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# routine death data linkage in Australia – current status and future directions

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# death data linkage

- current status
    - NSW, WA
    - NCRIS PHeRN
  - improving mortality measures using linked data
    - data quality
    - risk adjustment
    - hospital mortality
- things we can do now

**current status**

# CHeReL Master Linkage Key

- 23.1 million records; ~6.5 million people
- Admitted Patient Data Collection 2000/01 to 2006/07 (7 yrs)
- RBDM fact of death 1994–2007 (14 yrs)
- ABS cause of death 1994–2006 (13 yrs)
- 45 and Up Study (first 100,000)
- + others

# Population Health Research Network (PHeRN)

- 2006 Funding of \$A 20m through the National Collaborative Research Infrastructure Strategy (NCRIS)
- 2007 Investment Plan for PHeRN
- 2008 Funding Agreements
- 2009 Building the infrastructure

## PHeRN focus

- current focus on state and territory datasets
  - including hospital and death data
- commonwealth datasets could be considered in future
- mainly health but also human services data

# PHeRN elements

- total budget of \$A 51.4m over three years
  - including \$A 31.4m from states and territories
- Management Council
- Program Office
- six state-based nodes
- Network Linkage Centre

# PHeRN priorities

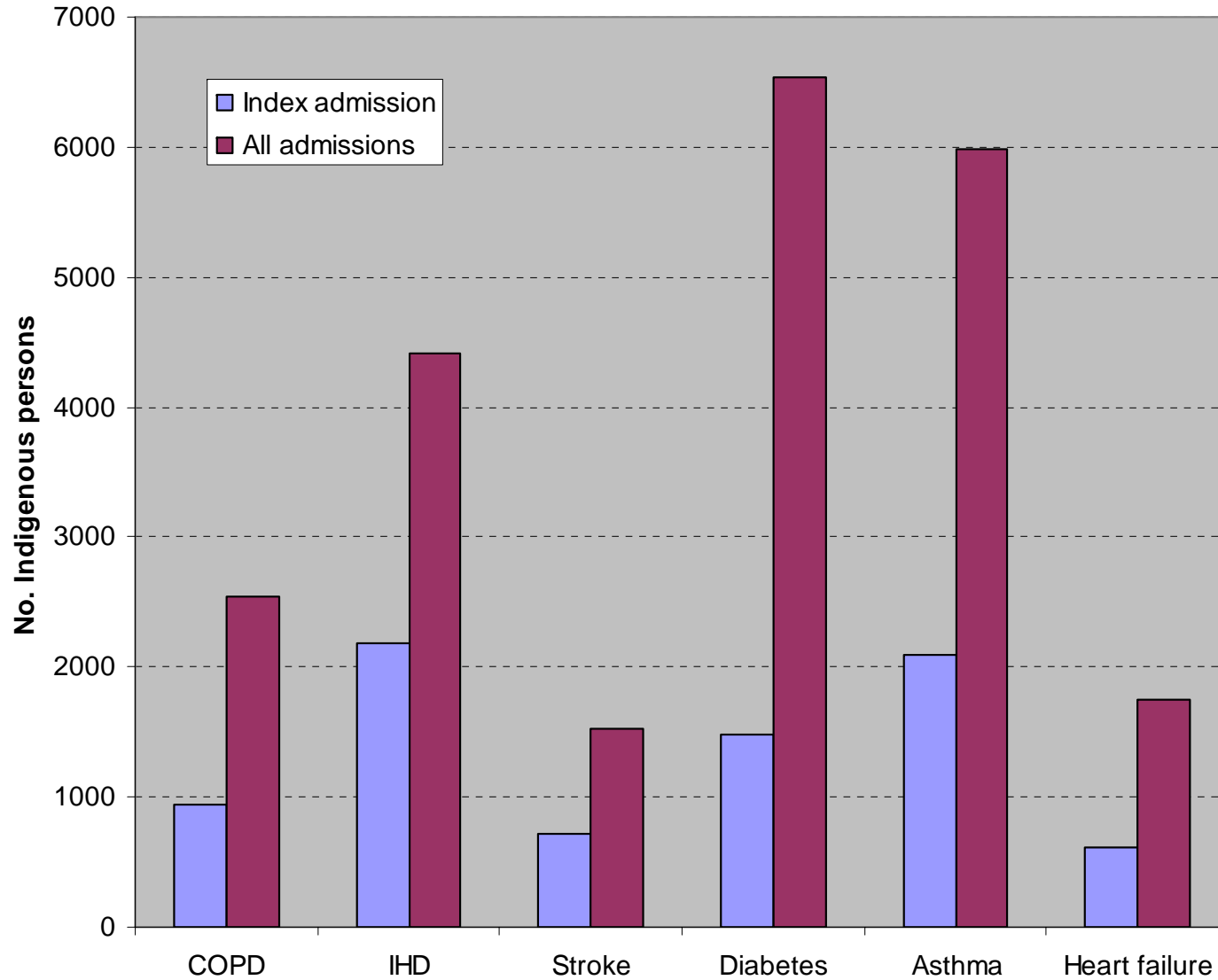
- governance processes
- access policies
- privacy, ethics and consumer engagement
- establishing nodes
- cross-node linkage
- data supply system
- proof of concept collaboration(s)

improving mortality measures using  
linked data

# data quality

- missing data on variables of interest has unknown impact on measurement of variation in outcomes
  - Indigenous status
  - country of birth
- linked data can be used to improve ascertainment

# Indigenous persons hospitalised with selected chronic diseases, NSW 2000-01 to 2005-06



Source: NSW Admitted Patient Data Collection, HOIST, NSW Department of Health

# risk adjustment

- comorbid illnesses may be under-reported for patients with acute conditions
  - diagnoses associated with the cause of the acute condition more likely to be captured than those associated with unrelated chronic illnesses
- index record may contain diagnosis codes for complications of the principal diagnosis, rather than comorbid conditions
- linked data can be used to provide information on comorbidities prior to the index admission (“lookback”)

# risk adjustment

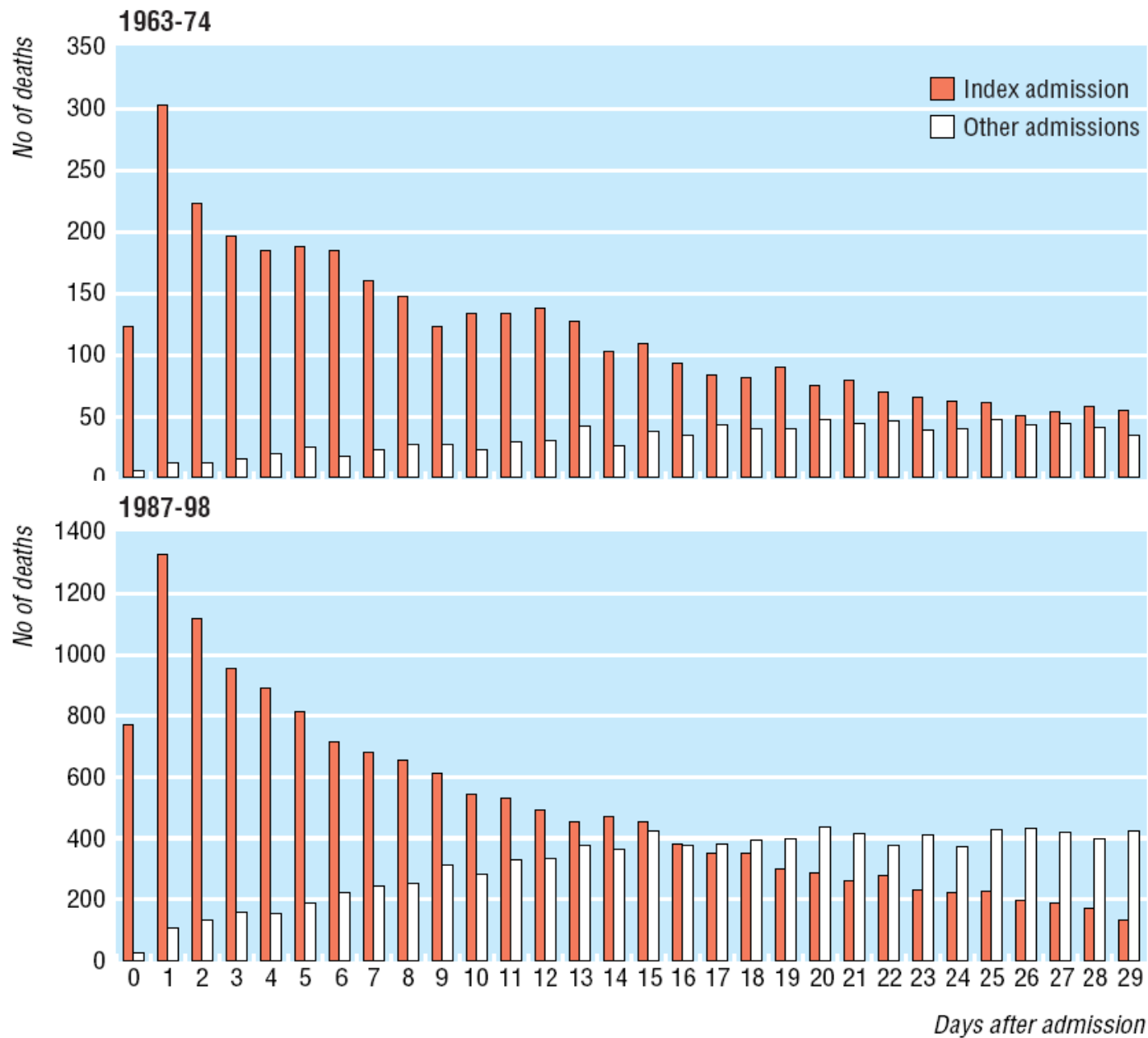
- Multipurpose Australian Comorbidity Scoring System (MACSS, Holman et. al. 2005)
  - developed using WA linked data, 102 comorbid conditions
  - using 12-month lookback
    - performs better than Charlson index for predicting:
      - death (1 year)
      - readmission (28 days)
      - LOS (difference  $\geq 0.5$  days)

# risk adjustment

- Elixhauser index
  - developed using unlinked data from California, 30 comorbid conditions (Elixhauser et al, 1998)
  - using 3-year lookback (Stukenborg et al, 2001):
    - only small improvement in predicting in-hospital mortality compared with index admission alone
    - best performance when information from the index and prior admissions separated into independent indicators

# hospital mortality

- interpretation of in-hospital mortality is complex
- varies with:
  - length of stay
  - level of social support in the local community
  - proportion of people taken home by relatives to die
  - differences in hospital "do not resuscitate" policies

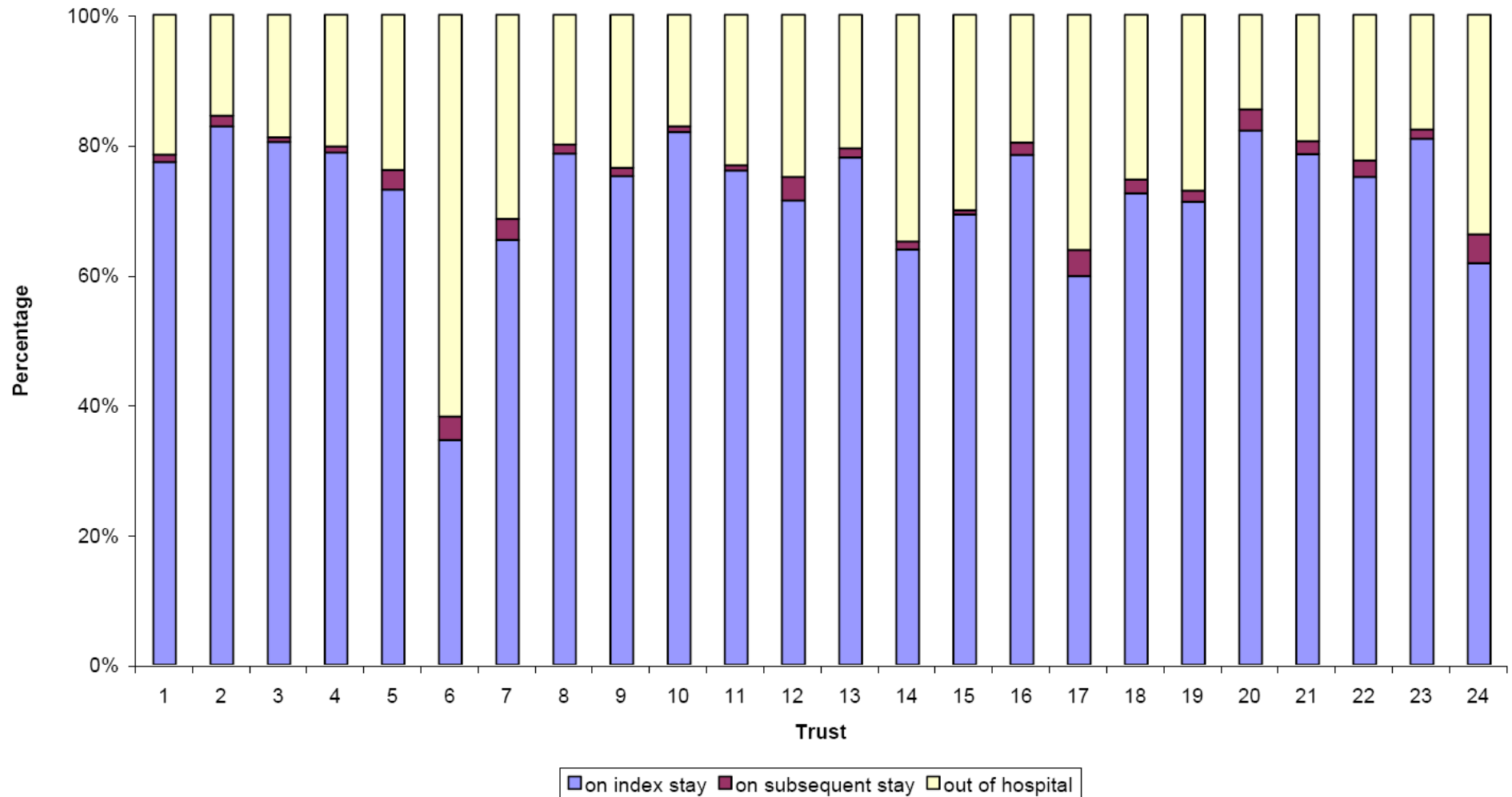


Source: Goldacre MJ et al. In-hospital deaths as fraction of all deaths within 30 days of hospital admission for surgery: analysis of routine statistics. *BMJ* 2002;324:1069–70

# hospital mortality using linked data

- identify all deaths within a specific period of index admission
  - 30, 90 or 365 days
- not dependent on length of stay

**Figure 3: Percentage of deaths within 30 days of a hip fracture admission which occur on index stay, subsequent hospital stay or not recorded on a SMR1 hospital discharge record**



Source: MacLeod M, Kendrick S. *30 day mortality rates after admission with AMI, stroke and hip fracture: a comparison of rates based on hospital discharge records and rates based on linkage with death records*. Edinburgh: NHS Scotland Clinical Indicators Support Team, 2001.

# hospital mortality using linked data

- ? some short-term deaths, particularly in older people, may be unrelated to the hospital stay
- compare with mortality in the general population (calculate SMR)
  - but patient group may not be typical of the general population of the same age in their background risk of dying

# hospital mortality using linked data

- use 90-364 day fatality rate in the specific patient group as an approximation of background mortality
  - express short term mortality as the ratio of early to later fatality rates
  - assumes that the background risk of death for patients surviving 90 days is similar to all patients
    - unlikely to be true for emergency conditions
    - likely to be valid for patients having elective surgery for conditions that are not life-threatening

**things we can do now**

## data quality: things we can do now

- use WA and NSW linked data
- develop and validate algorithms for assigning values to key variables
- e.g. assign Indigenous status:
  - when recorded as Indigenous on any record
  - when recorded as Indigenous on  $\geq 50\%$  of records
  - greater weighting given to specific records (e.g. death records, more recent admissions)

## risk adjustment: things we can do now

- use WA and NSW linked data
- for in-hospital and 30-day mortality, explore:
  - use of different lookback periods
  - using information from the index and prior admissions separately
  - variable reduction procedures to select most useful comorbid conditions for specific applications
  - incorporation of self-report comorbidities and risk factors (smoking, BMI) from 45 and Up Study (10% of NSW population aged 45+ years)

# hospital mortality: things we can do now

- use WA and NSW linked data
- for key conditions, explore:
  - proportion of 30-day deaths that occur in hospital, and elsewhere
  - impact of hospital transfers
  - contribution of out-of-hospital deaths to variations between hospitals
  - methods for adjustment for background mortality
- ? proof-of-concept project for the PHeRN

## references

- Holman CDJ, Preen DB, Baynham NJ et al. A multipurpose comorbidity scoring system performed better than the Charlson index. *J Clin Epidemiol* 2005;58:1006-1014
- Elixhauser A, Steiner C, Harris DR et al. Comorbidity measures for use with administrative data. *Med Care* 1998;36:8–27
- Stukenborg GJ, Wagner DP, Connors AF. Comparisons of the performance of two comorbidity measures with and without information from prior hospitalizations. *Med Care* 2001;39:727–39
- Goldacre MJ, Griffith M, Gill L et al. In-hospital deaths as fraction of all deaths within 30 days of hospital admission for surgery: analysis of routine statistics. *BMJ* 2002;324:1069–70
- MacLeod M, Kendrick S. *30 day mortality rates after admission with AMI, stroke and hip fracture: a comparison of rates based on hospital discharge records and rates based on linkage with death records*. Edinburgh: NHS Scotland Clinical Indicators Support Team, 2001. Available at: <http://www.indicators.scot.nhs.uk/Archive/Outcome.html>