Can you 'research exemption' to use or disclose the health information?



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Ethical review overlay

Permissions to access and use personal health information

Following the guidance within the Statutory Guidelines for the HRIPA

- Can de-identified data be used? (NS 5.1.17)
- Has consent been obtained?
- Was the data collected for the primary purpose of the research?
- Is the proposed research directly related to the primary purpose for which the health information was collected?
- Is the use or disclosure for the research reasonably required by any applicable law?
- Can you 'research exemption' to use or disclose the health information? (NS 2.3)

Low risk ethics

Legislation

High risk ethics

NS – National Statement



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Authority to disclose personal health information

In keeping with our various options for accessing personal health information.

- Can de-identified data be used?
- Has consent been obtained?
- Was the data collected for the primary purpose of the research?
- Is the proposed research directly related to the primary purpose for which the health information was collected?
- Is the use or disclosure for the research reasonably required by any applicable law?
- Can you 'research exemption' to use or disclose the health information?

● Linked to consent ● Legislation
● Person with authority



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Conditions for accessing and using personal health information

Conditions will likely be described in greatest clarity in policy directives / guidelines

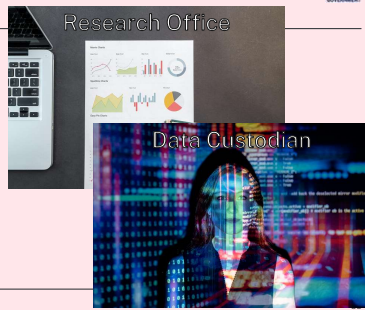
- Undertakings (written and signed statement on how data are accessed and used)
- Specification of data disclosed (in a schedule)
- Data storage, security, confidentiality and access
- List of other relevant conditions and data governance
- Some of these elements may be formalised as part of Data Transfer Agreements and described in Data Management Plans (e.g. may be a HREC requirement).



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Who can you contact for advice

- Research Office – will likely be best placed to provide jurisdiction-specific advice
- Data Custodian – may have greatest knowledge in how to access their data collection



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Data Linkage

What it is, how it's done & when it might be what you need.

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Data linkage – what, who & how



Data linkage is combining data from different sources about the same entity to create a richer dataset.

Usually, for health data linkage, the entity is a person.

Health data linkage is generally managed by a specialised unit in a given jurisdiction:

- NSW – [The Centre for Health Record Linkage \(CHeReL\)](#)
- QLD – [Statistical Analysis & Linkage Unit](#)
- National – [AIHW Data Integration Services Centre \(DISC\)](#)

Data linkage uses matching algorithms which run over identifying information to determine whether records belong to the same entity or not.

To limit privacy risks, personal information (identifying data) is separated from health service interaction data (content data), and then recombined after deidentification.

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Data linkage – when / why



Data linkage is typically used to answer two similar types of questions:

1. To answer a question that spans multiple care settings
 - E.g. – Does an intervention during patient transport decrease length of admitted patient stay?
2. To answer a question that requires data held outside health services
 - E.g. – Does a perinatal intervention affect NAPLAN scores?

There are broadly two types of linked data assets that are created by data linkage units:

1. Statutory linked data collections (In NSW – Public Health Registers).
2. Research linked data assets.

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Summary

Recap and some last thoughts

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Recap

We've covered off:

- Aspects of the creation of health data.
- The difference between open data and restricted data, where you can locate sources of both, and where you can locate more information about both.
- How access to restricted data is governed and how ethical approval fits into this.
- What data linkage is, and how you can find out more about linked data.

One more slide to go.

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A process for using data to support research

The following process is a high-level pragmatic approach to the use of data for research:

- Have a team with clinical, academic, and data analytics expertise – or be able to draw upon these.
- Approach data sources using a hierarchy investigating the simplest, most accessible data sources first.
- Ensure that you have at least investigated the other options before requesting research data via custom linkage.

```

graph LR
    A[Open Data] --> B[QIDS / other aggregated data sources]
    B --> C[Other restricted data (unlinked)]
    C --> D[Statutory linked data collections]
    D --> E[Research linked data assets]
  
```

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NSW

Thank you for your time.

Any questions?

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 **RR-CLaN**
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A dive into qualitative research

Wednesday 5th June 2024, 3:00-4:00pm

Seminar presented by:




A/Prof Dianne Reidlinger, Head of program for the Master of Nutrition and Dietetics program, Bond University



Dr Kate Odgers-Jewell, Conjoint Academic Researcher, Bond University and Northern NSW LHD

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Thank you for attending!

How did we do?



We would appreciate if you could take a couple of minutes to complete the evaluation survey