

National Stroke Data Linkage Interest Group

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Establishing integrated data for stroke to enable comprehensive monitoring of care and patient outcomes to provide evidence for clinical practice improvement (Stroke123)

In Australia approximately 50,000 people suffer a stroke each year. It has been reported that there is substantial variation in the quality of care received by patients with stroke in hospitals across Australia. As part of the Stroke123 study, the Australian Stroke Clinical Registry (AuSCR) was linked with data from routinely collected health information systems to enhance methods of monitoring and describing care variability and differences in patient outcomes. This approach is of particular value in stroke care, since multiple interactions across healthcare facilities and jurisdictions are common and it is inefficient to collect these data multiple times when they are readily available in different datasets.

The aims of the Stroke123 data linkage substudy are to:

- a) determine how to achieve reliable data linkage between an external (non-government) registry and hospital administrative datasets across multiple states
- b) assess case-ascertainment in the AuSCR efficiently using state-level information instead of individual hospital information
- c) assess the quality of stroke information by comparing AuSCR data with hospital admission data
- d) demonstrate the value of comprehensive linked data in describing variations in the quality of acute stroke care by permitting investigation of a range of research questions
- e) use the de-identified linked data to determine the costs of providing stroke care and describe any variations in costs which may be related to the quality of care.

The findings from this study will provide a platform for national roll-out of appropriate and enhanced data collection solutions linked to an effective model for improving clinical care and outcomes of stroke.

Primary Cohort	15,482 AuSCR registrants (years 2009 to 2013)
Datasets included in the linkage	<ul style="list-style-type: none">• AuSCR (primary dataset)• National Death Registry (mortality)• Admissions• Emergency
States included	<ul style="list-style-type: none">• Victoria• New South Wales• Queensland• Western Australia
Data access and storage	Data accessible via Monash University network
Project start date	2012
Project end date	2015 (Data available for analysis until 2019)
Study contact	Prof Dominique Cadilhac (Primary Chief Investigator) E: dominique.cadilhac@monash.edu
Funder	Four-year National Health and Medical Research Council Partnerships for Better Health grant

Identifying gaps and inequalities in access to general practitioner coordinated care for survivors of stroke (GP stroke)

The long-term needs of the 420,000 Australians living with stroke are not being met by our healthcare system. It is difficult to address this problem when little is known about how survivors are managed in the community. The aim of this study is to describe, in a nationally representative large cohort, how survivors are being managed under Medicare-funded Chronic Disease Management Programs (CDMP), and other models of general practitioner (GP) coordinated care, to identify inequalities in access to these enhanced primary care policies.

This project examines the care of stroke survivors under Medicare-funded programs and other models of GP-coordinated care to identify inequalities in availability and accessibility of care.

Using this linked dataset, we aim to determine patient, clinical and system factors associated with access to different primary care reimbursement items:

- a) for all registrants
- b) for those identified within 6 months of stroke as having chronic disability using quality of life data collected at AuSCR follow-up.

The outcome will be a robust evaluation that maximises the use of existing data to provide essential evidence to: inform policy; target quality improvement activities at the primary care level; and develop innovative solutions for providing better long-term care for survivors of stroke.

Primary Cohort	15,000 AuSCR registrants (years 2010 to 2015)
Datasets included in the linkage	<ul style="list-style-type: none">• AuSCR (primary dataset)• National Death Registry (mortality)• Pharmaceutical Benefits Scheme• Medicare Benefits Schedule
States included	<ul style="list-style-type: none">• Victoria• New South Wales• Queensland• Western Australia• Tasmania
Data access and storage	Data accessible via Secure Unified Research Environment
Project start date	2017
Project end date	2020
Contact person	A/Prof Nadine Andrew E: nadine.andrew@monash.edu
Funder	Stroke Foundation

Understanding the impact of hospital transition to primary care and follow-up interventions (GP stroke)

Survivors of stroke are at increased risk of subsequent vascular events, including recurrent stroke. Pharmacological interventions have been shown to prevent recurrent stroke within this high-risk population. Currently, measurement of adherence to secondary prevention medications is limited to cross-sectional observational and trials data.

The aims of this project are to:

- a) describe, in a nationally representative, large cohort of stroke survivors (n=25,000), long-term adherence and persistence with medications for secondary prevention
- b) to identify factors associated with adherence and persistence.

For the first time in Australia, person-level linkages between Australian Stroke Clinical Registry (AuSCR) and Pharmaceutical data will be available. Standard definitions will be used for non-adherence and poor persistence. Patient, clinical, acute care system and community factors associated with adherence will be described according to optimal care management (defined as patients who receive medications at discharge from hospital and general practice management plans).

These data will provide essential evidence to: inform practice and policy; target quality improvement activities at the hospital and primary care level, and develop interventions for improving adherence to secondary prevention medication. Primary healthcare providers (general practitioners, community pharmacists) and consumers (patients with stroke/TIA and carers) will contribute to the project to ensure results are immediately translatable.

Primary Cohort	15,000 AuSCR registrants (years 2010 to 2015)
Datasets included in the linkage	<ul style="list-style-type: none">• AuSCR (primary dataset)• National Death Registry (mortality)• Pharmaceutical Benefits Scheme• Medicare Benefits Schedule
States included	<ul style="list-style-type: none">• Victoria• New South Wales• Queensland• Western Australia• Tasmania
Data access and storage	Data accessible via Secure Unified Research Environment
Project start date	2017
Project end date	2020
Contact person	A/Prof Monique Kilkenny E: monique.kilkenny@monash.edu
Funder	Stroke Foundation

Evaluation of enhanced models of Primary care in the management of stroke and other Chronic diseases (PRECISE)

Since 1999 the government has invested substantial funds (\$1 billion per year) for enhanced models of primary care that are characterised by multidisciplinary care and self-management support. Despite these investments, a large-scale population-based evaluation of the effectiveness of these primary care models has not been performed in Australia. Such an evaluation is needed to determine whether these models of care really do improve patient health outcomes and are cost effective.

A comparative effectiveness study of these Medicare-funded models of care, using a population-based cohort design will be performed. The linked data will enable us to assess:

- a) the influence of enhanced models of primary care on hospital contacts, survival and quality of life following stroke. A full economic evaluation will also be undertaken.
- b) the effect of primary healthcare models on rates of hospitalisations and emergency department presentations among stroke patients
- c) the cost effectiveness of primary healthcare models.

The comprehensiveness of these data will allow an assessment of the effectiveness of these enhanced models of primary care within the context of "real world" healthcare provision. A multidisciplinary reference committee will be used to contribute to the interpretation of the results and assist with recommendations for policy and practice improvements. This will provide a qualitative approach in addition to the quantitative analysis. Results will provide information for guiding uptake of appropriate models of care and guiding health policy reform at the primary care level to optimise outcomes for those with chronic disease and stroke, as well as maximising the use of limited healthcare resources.

Primary Cohort	25,000 AuSCR registrants (years 2012 to 2016)
Datasets included in the linkage	<ul style="list-style-type: none"> • AuSCR (primary dataset) • National Death Registry (mortality) • Hospital admission databases • Emergency department presentation databases • Pharmaceutical Benefits Scheme • Medicare Benefits Schedule • Survey of subset of patients (n=1,000)
States included	<ul style="list-style-type: none"> • Queensland • Victoria
Data access and storage	Data accessible via Secure Unified Research Environment (SURE)
Project start date	2018
Project end date	2021
Contact persons	<p>A/Prof Nadine Andrew (Primary Chief Investigator) E: nadine.andrew@monash.edu</p> <p>A/Prof Monique Kilkenny E: monique.kilkenny@monash.edu</p> <p>Dr Joosup Kim E: joosup.kim@monash.edu</p>
Funder	National Health and Medical Research Council project grant

Predicting rehabilitation outcomes through data linkage of the Australian Stroke Clinical Registry (AuSCR) and Australasian Rehabilitation Outcomes Centre (AROC)

Data linkage of the AuSCR and AROC databases will be used to examine stroke recovery across the continuum of care and also to determine any differences in rehabilitation outcomes.

Information will be provided on rehabilitation outcomes, length of stay and speed of recovery for stroke patients captured on AUSCR who were admitted to inpatient rehabilitation. We expect to produce data on the differences in rehabilitation outcomes depending on age, sex and quality indicators of acute stroke care.

We will explore the complexity of linking these two data sets and aim to:

- a) compare outcomes for those undertaking rehabilitation in networked rehabilitation facilities (on site or in related facility) compared to non-networked (off site) facilities
- b) compare rehabilitation outcomes of those with longer versus shorter acute length of stays.

Primary Cohort	18,000 AuSCR registrants (years 2014 to 2017)
Datasets included in the linkage	<ul style="list-style-type: none"> • AuSCR (primary dataset) • National Death Registry (mortality) • Australasian Rehabilitation Outcomes Centre (AROC)
States included	<ul style="list-style-type: none"> • Victoria • New South Wales • Queensland • Western Australia • Tasmania
Data access and storage	Data accessible via Monash University network
Project start date	2018
Project end date	2020
Contact persons	A/Prof Monique Kilkenny (E: monique.kilkenny@monash.edu) A/Prof Steven Faux
Funder	National Health and Medical Research Council Centre of Research Excellence in Stroke Rehabilitation and Brain Recovery

Understanding factors that influence pre-hospital and hospital patient care to improve access to high quality acute stroke care

Acute stroke is complex and poor management including delays in accessing treatment can impact patient outcomes. The overall aim of this project is to quantify the impact of variances in pre-hospital and hospital management. The specific aims are to:

- a) determine whether patients are being managed appropriately under a new ambulance clinical response policy implemented in October 2016 within Victoria
- b) determine adherence to the national acute stroke care standards related to the pre-hospital and acute hospital phases of care
- c) identify factors (patient, clinical and system) that may explain variances in acute management and subsequent differences in 90-180 day outcomes for patients who do and do not receive acute care according to the national standards.

Observational cohort study design using patient-level linked data from a national registry with ambulance presentations data from Ambulance Victoria. A controlled before-after design is used for Aim (a) with a historical period of 2013-September 2016. The richness and size of the combined datasets will enable fully-powered (>80%) analyses using multilevel, multivariable regression statistical models.

For the first time, we will be able to explore the impact of pre-hospital and hospital assessment and treatment times on patient outcomes at discharge and at 90-180 days post-stroke.

Primary Cohort	11,000 AuSCR registrants (years 2013 to 2017)
Datasets included in the linkage	<ul style="list-style-type: none">• AuSCR (primary dataset)• National Death Registry (mortality)• Hospital admission databases• Emergency department presentation databases• Ambulance Victoria Database
States included	<ul style="list-style-type: none">• Victoria
Data access and storage	Data accessible via Monash University network
Project start date	2018
Project end date	2019
Contact person	Prof Dominique Cadilhac (Primary Chief Investigator) E: dominique.cadilhac@monash.edu
Funder	Stroke Foundation

Understanding the prevention and long-term management of stroke by general practitioners

In Australia, general practitioners (GPs) are well placed to provide the care recommended in the guidelines for the prevention and management of stroke. The overall aim of this project is to understand the prevention and long-term management of stroke/TIA by GPs in the states of Victoria. The specific aims are to:

- (1) Assess the feasibility of linking data from the AuSCR to POLAR (general practice).
- (2) Describe the extent to which GPs provide the processes of care recommended in the clinical guidelines for the management of cardiovascular disease risk and for secondary prevention of stroke.
- (3) Identify factors associated with the use, by GPs, of processes of care recommended for primary and secondary prevention of stroke.
- (4) Ascertain whether patients attain targets for the control of risk factors before and after a stroke/TIA based on definitions in the clinical guidelines, and associated factors.
- (5) Investigate the association between the use, by GPs, of processes of care recommended for the secondary prevention of stroke and patient outcomes, including the attainment of targets for the control of risk factors after stroke/TIA and mortality.

The AuSCR-POLAR data linkage will provide a robust opportunity to unearth novel insights on evidence-practice gaps in managing risk factors and comorbidities for the primary prevention of stroke. Findings from this study could help inform strategies for the general practices to: better individualise care for the prevention of stroke; develop processes of care indicators for monitoring the quality of care after stroke; inform the development of interventions for improving care management and patient recovery after stroke; and ultimately inform policy on effective prevention and long-term management of stroke in the community.

Primary Cohort	11,000 AuSCR registrants (years 2013 to 2018)
Datasets included in the linkage	<ul style="list-style-type: none">• AuSCR (primary dataset)• National Death Registry (mortality)• POLAR (general practice) datasets
States included	<ul style="list-style-type: none">• Victoria
Data access and storage	Data accessible via SeRP.
Project start date	2021
Project end date	2022
Contact person	Dr Joosup Kim (Primary Chief Investigator) E: joosup.kim@monash.edu Dr Muideen Olaiya E: muideen.olaiya@monash.edu A/Prof Monique Kilkenny E: monique.kilkenny@monash.edu
Funder	Stroke Foundation

Establishing high quality, integrated data for chronic disease management plans and secondary prevention medications and their effectiveness for patients after stroke: a substudy of STAND FIRM

The Shared Team Approach between Nurses and Doctors for Improved Risk Factor Management for stroke patients (STAND FIRM) was a clinical trial aimed at assessing whether risk factor management after stroke can be successfully improved.

In this clinical trial, 563 participants with stroke were recruited from four hospitals (The Alfred, Box Hill, Dandenong and Monash Medical Centre). Patients were randomly allocated to receive either an individualised management plan or usual care after a stroke (secondary prevention).

The Chronic Disease Management (CDM) Medicare items, which include increased Medicare-funded rebates for clinicians, are aimed at encouraging General Practitioners (GPs) to provide better management of risk factors in those with a chronic disease such as stroke, but there is limited evidence of its effectiveness.

The aims of this STAND FIRM data-linkage substudy are to:

- a) describe the uptake of CDM plans within 12 and 24 months after stroke through data linkages between STAND FIRM (clinical trial) and the Medicare Benefits Schedule (MBS)
- b) evaluate the effectiveness of CDM plans based on health outcomes (e.g. rehospitalisations (from STAND FIRM), death (NDI), etc.) at 12 and 24 months through data linkages between STAND FIRM and the MBS and National Death Index (NDI)
- c) evaluate the effectiveness of secondary prevention medications prescribed according to guidelines based on health outcomes at 12 and 24 months through data linkages between STAND FIRM and the Pharmaceutical Benefits Scheme, Medicare Benefits Schedule and the National Death Index.

Primary Cohort	563 patients with stroke/TIA (years 2010 to 2013)
Datasets included in the linkage	<ul style="list-style-type: none"> • STAND FIRM data (primary dataset) • Pharmaceutical Benefits Scheme • Medicare Benefits Schedule • National Death Index
States included	<ul style="list-style-type: none"> • Victoria
Data access and storage	Data accessible via Secure Unified Research Environment
Project start date	2018
Project end date	2020
Contact person	Prof Amanda Thrift (Primary Chief Investigator) E: Amanda.thrift@monash.edu
Funder	Medical Research Future Fund

South West And North Australian Indigenous StrOke data linkiNG Study (SWANSONG)

The SWANSONG Study aims to understand disparities in stroke risk factors, treatment and care, and outcomes between Aboriginal and Torres Strait Islander people and non-Indigenous Australians across South Australia, the Northern Territory and Western Australia.

Stroke is the leading cause of disability and the second biggest killer in Australia. An estimated 350,000 people in Australia live with the consequences of a stroke. The burden of stroke disease for Aboriginal and Torres Strait Islander people is higher than that for the non-Indigenous population. This data linkage project is a cohort study designed to:

- a) analyse and understand stroke risk, and subsequent disability and death due to stroke in Aboriginal and Torres Strait Islander people
- b) investigate stroke unit hospital access and thrombolysis therapy provision in Aboriginal and Torres Strait Islander people.

The outcomes from the project will be provided to local communities and local health authorities to influence policy.

Primary Cohort	Patients located across South Australia and Northern Territory
Datasets included in the linkage	<ul style="list-style-type: none">• Hospital admission database• Emergency department presentation database• Mortality data
States included	<ul style="list-style-type: none">• South Australia• Northern Territory• Western Australia
Project start date	2016
Project end date	2021
Contact persons	<p>Dr Judy Katzenellenbogen E: judith.katzenellenbogen@uwa.edu.au</p> <p>Dr Lee Nedkoff E: lee.nedkoff@uwa.edu.au</p> <p>Dr Tim Kleinig (Primary Chief Investigator) E: Timothy.Kleinig@sa.gov.au</p>
Funder	Heart Foundation

Reducing the evidence practice gap in preventing rehospitalisation and recurrence following stroke

Approximately 50,000 Australians suffer a stroke each year, with a lifetime cost per case of \$86,840. Survivors of stroke are at increased risk of subsequent vascular events, including recurrent stroke (9% at 6 months). To reduce the personal and economic costs, we must find simple, individualised and efficient approaches to prevent further vascular occurrences. Although there are many proven therapies for preventing stroke recurrence (e.g. blood pressure lowering), uptake of treatments is poor.

The Chronic Disease Management (CDM) Medicare items, which include increased Medicare-funded rebates for clinicians, are aimed at encouraging General Practitioners (GPs) to provide better management of risk factors in those with a chronic disease, including stroke. These CDM items may provide a means to improve patient knowledge about risk factors, as well as knowledge about appropriate use of medications and changes to lifestyle factors to reduce the risk of further vascular events.

Adoption of CDM plans among GPs in their care of patients has risen in Victoria by 325% in the past 10 years (2007 - 2016) and 58% in the past 5 years (2012 - 2016).

We aim to determine in patients after stroke/TIA:

- a) where there has been a change in GP use of CDM plans over time
- b) the effectiveness and cost-effectiveness of CDM plans on long-term (5-year) health outcomes (e.g. recurrences, rehospitalisations, deaths) and prescription of secondary prevention medications
- c) whether there is variation in clinical practice, and outcome, between rural and urban regions.

This planned data linkage will enable us to understand the changes that have occurred in use of the CDM items, and the impact that this has had on re-admissions following stroke, mortality, and use of secondary prevention medications. It will also enable us to determine whether the use of these CDM plans affects the utilisation of other healthcare resources. This would fill a critical evidence gap in understanding the benefit of CDM plans in stroke.

Primary Cohort	First-ever hospital cases of acute stroke/TIA (years 2006 to 2012)
Datasets included in the linkage	<ul style="list-style-type: none"> • Hospital admission databases (primary database) • Emergency department presentation databases • National Death Registry (mortality) • Pharmaceutical Benefits Scheme • Medicare Benefits Schedule
States included	<ul style="list-style-type: none"> • Victoria • New South Wales
Data access and storage	Data accessible via Secure Unified Research Environment
Project start date	2019
Project end date	2022
Contact Person	Prof Amanda Thrift (Primary Chief Investigator) E: Amanda.thrift@monash.edu
Funder	Medical Research Future Fund (partial funding)

Investigation of the pre-hospital clinical, non-clinical and system factors that impact on the delivery of reperfusion therapies in acute stroke

This is an epidemiological and clinical review of factors, present in the pre-hospital phase of acute stroke care, that impact on the delivery of acute reperfusion therapies. As part of this project, we aim to:

- a) map the epidemiological profile of acute stroke in the Queensland prehospital environment
- b) identify clinical, non-clinical and system factors that predict patients eligible for thrombolysis
- c) identify clinical, non-clinical and system factors that predict patients eligible for ECR
- d) identify the relative impact of each factor on determining eligibility for each reperfusion therapy.

The findings from this project will help to inform clinical and policy decisions in the pre-hospital identification and management of acute stroke patients.

Primary Cohort	Patients transported by Queensland Ambulance Service with a diagnosis related to stroke/TIA or other stroke subgroup from 1 January 2016 to 31 December 2017
Datasets included in the linkage	<ul style="list-style-type: none">• Queensland Ambulance Service electronic Ambulance Report Form (eARF) and Computer Aided Dispatch (CAD) data (primary database)• Australian Stroke Clinical Registry• Hospital admission databases• Emergency department presentation databases• Death Registry (mortality)
States included	<ul style="list-style-type: none">• Queensland
Project start date	2014
Project end date	2020
Contact person	Mr. Wayne Loudon E: wayne.loudon@ambulance.qld.gov.au
Funder	National Health and Medical Research Council

Is the incidence of heart attack still decreasing in Australia? Developing more reliable methods for monitoring trends in myocardial infarction and coronary heart disease

Our objectives are to:

- a) determine the consistency of diagnostic codes over time in hospital morbidity data for subgroups of acute coronary heart disease (myocardial infarction, unstable angina, stable angina, other coronary heart disease) and chest pain and, from these, define subgroups that permit reliable analysis of trends in admissions and outcome;
- b) examine trends in incidence and outcomes for defined subgroups of acute coronary heart disease and chest pain
- c) recommend evidence-based methods from both linked and unlinked hospital and mortality data for monitoring trends in acute coronary heart disease using national data in collaboration with the AIHW.

Primary Cohort	Patients with coronary heart disease
Datasets included in the linkage	<ul style="list-style-type: none">• Hospital admission database (primary database)• Emergency department presentation database
Project start date	2015
Project end date	2019
Contact person	A/Prof Frank Sanfilippo E: frank.sanfilippo@uwa.edu.au
Funder	National Health and Medical Research Council

Long-term use and cost-effectiveness of secondary prevention medications for heart disease in Western Australian seniors

There is strong evidence for selected drug therapy in the secondary prevention of heart disease. However, the level of long-term adherence with these drugs after hospital discharge is unknown. Furthermore, long-term outcomes in routine clinical practice will depend on the level of adherence in the population. Our study offers a unique opportunity to assess long-term adherence and its determinants, as well as long-term outcomes and cost-effectiveness, to evidence-based medication following discharge from hospital. We will use recently acquired linked datasets of State and Commonwealth records, including Pharmaceutical Benefits Scheme and Medicare Benefits Scheme data. We will examine three cardiac conditions: coronary heart disease, heart failure and atrial fibrillation. These are overlapping conditions, are age-related, common diseases and impose a large cost burden to society, governments and individuals.

Project start date	2014
Project end date	2019
Contact person	A/Prof Frank Sanfilippo E: frank.sanfilippo@uwa.edu.au
Funder	National Health and Medical Research Council

Burden of rheumatic heart disease (RHD) and impact of prevention strategies: comprehensive evidence to drive the RHD Endgame

Rheumatic heart disease is chronic damage to the heart valves caused by repeated bouts of acute rheumatic fever. Both are preventable, yet rates among Indigenous Australians are of the highest recorded. We propose to undertake the first multi-jurisdictional study of these conditions to determine trends in occurrence and evaluate the impact of existing interventions in Australia. Findings will be used to inform the development of a roadmap to remove RHD as a public health problem in Australia.

Project start date	2018
Project end date	2020
Contact person	A/Prof Frank Sanfilippo E: frank.sanfilippo@uwa.edu.au
Funder	National Health and Medical Research Council