

THIS WORKSHOP

“... we present and discuss challenges in the use of electronic health data for research, as well as explore the unique opportunities provided by these data.”

1. Overview of health data in NZ
2. First hand experience with studies involving coded hospitalisation data
3. Example of when a condition needs multiple data sources to define
4. Demonstration using data from and intensive care unit

OVERVIEW OF HEALTH DATA AVAILABLE IN NEW ZEALAND

Katrina Poppe PhD COPSCT FESC

Director VIEW Data Ecosystem and Analytical Practice

Heart Foundation Hynds Senior Fellow

University of Auckland, NZ

Vanessa Selak PhD MBChB FNZCPHM

Course Director Quality in Health Care

Senior Lecturer, School of Population Health

University of Auckland, NZ

CONTENT

Health data in New Zealand

Major sources of health data

- Ministry of Health (MoH)
- Regional
- District Health Board (DHB)
- Primary care
- Clinical registries
- Integrated Data Infrastructure (IDI)

Major sources of pitfalls

HEALTH DATA IN NZ

New Zealand well placed to collect and use health data

- 95% of healthcare in NZ is publicly funded
- People have a unique National Health Index (NHI) number

Experience

- Academics, clinicians, statisticians, epidemiologists have been accessing routinely collected health data for decades, eg. CV research last 15 years

Data security and ethics

- Vital to respect the source of the data (= people)

MINISTRY OF HEALTH

Health statistics

- Summary statistics by health condition, eg. number and type of new cancer registrations per year.
- Reports publically available through MoH website

National surveys

- Health, mental health, nutrition, oral health, tobacco use, alcohol & drug use
- To evaluate evidence-informed policies and strategies, allocate resources to services
- Modified unit record data held by Statistics NZ; available on request to public-good researchers, government agencies, NGOs, DHBs

Collections

- Hospitalisation discharges, deaths... list next page
- Unit record data held by the MoH; available on request to researchers and the public

MINISTRY OF HEALTH

Collections

- National Health Index (NHI)
- Primary Health Organisation (PHO) enrolment
- National minimum dataset (NMDS) - hospitalisation discharge codes, patient demographics
- Mortality
- Pharms – dispensing of subsidised medications from community pharmacies
- Lab claims – type of lab test done in community laboratories
- National Non-Admitted Patient Collection
- General Medical Subsidy
- National Maternity Collection
- Medical Warning System
- NZ Cancer Registry; National Immunisation Register; PRIMHD – mental health data

MINISTRY OF HEALTH

Collections

- **National Health Index (NHI)**
- **Primary Health Organisation (PHO) enrolment**
- National minimum dataset (NMDS) - hospitalisation discharge codes, patient demographics
- Mortality
- Pharms – dispensing of subsidised medications from community pharmacies
- Lab claims – type of lab test done in community laboratories
- National Non-Admitted Patient Collection
- General Medical Subsidy
- National Maternity Collection
- Medical Warning System
- NZ Cancer Registry; National Immunisation Register; PRIMHD – mental health data

MINISTRY OF HEALTH

Collections

- National Health Index (NHI)
- Primary Health Organisation (PHO) enrolment
- **National minimum dataset (NMDS) - hospitalisation discharge codes, demographics**
- **Mortality**
- **Pharms – dispensing of subsidised medications from community pharmacies**
- Lab claims – type of lab test done in community laboratories
- National Non-Admitted Patient Collection
- General Medical Subsidy
- National Maternity Collection
- Medical Warning System
- NZ Cancer Registry; National Immunisation Register; PRIMHD – mental health data

REGIONAL

TestSafe

- Repository for clinical information provided by northern region DHBs
- Laboratory results, radiology results, medications
- Available for use since early 2010
- Patients can opt out of having their clinical data added to the repository

DHB, PRIMARY CARE, REGISTRIES

DHB

- Patient Administration Systems
- Coding data for inpatient events and procedures; discharge summaries; clinic letters
- Radiology images and reports

Primary Care

- Current conditions, presenting complaint, current and previous prescriptions, narrative of encounter.

Clinical registries

- Many; may not be completed nationally
- eg. ANZACS-QI – patients admitted with a heart attack (ACS)

EXAMPLE – ANZACS-QI

- Patients admitted with a heart attack (ACS) and had an invasive diagnostic procedure (angiogram).
- Gives clinical information about the event that can't be obtained from other data sources, eg. repeated blood tests, findings of the angiogram.
- Data can be linked to national data on hospitalisations, medications, death. Any data that is identified with an NHI, before or after the heart attack.
- Doesn't represent all patients who have a heart attack.
- Quality improvement is primary aim.

INTEGRATED DATA INFRASTRUCTURE (IDI)

De-identified data from government and non-government agencies

- Education
- Income
- Social services
- Migration
- Justice
- National census
- Health

SOURCES OF PITFALLS

Data provenance

Why is someone's data in the dataset?

Who is and isn't in it?

Who entered or coded the data?

Is data entry standardised or variable?

Idiosyncrasies of data collection

eg. death certificates

What do the variables mean?

Not necessarily what the name suggests

SOURCES OF PITFALLS

Data provenance

Why is someone's

Who entered or co

Idiosyncrasies of da

What do the variables mean:

**Routinely collected
data was not
collected for what
you want to use it for**

dised or variable?

not necessarily what the name suggests

SOURCES OF PITFALLS

Merging different datasets

Unique identifier, duplicate entries

Defining the question

What is the question, really?

Can it be answered with the data that is available?

Need repeated communication between people manipulating the data and people who want information from the data.