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

Dr Monique Kilkenny

Head, National Stroke Data Linkage Program,

Translational Public Health and Evaluation Division

Stroke and Ageing Research, Monash University

monique.kilkenny@monash.edu

@KilkennyMonique

What is Data Linkage?

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

Types of Data Linkage

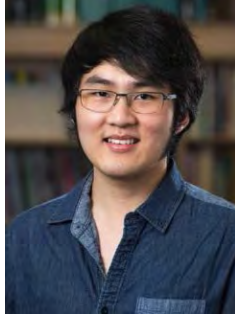
- Administrative data to Registry data

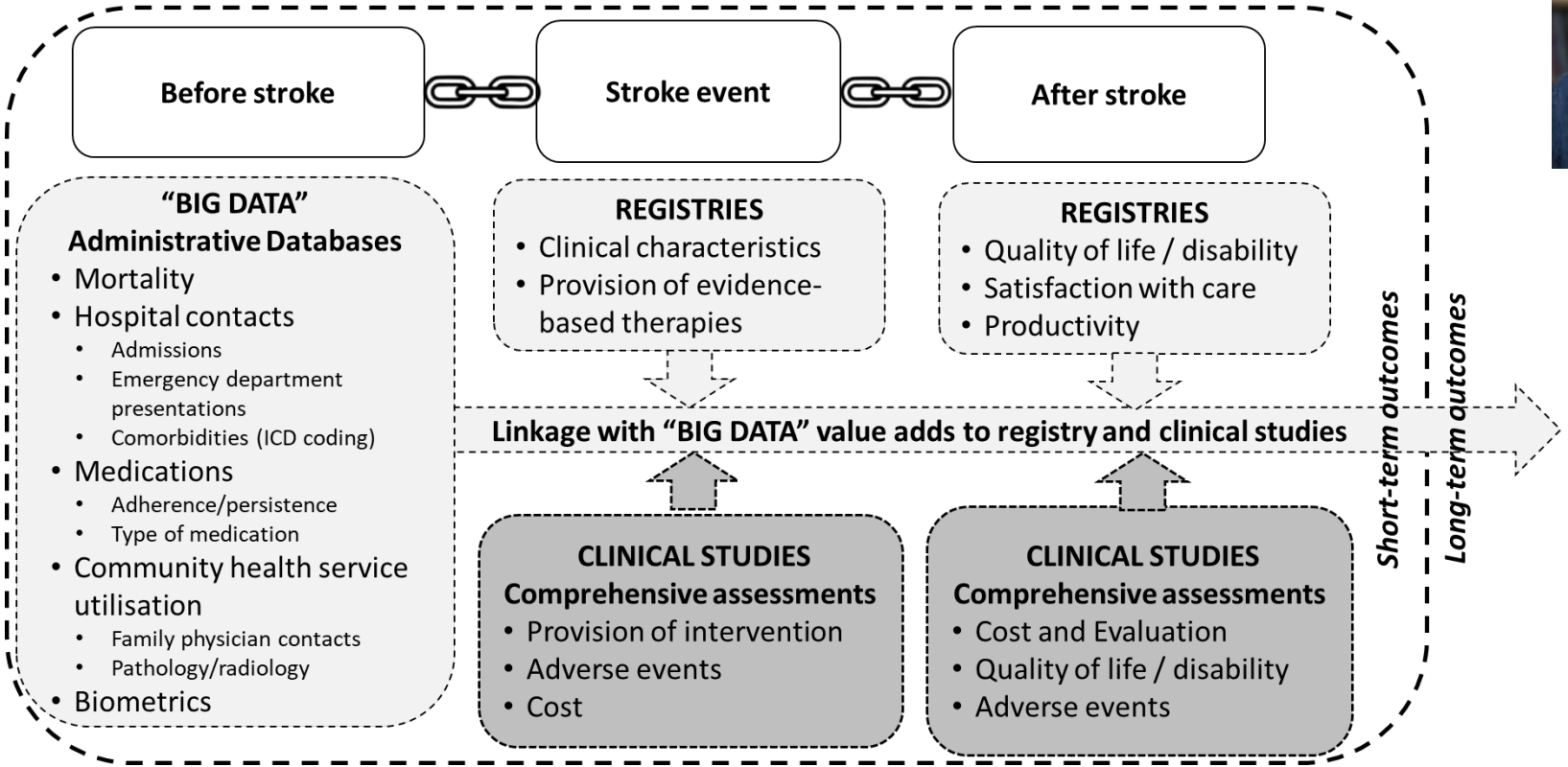
- Trials data to Registry data

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

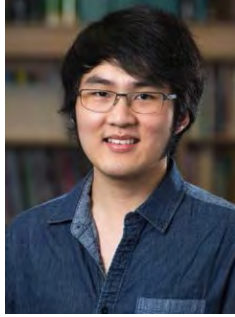
The Promising Use of 'Big Data' for stroke





Ung D, Kim J, Thrift AG, Cadilhac DA, Andrew N, Sundararajan V, Kapral M, Reeves M, Kilkenny MF. Stroke 2019

'Big Data' increases the Efficiency and Comprehensiveness of Stroke Outcomes



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*

Ung D, Kim J, Thrift AG, Cadilhac DA, Andrew N, Sundararajan V, Kapral M, Reeves M, Kilkenny MF. Stroke 2019

Big data set to increase the efficiency of stroke outcomes research

Continued from page 1

reason a patient is hospitalised." According to the authors, the latter phenomenon is termed "code creep", and has been estimated in an American study to increase payments for physician visits by 2.2% every year. In light of the aforementioned factors, Ung *et al* surmise: "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 and compare performance across health centres or hospitals."

The expansion of data linkage

In the context of patient records, the process of data linkage can be defined as the merger of administrative databases with registries or clinical studies. "It can be particularly valuable in stroke research," say the authors, "as, in developing countries at least, most people attend healthcare-related services before, during and after their stroke event."

Ung and colleagues further put forward that as excessive resources are required to track outcomes after discharge, linkages with administrative data can provide "an adjunct approach to cost-effectively and longitudinally capture longer-term outcomes in both clinical studies and registries".

Referring to the key benefits of data linkage, the authors postulate that cost-effectiveness and efficiency comes out on top. "Not only does it reduce the overall time and financial cost associated with collecting these data, but it also reduces responder burden."

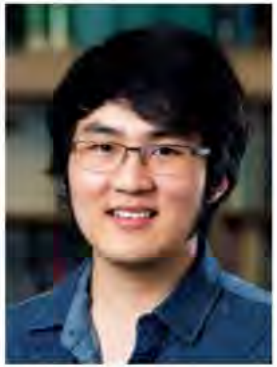
Moreover, alluding to examples of successful linkage between prospective stroke research cohorts and registries, and administrative data, Ung and colleagues acknowledge: "These linkages have provided the opportunity to determine outcomes after patients are discharged from hospital, validate the diagnosis of the index stroke, and enable capture of comorbidities." Additionally, the use of data linkage in prospective studies can minimise 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 overtime.

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 Ung and his team. They 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-Yang Hsieh (Department of Neurology, Tainan Sin Lau Hospital, Tainan, Taiwan) and colleagues, in *Epidemiol Health*, confirming that researchers in Taiwan are prevented from linking clinical registry databases with administrative databases due to the public's concern for privacy, protests from human rights organisation, and the amount of red tape necessary to get permission to link data.

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



David Ung

Monique F Kilkenny

> "Unlocking this wealth of data could help generate new hypotheses in stroke, minimise data waste and justify future comprehensive research."

> "Not only does [data linkage] reduce the overall time and financial cost associated with collecting these data, but it also reduces responder burden."

The future

Throughout the past two decades, the authors recognise that only a handful of countries, such as Sweden, Denmark, Finland, Scotland, New Zealand, Canada, and Australia, claim to realise the utility of such "high-quality, complete, and linked heath data".

The use of data linkage in the context of stroke-related outcomes remains in its infancy, state the authors, as currently many population-based studies only link with a national death registry to ascertain mortality. Yet, Ung *et al* 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, Ung 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 into important and untested outcomes."

Introduction to the Australian Stroke Clinical Registry (AuSCR)

AuSCR
Australian Stroke Clinical Registry

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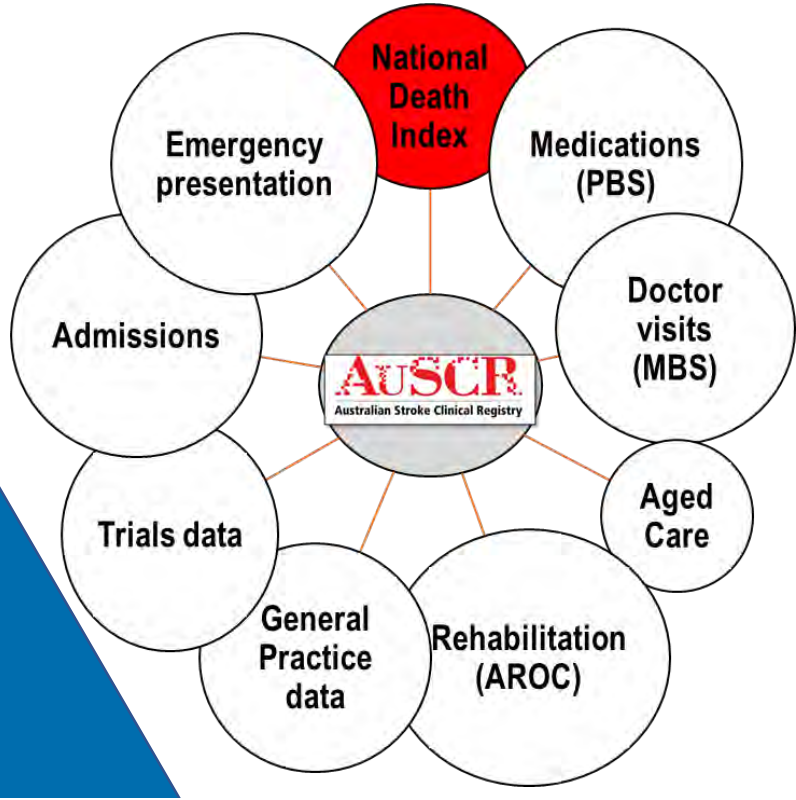
Australian Stroke Clinical Registry

- 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

Ascertaining fact and cause of death



AuSCR
Australian Stroke Clinical Registry

National Death Index
(Australian Institute of Health and Welfare)

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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

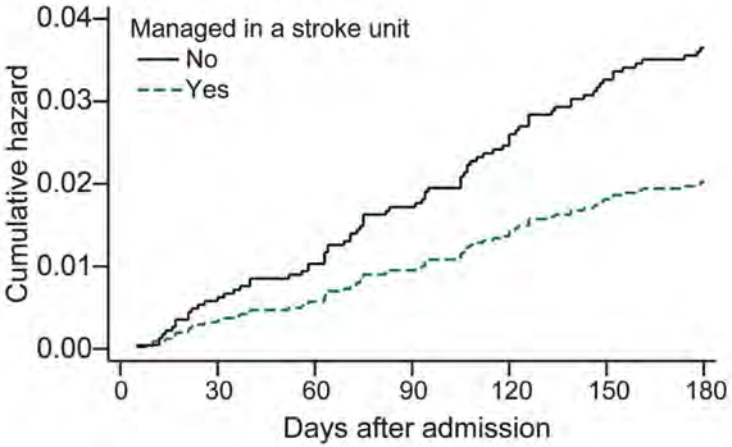
In-hospital deaths				
		National Death Index		
		Yes	No	Total
AuSCR	Yes	1440	58	1498
	No	19	14697	14716
	Total	1459	14755	16214

	Accuracy
Sensitivity	98.7%
Specificity	99.6%
Negative predictive value	99.9%
Positive predictive value	96.1%

Kilkenny MF, Kim J, Andrew NE, Sundararajan V, Thrift AG, Katzenellenbogen J, et. al. Med. J Australia 2019

Better outcomes for hospitalized patients with TIA when in stroke units

Figure Cumulative hazard of death to 180 days after TIA according to management in a stroke unit

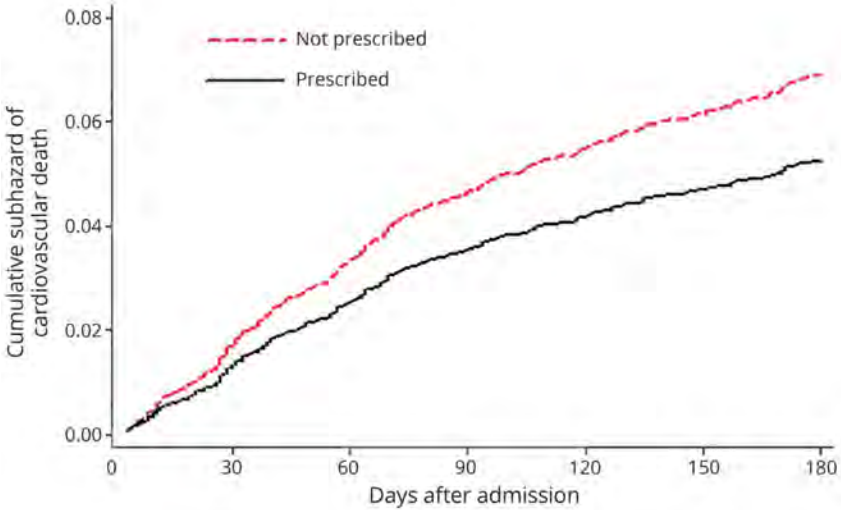



Better outcomes for hospitalized patients with TIA when in stroke units
An observational study

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

Cadilhac DA, Kim J, Lannin NA, Levi CR, Dewey HM, Hill K, Faux S, Andrew N, Kilkenny MF, Grimley R, Thrift AG, Grabsch B, Middleton S, Anderson CS and Donnan GA. Neurology 2016

Prescription of antihypertensive medication at discharge influences survival following stroke




ARTICLE

Prescription of antihypertensive medication at discharge influences survival following stroke

Abstract

Objective

Methods

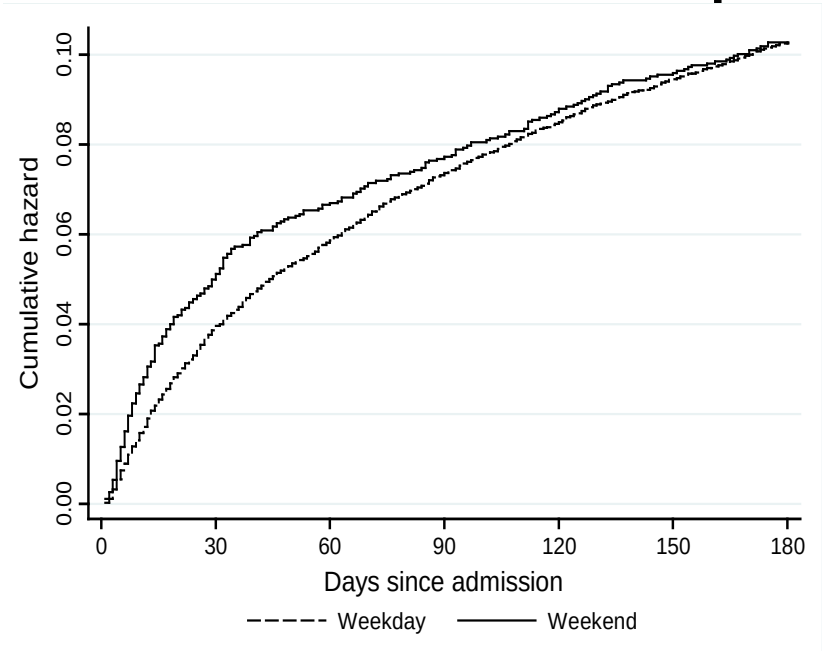
Results

Conclusions

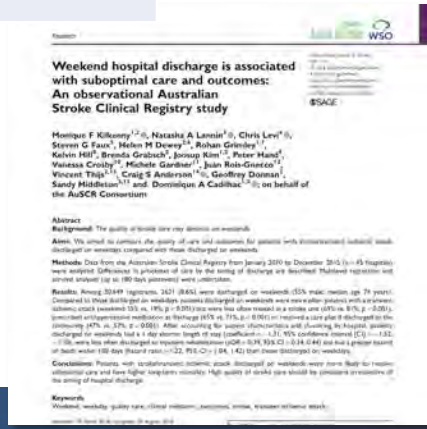
Patients discharged with antihypertensives have **23%** reduced hazard of cardiovascular death compared to those not discharged with these agents

Andrew NE, Kim J, Thrift AG, Kilkenny MF, Lannin NA, Anderson C, Donnan GA, Hill K, Middleton S, Levi C, Faux S, Grimley R, Gange N, Geraghty R, Ermel S, Cadilhac DA. Neurology 2018

Weekend discharge after stroke is associated with poor outcomes



Discharged	Weekend	Weekday
Treated in a stroke unit	69%	81%
Discharged on an antihypertensive medication	65%	71%
Discharge to the community with a care plan	47%	53%
Swallow screen or assessment	63%	86%



Weekend hospital discharge is associated with suboptimal care and outcomes: An observational Australian Stroke Clinical Registry study

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

Kilkenny MF, Lannin NA, Levi C, Faux SG, Dewey HM, Grimley R, et al. Int. J. Stroke. 2018

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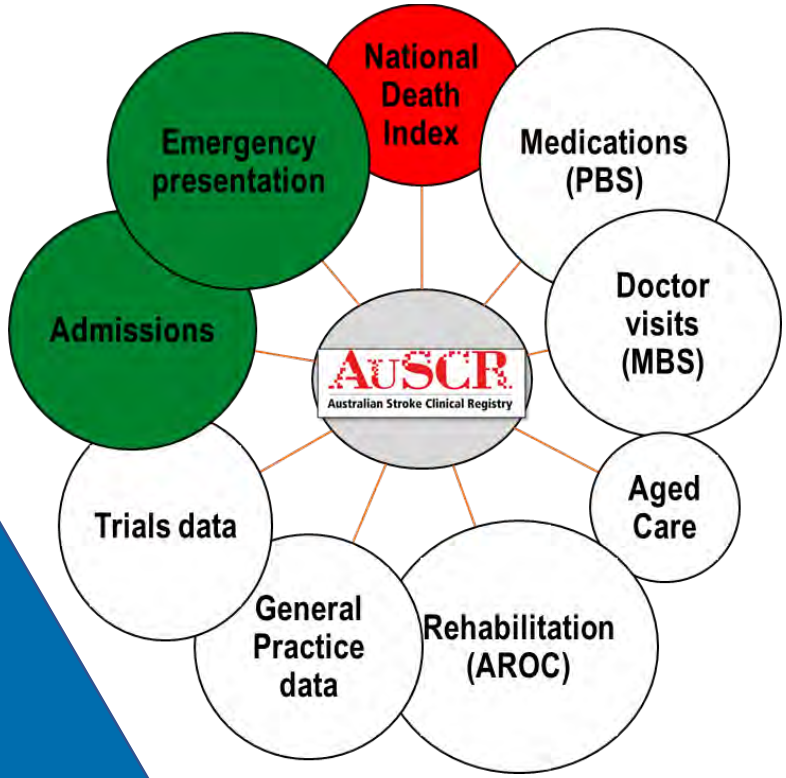
Ascertaining hospital presentations and comorbidities



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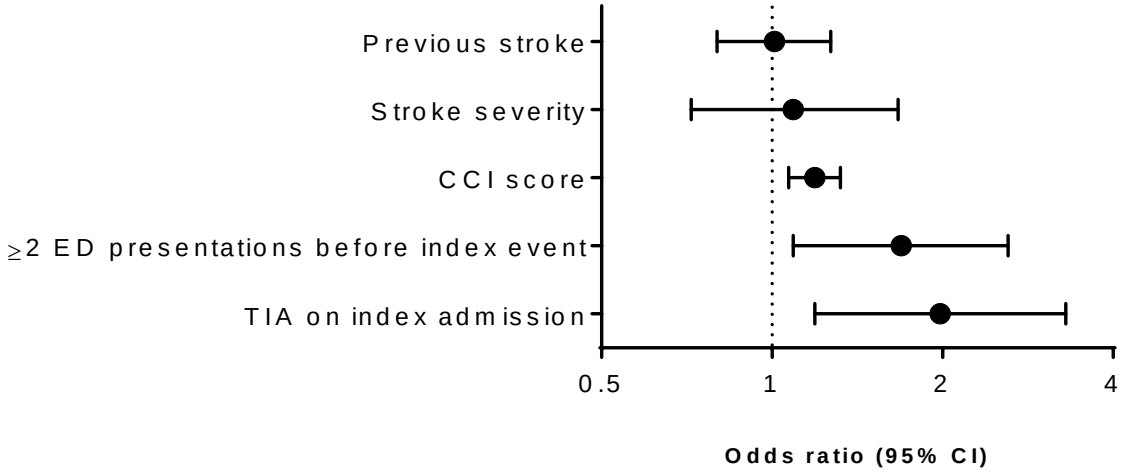
Pilot linkage of AuSCR data from one hospital




Research

Readmissions after stroke: linked data from the Australian Stroke Clinical Registry and hospital databases

Abstract

Methods

Data Linkage

Ethics approval for this project was obtained from the ethics committee at the participating hospital and the data custodians (AuSCR and the Victorian Department of Health).

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

Kilkenny MF, Dewey HM, Sundararajan V, Andrew NE, Lannin N, Anderson CS, et al. Med. J. Aust. 2015

Stroke123 (NHMRC Partnership grant)

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

State	New South Wales	Queensland	Victoria	Western Australia
Technique	Probabilistic	Probabilistic and deterministic	Stepwise deterministic	Probabilistic

- 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)

AuSCR
Australian Stroke Clinical Registry

National Death Index
(Australian Institute of Health and Welfare)

COMPREHENSIVE DATASET ON THE PATIENT JOURNEY

Prior to Stroke/TIA → Stroke/TIA registered in the AuSCR → After Stroke/TIA

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

In hospital
- Clinical characteristics
- Evidence-based therapies

Patient-reported outcome measures at follow-up
- Quality of life

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

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

STROKE123

Kilkenny MF, Kim J, Andrew NE, Sundararajan V, Thrift AG, Katzenellenbogen J, et. al. Med. J Australia 2019

Matching with hospital administrative datasets

% matched to Registry	Total N=16214	New South Wales N=4090	Queensland N=5616	Victoria N=5529	Western Australia N=999
Emergency	80%	94%	75%	71%	94%
Admissions	95%	91%	98%	95%	97%
Either*	98%	97%	99%	96%	99%

*linked to emergency, admissions or both

AUSCR Australian Stroke Clinical Registry

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

Kilkenny MF, Kim J, Andrew NE, Sundararajan V, Thrift AG, Katzenellenbogen J, et. al. Med. J Australia 2019

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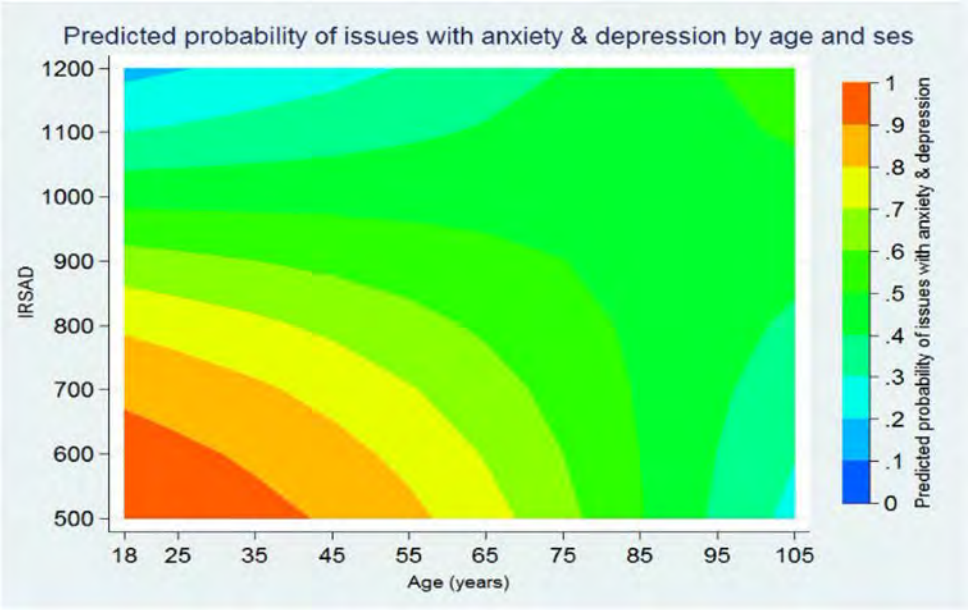
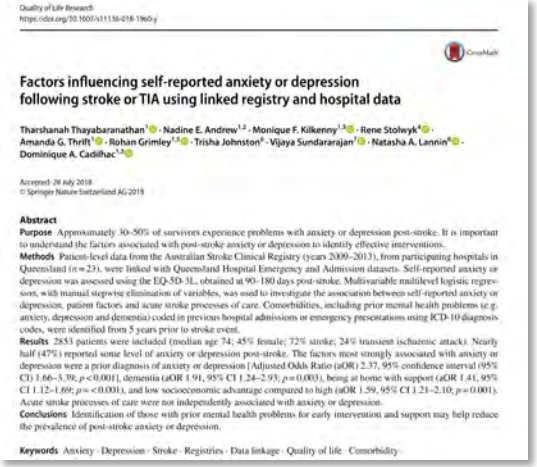
Anxiety/depression after stroke is related to socioeconomic position





Quality of Life Research
https://doi.org/10.1007/s11136-018-1960-y

Factors influencing self-reported anxiety or depression following stroke or TIA using linked registry and hospital data

Tharshanah Thayabaranathan[1] · Nadine E. Andrew[1,2] · Monique F. Kilkenny[1,3] · Rene Stolwyk[4] · Amanda G. Thrift[1] · Rohan Grimley[1,5] · Trisha Johnston[6] · Vijaya Sundararajan[7] · Natasha A. Lannin[8] · Dominique A. Cadilhac[1,5]

Accepted: 28 July 2018

Abstract

Purpose Approximately 30–50% of survivors experience problems with anxiety or depression post-stroke. It is important to understand the factors associated with post-stroke anxiety or depression to identify effective interventions.

Methods Patient-level data from the Australian Stroke Clinical Registry (years 2009–2013), from participating hospitals in Queensland (n = 23), were linked with Queensland Hospital Emergency and Admission datasets. Self-reported anxiety or depression was assessed using the EQ-5D-3L, obtained at 90–180 days post-stroke. Multivariable multilevel logistic regression, with manual stepwise elimination of variables, was used to investigate the association between self-reported anxiety or depression, patient factors and acute stroke processes of care. Comorbidities, including prior mental health problems (e.g. anxiety, depression and dementia) coded in previous hospital admissions or emergency presentations using ICD-10 diagnosis codes, were identified from 5 years prior to stroke event.

Results 2853 patients were included (median age 74; 45% female; 72% stroke; 24% transient ischaemic attack). Nearly half (47%) reported some level of anxiety or depression post-stroke. The factors most strongly associated with anxiety or depression were a prior diagnosis of anxiety or depression [Adjusted Odds Ratio (aOR) 2.37, 95% confidence interval (95% CI) 1.66–3.39; $p < 0.001$], dementia (aOR 1.91, 95% CI 1.24–2.93; $p = 0.003$), being at home with support (aOR 1.41, 95% CI 1.12–1.69; $p = < 0.001$), and low socioeconomic advantage compared to high (aOR 1.59, 95% CI 1.21–2.10; $p = 0.001$). Acute stroke processes of care were not independently associated with anxiety or depression.

Conclusions Identification of those with prior mental health problems for early intervention and support may help reduce the prevalence of post-stroke anxiety or depression.

Keywords Anxiety · Depression · Stroke · Registries · Data linkage · Quality of life · Comorbidity

*Patients in the **lowest** category of **socioeconomic** position **were 59% more likely** to report problems with **anxiety/depression***

Thayabaranathan T, Andrew NE, Kilkenny MF, Stolwyk R, Thrift AG, Grimley R, et al. Qual. Life Res. 2018

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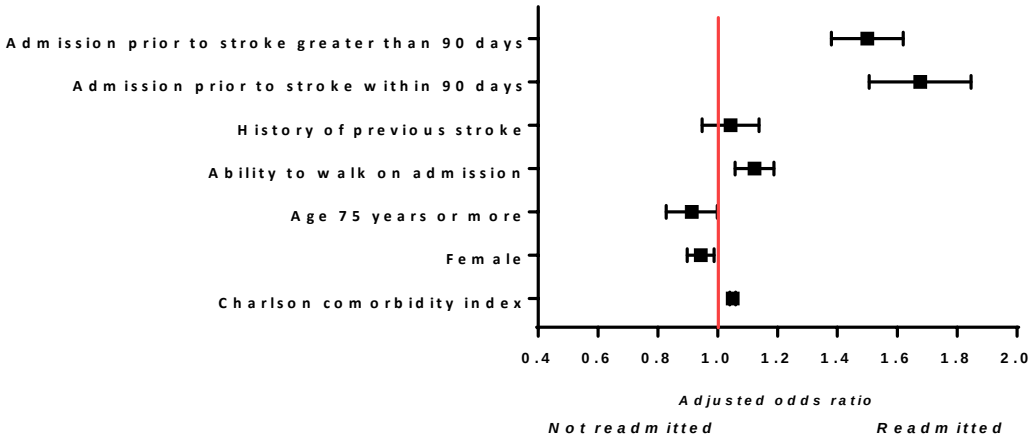
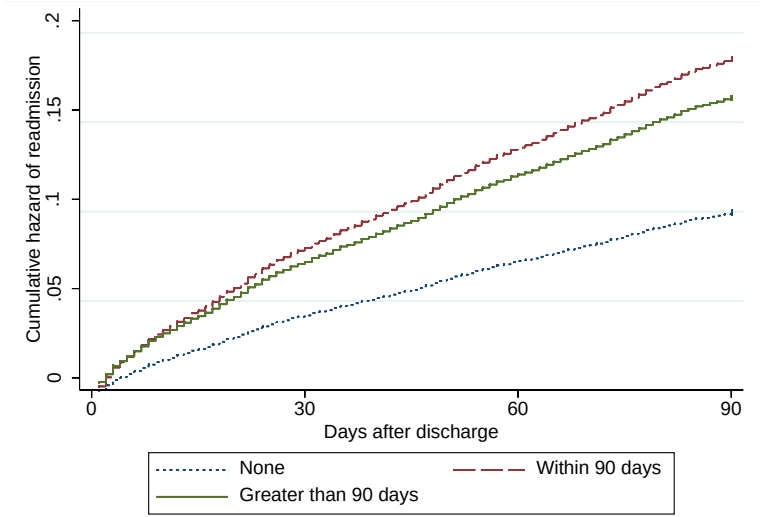
Factors associated with 90-day readmission





*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*

Kilkenny MF, Dalli LL, Kim J, Sundararajan V, Andrew NE, Dewey H, et al. 2019 [accepted Stroke 2019]

Models adjusted for factors shown and socioeconomic position, in-hospital stroke, transfer, treatment in a stroke unit and length of stay

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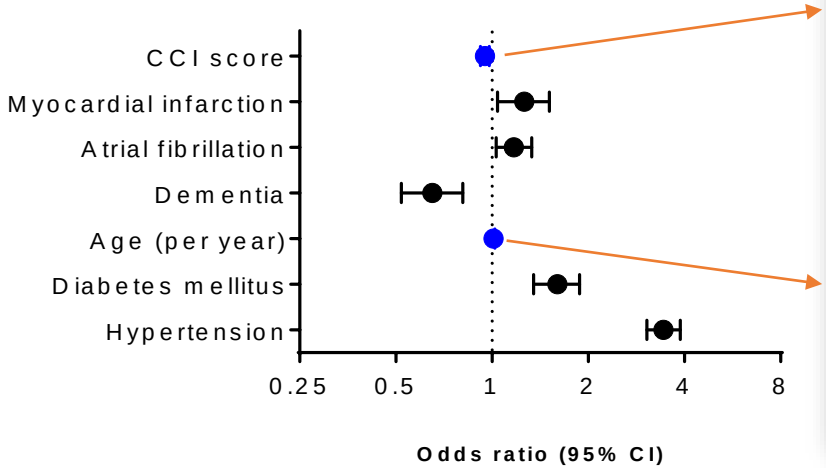
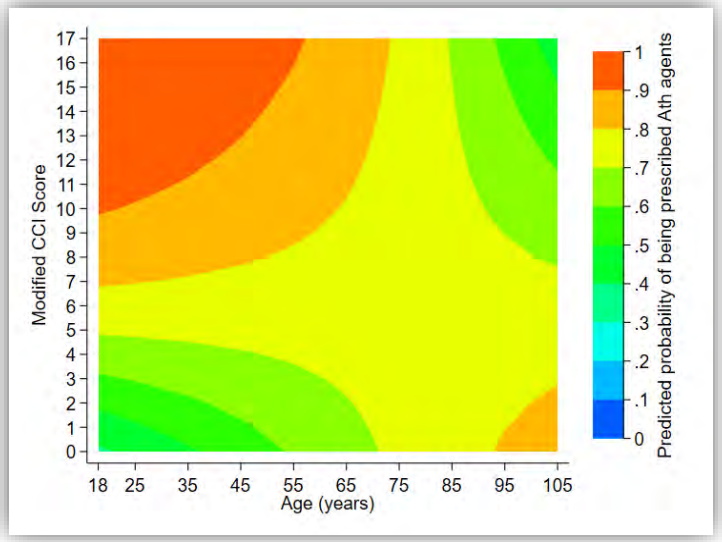
Antihypertensive prescription after stroke related to age and comorbidities





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

Dalli LL, Kim J, Thrift AG, Andrew NE, Lannin NA, Anderson CS, Grimley R, Katzenellenbogen J, Boyd J, Lindley R, Pollack M, Jude M, Durairaj R, Shah D, Cadilhac DA, Kilkenny MF. Stroke. 2019

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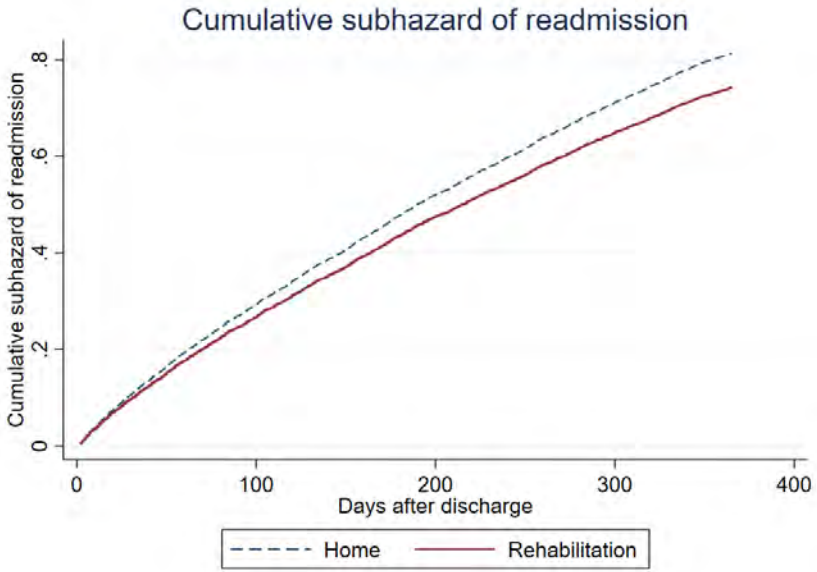
Patients discharged to inpatient rehabilitation after acute stroke less likely to be readmitted



Patients **discharged to inpatient rehabilitation had fewer readmissions** within 90 and 180 days compared to patients discharged home.

Lynch EA, Labberton AS, Kim J, Kilkenny MF, Andrew NE, Lannin NA, Grimley R, Faux SG, Cadilhac DA. 2019 [under review]

Disagreement in stroke ICD-10-AM coding

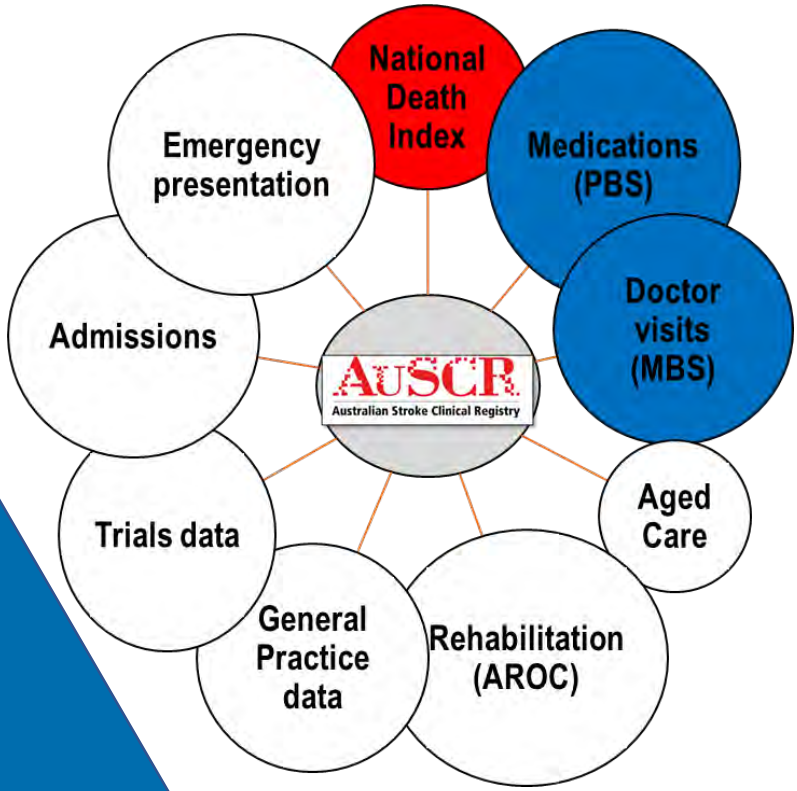
Ischaemic stroke based on administrative data ICD-10 (principal diagnosis code only)*	'Reference standard' based on AuSCR clinician-assigned ischaemic stroke diagnosis		
	Yes	**No**	Total
Yes	6,693 True positive (TP)	302 False positive (FP)	6,995 (47.5%)
No	2,578 False negative (FN)	5,143 True negative (TN)	7,721 (52.5%)
Total	9,271 (63.0%)	5,445 (37.0%)	14,716 (100.0%)

2,578
False negative (FN)
records

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

Ryan O, Cadilhac DA, Kilkenny MF. 2019 [In draft]

Ascertaining medication dispensing and doctor visits



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Utilisation of secondary prevention medications after stroke*

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

AuSCR
Australian Stroke Clinical Registry

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

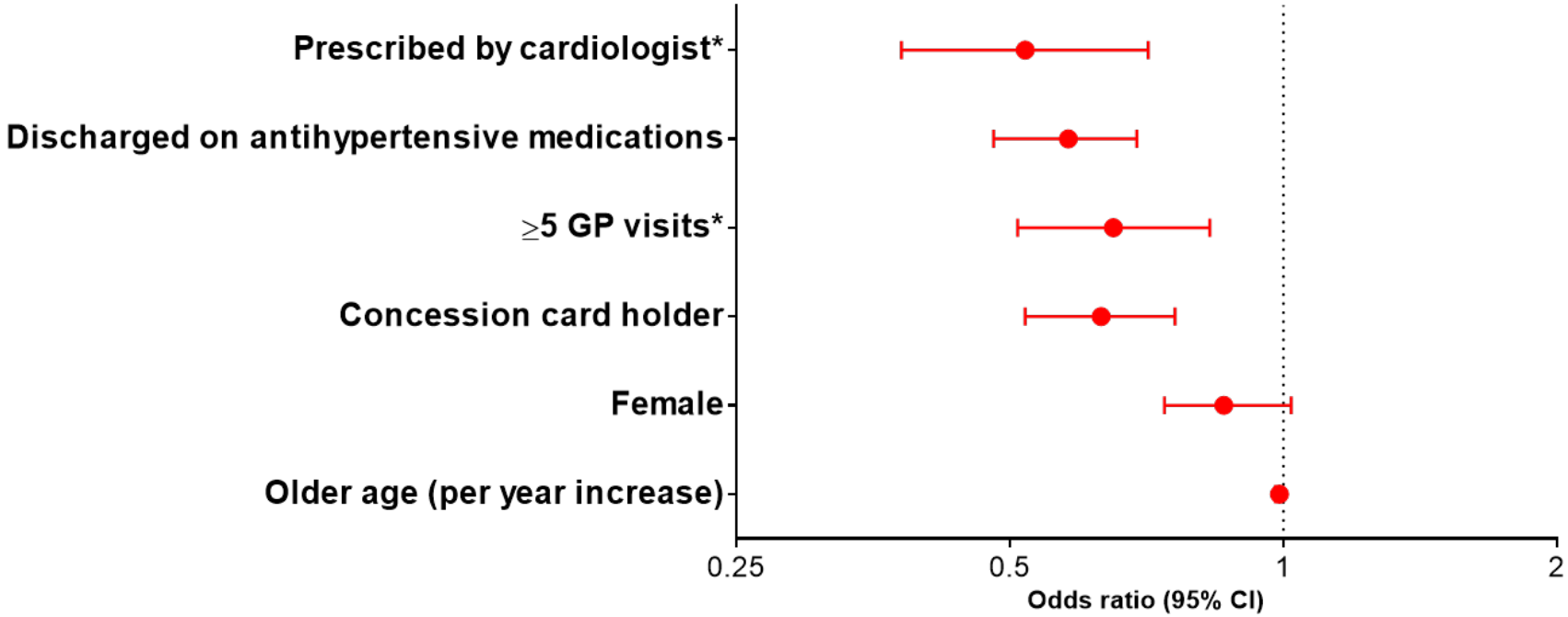
**excludes patients with intracerebral haemorrhage

Discontinuation* of secondary prevention medications after stroke

Antihypertensive	Antithrombotic	Lipid-lowering
8,911 users	6,104 users	7,267 users
26% discontinued	45% discontinued	30% discontinued
Median time to discontinuation: 198 days (Q1: 125; Q3: 277)	*Median time to discontinuation:* 201 days (Q1: 141; Q3: 267)	*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



***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.

Specialist updates Neurology

SPECIALIST UPDATES **NEUROLOGY**

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

0 Comment

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.

Dr Monique Kilkenny (PhD).

"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.

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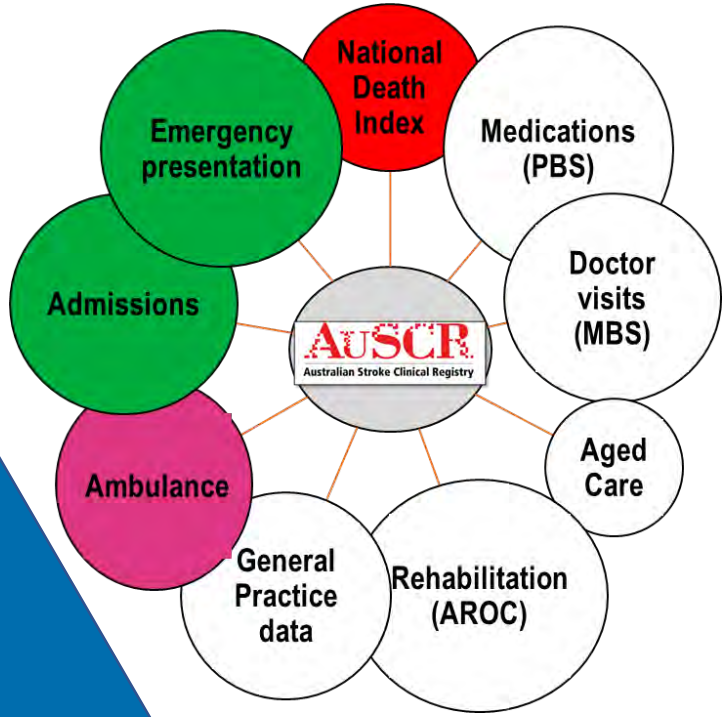
Ascertaining Ambulance presentations



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Feasibility AuSCR-Ambulance linkage

N=12,197 AuSCR cases

2013-2017

N=1,900,000 000 cases

AuSCR Australian Stroke Clinical Registry

Ambulance Victoria

N=7,373

Excluded:

In-hospital strokes

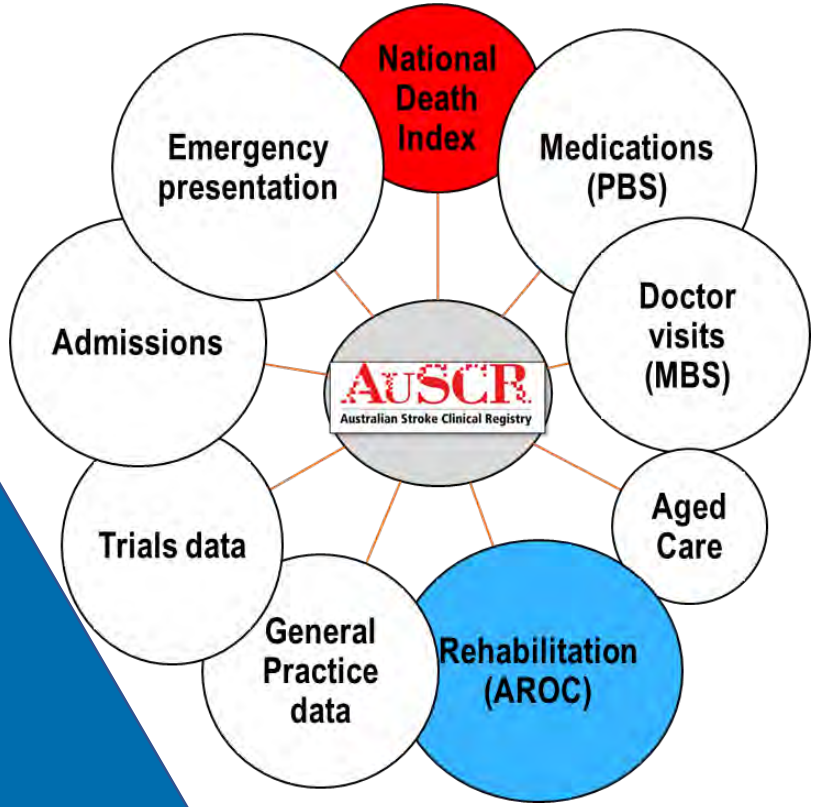
Transfers from another hospital

Year 2013 and 2014

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

AuSCR Clinical Diagnosis	ICH	Ischaemic	TIA	Undetermined
N=4,202	N=519	N=2783	N=730	N=170
Call-taker assessment				
Stroke	44%	56%	66%	60%
Other diagnosis	43%	43%	33%	38%
Headache	3%	<1%	<1%	2%
Paramedic assessment				
Stroke	62%	62%	38%	54%
Transient ischemic attack	2%	7%	32%	13%
Subarachnoid haemorrhage	<1%	<1%	0%	0%
Other assessment	35%	30%	31%	33%
Urgency of dispatch				
Non-emergency	<1%	2%	1%	1%
Lights and sirens	81%	79%	85%	82%
Urgent	13%	15%	10%	11%
Non-urgent	4%	5%	4%	6%

Ascertaining Inpatient rehabilitation admissions



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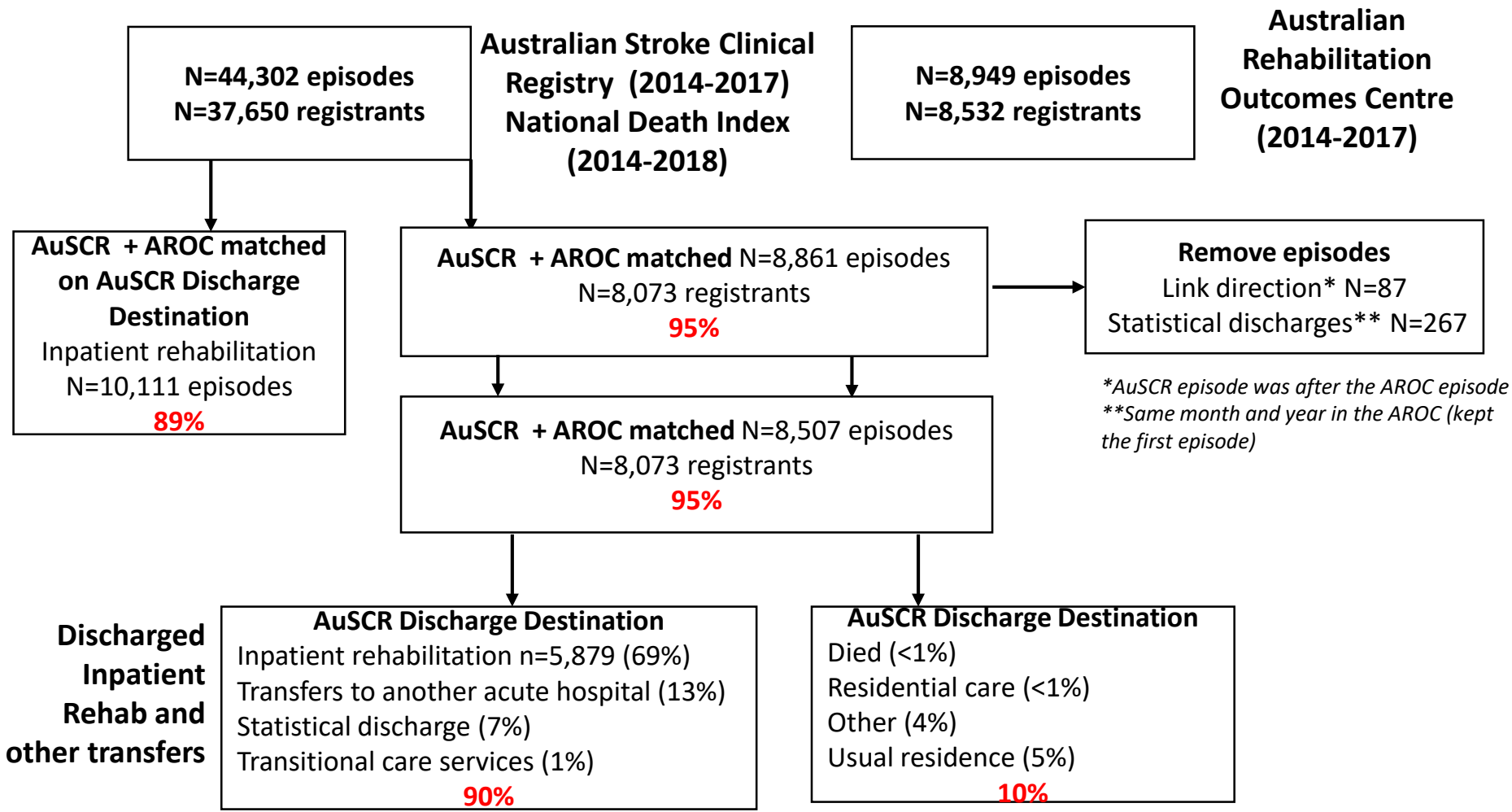
Feasibility AuSCR-AROC linkage



Capturing the entire continuum of care

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Capture the stroke continuum of care

Hospital administrative datasets

AuSCR
Australian Stroke Clinical Registry

National Death Index

COMPREHENSIVE DATASET ON THE PATIENT JOURNEY

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

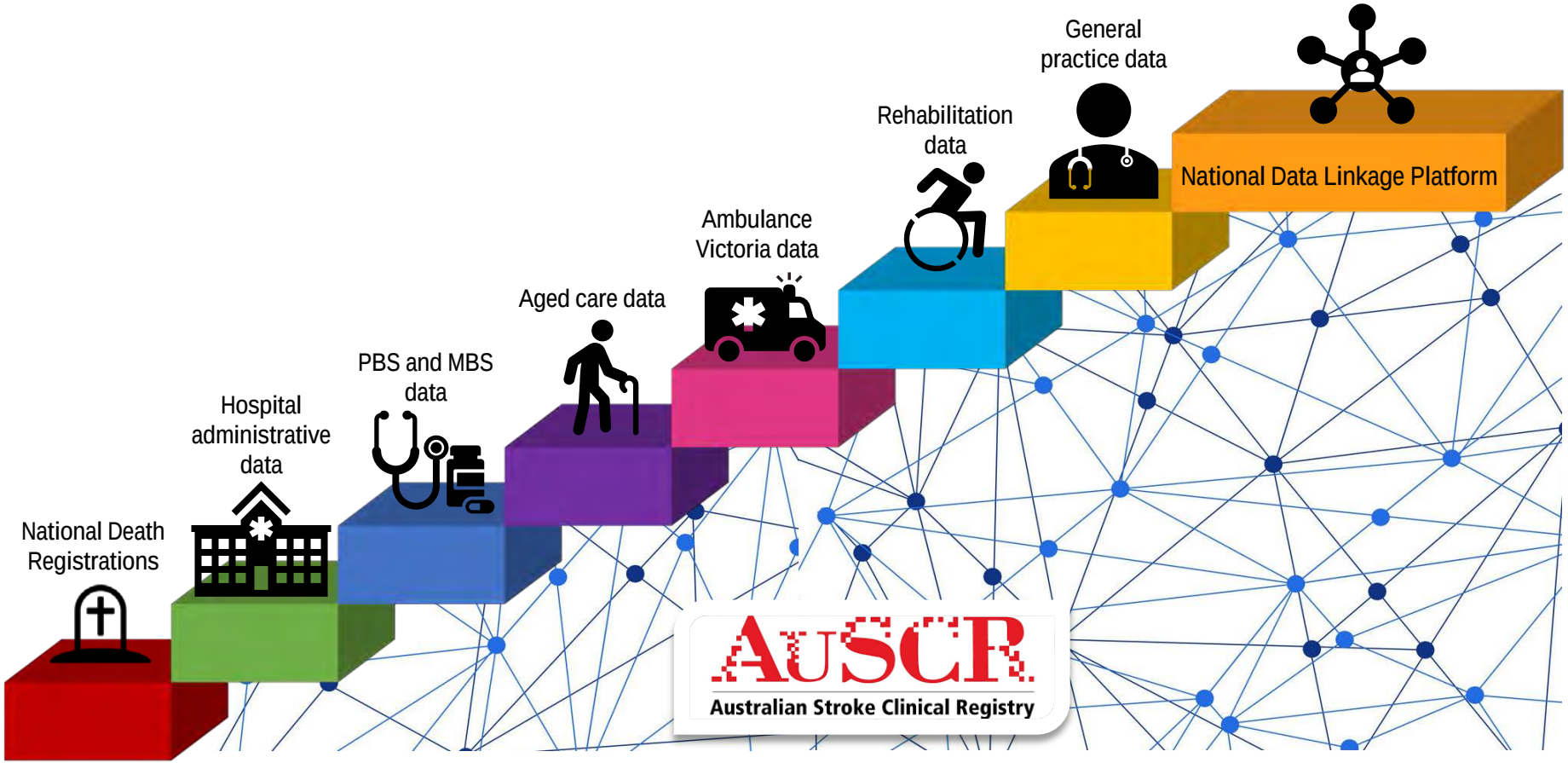
Patient-reported outcome measures at follow-up

- Quality of life

After Stroke/TIA

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

Towards an integrated national data platform for stroke



Tips for planning your data linkage project

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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
Monash research/ AuSCR Office staff
State Data Linkage unit Heads
Population Health Research Network
Centre for Data Linkage
Australian Institute of Health and Welfare
Data linkage research experts

Co-chairpersons:

Professors Dominique Cadilhac

Professor Vijaya Sundararajan

Co-ordinator: Dr Monique Kilkenny

Hospital staff & patients

AuSCR Consortium partners

THE FLOREY INSTITUTE OF NEUROSCIENCE & MENTAL HEALTH

The George Institute for Global Health

stroke society OF AUSTRALASIA

Stroke FOUNDATION

Initial AuSCR support

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTHCARE

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State Government Victoria

Queensland Government

Tasmanian Government

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Victorian Stroke Clinical Network

ACI NSW Agency for Clinical Innovation

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Stroke FOUNDATION

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Queensland Government

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For further information:

Monique.Kilkenny@monash.edu

MONASH University