Australian Stroke Clinical Registry: value of linking clinical registry data with administrative health data

Dr Monique Kilkenny

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What is Data Linkage?

Joining together two or more sets of data to produce a single dataset
Types of Data Linkage

• Administrative data to Registry data

• Trials data to Registry data
Value of linked data for quality of care

- Data already available: cost effective $$$
- Adds extra information to routinely collected data e.g. use of medication
- Validates quality e.g. missing data, clinical coding practices
- Allows longitudinal analysis
  - Long-term mortality related to treatment vs no treatment in a stroke unit
- Supports various study designs
  - Trends over time
  - Cost and economic evaluations
- Research into rare events or small sub-populations e.g. Aboriginal, non-English speaking background
The Promising Use of 'Big Data' for stroke

Before stroke

"BIG DATA"
Administrative Databases
- Mortality
- Hospital contacts
  - Admissions
  - Emergency department presentations
  - Comorbidities (ICD coding)
- Medications
  - Adherence/persistence
  - Type of medication
- Community health service utilisation
  - Family physician contacts
  - Pathology/radiology
- Biometrics

Stroke event

REGISTRIES
- Clinical characteristics
- Provision of evidence-based therapies

After stroke

REGISTRIES
- Quality of life / disability
- Satisfaction with care
- Productivity

Linkage with “BIG DATA” value adds to registry and clinical studies

CLINICAL STUDIES
Comprehensive assessments
- Provision of intervention
- Adverse events
- Cost

CLINICAL STUDIES
Comprehensive assessments
- Cost and Evaluation
- Quality of life / disability
- Adverse events


AuSCR
Australian Stroke Clinical Registry

MONASH University
Researchers should use data linkage as adjuncts to address their outcomes when the databases of interest are of appropriate quality, scope, and coverage.

This minimizes
• data waste
• responder burden
Big data set to increase the efficiency of stroke outcomes research

According to the authors, the latter phenomenon is known as "code sway," and has been estimated in an American study to increase payments for physician "visits" by 2.2% every year. In light of these data, Ng and colleagues emphasize the combination of these factors not only impacts the ability to identify stroke cases, but also affects the ability to adjust outcomes by stroke severity. The fact that patients are discharged from hospital, validate the diagnosis of the index stroke, and enable capture of comorbidities. Additionally, the use of data linkage in prospective studies can minimize the effect of patients lost to follow-up, say the authors. Lastly, they posit that a further area where this technological asset may serve to be useful is in evaluating the translation of research knowledge, or an evidence-based treatment, into routine practice by enabling the observation of trends in treatment outcomes.

Yet, limitations of data linkages exist, while its application poses an array of challenges. The availability and quality of databases for linkage are country-dependent and can be inconsistent, say Ng and his team. These also highlight the issue of public approval and governance, claiming that they are "impediments to linking data in some countries, such as Taiwan and Australia.

For instance, they allude to a study published last year by Cheng and colleagues in the Department of Neurology, Tainan Shin Lung Hospital, Tainan, Taiwan, indicating that researchers in Taiwan are presented from linking clinical registry databases with administrative databases due to the public's concern for privacy. Protocols from human rights organization, and the amount of red tape necessary to get permission to link data.

In accordance, Ng and colleagues agree that in this increasingly digitalized world, patients have increasing rights to control their own digital fingerprint. Yet, they argue, "By understanding the nature, historic context and limitations of individual administration databases, researchers can unlock these large data and use these to enrich comprehensive assessment in clinical studies for outcomes of stroke.

The future

Throughout the past two decades, the authors recognize that only a handful of countries, such as Sweden, Denmark, Finland, Scotland, New Zealand, Canada, and Australia, claim to realise the utility of such "large, high quality, complete, and linked health data". The use of data linkage in the context of stroke-related outcomes remains in its infancy, states the authors, as currently many population-based studies only link with a national death registry to ascertain mortality. Yet, Ng and colleagues argue that after successful examples of data linkage in the research of stroke, "there is a renewed impetus to use this approach around the world." Ultimately, Ng and his team propose: "Many countries that do not currently use linked data in stroke research already possess systems capable of collecting routine health information at local and national levels, especially with the increasing adoption of electronic medical records. Unlocking this wealth of data could help generate new hypotheses in stroke, minimise data waste, and justify future comprehensive research."
Introduction to the Australian Stroke Clinical Registry (AuSCR)
Australian Stroke Clinical Registry

- Established in 2009
- Includes patients admitted with Diagnosis of acute stroke or TIA
- Follows national clinical quality registry standards
  - Governance, policies & data security
- Opt-out approach, with waiver for deaths in hospital
- Data collected on the online, integrated stroke data management system, the Australian Stroke Data Tool (AuSDaT)
- Collection of stroke outcomes 90-180 days post admission
Australian Stroke Data Linkage Program
Ascertain fact and cause of death

National Death Index (Australian Institute of Health and Welfare)
Matching with the National Death Index

- Linkage to death registrations identified 1440 in-hospital deaths in both data sets
- In-hospital death classification in the AuSCR: 98.7% sensitivity; 99.6% specificity

<table>
<thead>
<tr>
<th>In-hospital deaths</th>
<th>National Death Index</th>
<th>Accuracy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>AuSCR</td>
<td>Yes</td>
<td>1440</td>
</tr>
<tr>
<td></td>
<td>19</td>
<td>14697</td>
</tr>
<tr>
<td>Total</td>
<td>1459</td>
<td>14755</td>
</tr>
<tr>
<td></td>
<td>Positive predictive value</td>
<td>96.1%</td>
</tr>
</tbody>
</table>
Better outcomes for hospitalized patients with TIA when in stroke units

Patients with TIA managed in a stroke unit have 43% improved cumulative survival at 180 days

Prescription of antihypertensive medication at discharge influences survival following stroke

Patients discharged with antihypertensives have 23% reduced hazard of cardiovascular death compared to those not discharged with these agents

Weekend discharge after stroke is associated with poor outcomes

Patients discharged during the weekend at **22% greater hazard** of **180-day mortality** compared to patients discharged on a weekday

Ascertaining hospital presentations and comorbidities
Pilot linkage of AuSCR data from one hospital


Readmissions within 180-days influenced by **Charlson Comorbidity Index score, TIA on admission** and **number of ED presentations before the index event**
Stroke123 (NHMRC Partnership grant)

- Cohort design with data linkage to merge patient-level records

<table>
<thead>
<tr>
<th>State</th>
<th>New South Wales</th>
<th>Queensland</th>
<th>Victoria</th>
<th>Western Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technique</td>
<td>Probabilistic</td>
<td>Probabilistic and deterministic</td>
<td>Stepwise deterministic</td>
<td>Probabilistic</td>
</tr>
</tbody>
</table>

- Identifiers in the AuSCR from 2009-2013 were linked with:
  - deaths, emergency department and admissions records
  - from April 2004 to December 2016

- Patient identifiers used for linkage included:
  - name, address, sex, date of birth,
  - admission date, hospital code, Medicare number (Victoria)
Stroke 123 Data Linkage Project

Hospital administrative datasets
(New South Wales, Queensland, Victoria, Western Australia)

Australian Stroke Clinical Registry
(AuSCR)

National Death Index
(Australian Institute of Health and Welfare)

Prior to Stroke/TIA

• Hospital contacts
  o Admissions
  o Emergency presentations
• Comorbidities (from ICD-10 coding)

Stroke/TIA registered in the AuSCR

• In hospital
  • Clinical characteristics
  • Evidence-based therapies
  Patient-reported outcome measures at follow-up
    • Quality of life

After Stroke/TIA

• Mortality
• Hospital contacts
  o Admissions
  o Emergency presentations
• Comorbidities (from ICD-10 coding)

COMPREHENSIVE DATASET ON THE PATIENT JOURNEY

15,482 patients with stroke or transient ischemic attack from 40 hospitals (2009 and 2013)

Matching with hospital administrative datasets

<table>
<thead>
<tr>
<th>% matched to Registry</th>
<th>Total N=16214</th>
<th>New South Wales N=4090</th>
<th>Queensland N=5616</th>
<th>Victoria N=5529</th>
<th>Western Australia N=999</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency</td>
<td>80%</td>
<td>94%</td>
<td>75%</td>
<td>71%</td>
<td>94%</td>
</tr>
<tr>
<td>Admissions</td>
<td>95%</td>
<td>91%</td>
<td>98%</td>
<td>95%</td>
<td>97%</td>
</tr>
<tr>
<td>Either*</td>
<td>98%</td>
<td>97%</td>
<td>99%</td>
<td>96%</td>
<td>99%</td>
</tr>
</tbody>
</table>

*linked to emergency, admissions or both

Hospital administrative datasets
(New South Wales, Queensland, Victoria, Western Australia)

Anxiety/depression after stroke is related to socioeconomic position

Patients in the lowest category of socioeconomic position were 59% more likely to report problems with anxiety/depression.
Factors associated with 90-day readmission

Patients with an admission ≤90 days prior to the index event **85% more likely** to be readmitted within **90 days** of discharge from acute care


Models adjusted for factors shown and socioeconomic position, in-hospital stroke, transfer, treatment in a stroke unit and length of stay
**Antihypertensive prescription after stroke related to age and comorbidities**

Younger patients with fewer comorbidities less likely to be prescribed antihypertensives compared to older patients with comparable comorbidities.

Patients discharged to inpatient rehabilitation after acute stroke less likely to be readmitted.

Disagreement in stroke ICD-10-AM coding

<table>
<thead>
<tr>
<th>Ischaemic stroke based on administrative data ICD-10 (principal diagnosis code only)*</th>
<th>‘Reference standard’ based on AuSCR clinician-assigned ischaemic stroke diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>True positive (TP)</td>
<td>6,693</td>
<td>302</td>
</tr>
<tr>
<td>False positive (FP)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>True negative (TN)</td>
<td>2,578</td>
<td>5,143</td>
</tr>
<tr>
<td>False negative (FN)</td>
<td></td>
<td>7,721</td>
</tr>
<tr>
<td>Total</td>
<td>9,271</td>
<td>5,445</td>
</tr>
</tbody>
</table>

2,578 False negative (FN) records

<table>
<thead>
<tr>
<th>Alternative principal ICD diagnosis code category</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any cerebrovascular disease code (ICD codes: I60-I69)</td>
<td>1,681</td>
<td>65%</td>
</tr>
<tr>
<td>Intracerebral haemorrhage</td>
<td>118</td>
<td>5%</td>
</tr>
<tr>
<td>Subarachnoid haemorrhage</td>
<td>14</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Other traumatic intracranial haemorrhage</td>
<td>22</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Undetermined/unspecified stroke</td>
<td>1,224</td>
<td>47%</td>
</tr>
<tr>
<td>TIA and related syndromes</td>
<td>278</td>
<td>11%</td>
</tr>
<tr>
<td>Symptoms signs and abnormal clinical findings, not elsewhere classified</td>
<td>144</td>
<td>6%</td>
</tr>
<tr>
<td>Hemiplegia</td>
<td>40</td>
<td>2%</td>
</tr>
</tbody>
</table>

Ryan O, Cadilhac DA, Kilkenny MF. 2019 [In draft]
Ascertainment of medication dispensing and doctor visits.
Utilisation of secondary prevention medications after stroke*

9,946 AuSCR first-ever stroke/ TIA registrants discharged April 2010 to June 2014

97% linked to Medications and Doctor Visits

81% dispensed an antihypertensive medication
82% dispensed an antithrombotic medication**
82% dispensed a lipid-lowering medication**

* one-year following discharge
**excludes patients with intracerebral haemorrhage
Discontinuation* of secondary prevention medications after stroke

- **Antihypertensive**
  - 8,911 users
  - 26% discontinued
  - Median time to discontinuation: **198 days**
    - Q1: 125; Q3: 277

- **Antithrombotic**
  - 6,104 users
  - 45% discontinued
  - Median time to discontinuation: **201 days**
    - Q1: 141; Q3: 267

- **Lipid-lowering**
  - 7,267 users
  - 30% discontinued
  - Median time to discontinuation: **191 days**
    - Q1: 106; Q3: 272

*for a period ≥90 days during the year following discharge
Factors associated with discontinuation of antihypertensive medications

- Prescribed by cardiologist
- Discharged on antihypertensive medications
- ≥5 GP visits
- Concession card holder
- Female
- Older age (per year increase)

*Within 12 months following hospital discharge for stroke/TIA. Also adjusted for type of stroke, management in a stroke unit, stroke severity, history of previous stroke/TIA and socioeconomic position.
One-third of stroke patients ditch meds within a year

Only around half are fully adherent, says lead researcher Dr Monique Kilkenny (PhD)

19th September 2019
By Lydia Hales

Up to one-third of patients who have experienced an ischaemic or haemorrhagic stroke, or a TIA, discontinue preventive medications within the first year after the event, according to the largest Australian study of its kind.

In the study, presented at a stroke conference in mid-September, researchers found four out of five patients were dispensed one or more antihypertensive, antithrombotic or lipid-lowering medications post-stroke, but many abandoned the drugs within months.

“Most patients utilise these recommended secondary preventions after stroke but only about half of them fully adhere ... and up to a third discontinue them,” said lead researcher Dr Monique Kilkenny (PhD), a senior research fellow at Monash Health in Melbourne.

Discontinuation was defined as the first 90-day gap without a medication supply.

Patients were more likely to continue with their medications if they were discharged from hospital on them, if they were concession card holders, and if they regularly visited their GP or a specialist, said Dr Kilkenny, who heads the National Stroke Data Linkage Program.
Ascertaining Ambulance presentations
Feasibility AuSCR-Ambulance linkage

N=12,197 AuSCR cases

N=1,900,000 000 cases

N=7,373

Excluded:
- In-hospital strokes
- Transfers from another hospital
- Year 2013 and 2014

AuSCR + Ambulance matched
N=4,616 (80%)

<table>
<thead>
<tr>
<th>AuSCR Clinical Diagnosis</th>
<th>ICH</th>
<th>Ischaemic</th>
<th>TIA</th>
<th>Undetermined</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=4,202</td>
<td>N=519</td>
<td>N=2783</td>
<td>N=730</td>
<td>N=170</td>
</tr>
</tbody>
</table>

Call-taker assessment

- Stroke: 44% ICH, 56% Ischaemic, 66% TIA, 60% Undetermined
- Other diagnosis: 43% ICH, 43% Ischaemic, 33% TIA, 38% Undetermined
- Headache: 3% ICH, <1% Ischaemic, <1% TIA, 2% Undetermined

Paramedic assessment

- Stroke: 62% ICH, 62% Ischaemic, 38% TIA, 54% Undetermined
- Transient ischemic attack: 2% ICH, 7% Ischaemic, 32% TIA, 13% Undetermined
- Subarachnoid haemorrhage: <1% ICH, <1% Ischaemic, 0% TIA, 0% Undetermined
- Other assessment: 35% ICH, 30% Ischaemic, 31% TIA, 33% Undetermined

Urgency of dispatch

- Non-emergency: <1% ICH, 2% Ischaemic, 1% TIA, 1% Undetermined
- Lights and sirens: 81% ICH, 79% Ischaemic, 85% TIA, 82% Undetermined
- Urgent: 13% ICH, 15% Ischaemic, 10% TIA, 11% Undetermined
- Non-urgent: 4% ICH, 5% Ischaemic, 4% TIA, 6% Undetermined
Ascertaining Inpatient rehabilitation admissions
Feasibility AuSCR-AROC linkage

N=44,302 episodes
N=37,650 registrants

National Death Index (2014-2018)

AuSCR + AROC matched on AuSCR Discharge Destination
Inpatient rehabilitation N=10,111 episodes 89%

AuSCR + AROC matched N=8,861 episodes
N=8,073 registrants 95%

Remove episodes
Link direction* N=87
Statistical discharges** N=267

*AuSCR episode was after the AROC episode
**Same month and year in the AROC (kept the first episode)

Discharged
Inpatient Rehab and other transfers

AuSCR Discharge Destination
Inpatient rehabilitation n=5,879 (69%)
Transfers to another acute hospital (13%)
Statistical discharge (7%)
Transitional care services (1%)
90%

Australian Rehabilitation Outcomes Centre (2014-2017)

N=8,949 episodes
N=8,532 registrants

AuSCR + AROC matched
N=8,507 episodes
N=8,073 registrants 95%

AuSCR Discharge Destination
Died (<1%)
Residential care (<1%)
Other (4%)
Usual residence (5%)
10%
Capturing the entire continuum of care
Capture the stroke continuum of care

**Hospital administrative datasets**
- Prior to Stroke/TIA
  - Hospital contacts
    - Admissions
    - Emergency presentations
  - Comorbidities (from ICD-10 coding)

**AuSCR (Australian Stroke Clinical Registry)**
- Stroke/TIA registered in the AuSCR
  - In hospital
    - Clinical characteristics
    - Evidence-based therapies
  - Patient-reported outcome measures at follow-up
    - Quality of life

**National Death Index**
- After Stroke/TIA
  - Mortality
  - Hospital contacts
    - Admissions
    - Emergency presentations
  - Comorbidities (from ICD-10 coding)

**COMPREHENSIVE DATASET ON THE PATIENT JOURNEY**
Towards an integrated national data platform for stroke

National Death Registrations

Hospital administrative data

PBS and MBS data

Aged care data

Ambulance Victoria data

Rehabilitation data

General practice data

National Data Linkage Platform

AuSCR
Australian Stroke Clinical Registry

MONASH University
Tips for planning your data linkage project
Steps: Data Linkage Process

1. Obtain advice from experts in the field: “National Stroke Data Linkage Interest Group”
2. Plan your project
3. Obtain relevant approvals
4. Set up secure data transfer and storage systems
5. Merge, clean the linked data sets and analyse the final linked data set or data sets…..the fun begins…😊 😊
National Stroke Data Linkage Interest Group

- Build capacity… from novice to expert…analyses
- Share expertise and provide advice related to ethics and data custodian
- Collaborate on solving barriers to data acquisition or transfer, linkage processes
- Share knowledge, expertise and know-how
  - data coding
  - preparation of datasets
  - analyses of linked data

Members of group

<table>
<thead>
<tr>
<th>Members of group</th>
</tr>
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<tbody>
<tr>
<td>Monash research/ AuSCR Office staff</td>
</tr>
<tr>
<td>State Data Linkage unit Heads</td>
</tr>
<tr>
<td>Population Health Research Network</td>
</tr>
<tr>
<td>Centre for Data Linkage</td>
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<tr>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>Data linkage research experts</td>
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Co-chairpersons:
Professors Dominique Cadilhac
Professor Vijaya Sundararajan

Co-ordinator: Dr Monique Kilkenny
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AuSCR Consortium partners

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Boehringer Ingelheim
Medtronic

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Other

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Hospital staff
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