




# First stroke incidence, causes, treatments, and outcomes for Aboriginal Peoples in South Australia and the Northern Territory: a pilot prospective study

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**The known:** Most information about stroke in Aboriginal and Torres Strait Islander Peoples is based on retrospective studies and historical records of limited accuracy.

**The new:** In a pilot study undertaken in the Northern Territory and South Australia, we found that a population-based study of the incidence of stroke in Aboriginal people, reported according to CONSIDER guidelines, is feasible.

**The implications:** Our stroke incidence pilot study indicates the potential of a more comprehensive study. To serve Aboriginal communities, research reports should follow the CONSIDER principles, and our pilot study excelled in this regard.

In Australia, about 38 000 strokes are recorded each year, and stroke is the leading cause of disability and the third leading cause of death.<sup>1,2</sup> For Aboriginal and Torres Strait Islander Peoples (hereinafter respectfully, Aboriginal people), detailed stroke incidence data are sparse; most studies provide evidence that the age-standardised incidence is two to three times as high as for non-Indigenous people,<sup>3-5</sup> and as much as 6.5 times as for those aged under 55 years.<sup>4</sup> Aboriginal stroke incidence data are mostly derived from retrospective sources (linked administrative data and retrospective clinical collections); the single, prospective ideal report included very small cell sizes, affecting precision, generalisability, and clinical utility.<sup>4</sup>

Complex historical, political, and social factors contribute to health disparities between Aboriginal and other Australians, and these factors influence modifiable cardiovascular risk factors.<sup>6,7</sup> Clarifying which risk factors contribute most to population-attributable stroke risk would enable more effective primary and secondary prevention.<sup>8</sup> In hospital, it is uncertain whether Aboriginal people receive the same evidence-based stroke-related care as other people. Such management includes time-critical investigations required for emergency treatments, access to multidisciplinary stroke assessments, and secondary prevention.<sup>9,10</sup>

We undertook a three-month pilot study in the Northern Territory and South Australia to determine the feasibility of a prospective, population-based stroke incidence study, assessing the antecedents, management, and short term outcomes of stroke in Aboriginal people, that satisfied both the criteria of an ideal stroke incidence study,<sup>11</sup> and the Consolidated criteria for strengthening reporting of health research involving Indigenous peoples (CONSIDER).<sup>12</sup>

## Abstract

**Objective:** We performed a pilot stroke incidence study, focused on feasibility and inclusion of the CONSIDER reporting guidelines, to model the design of a future population-based study aiming to definitively determine stroke incidence, antecedents, treatment, and outcomes.

**Study design:** Prospective stroke incidence study (pilot study).

**Setting, participants:** All people aged 15 years or older who lived in postcode-defined areas of South Australia and Northern Territory (885 472 people, including 45 127 Aboriginal people [5.1%]) diagnosed with stroke for the first time during 1 October – 31 December 2015 and admitted to public hospitals or stroke and transient ischaemic attack clinics.

**Main outcome measures:** Feasibility of a prospective population-based stroke incidence study.

**Results:** Of the 123 participants with first strokes, ten were Aboriginal (8%); the median age of Aboriginal people was 45 years (interquartile range [IQR], 33–55 years), of non-Indigenous people 73 years (IQR, 62–84 years). For Aboriginal people, the age-standardised incidence of stroke was 104 (95% confidence interval [CI], 84–124) per 100 000 person-years, for non-Indigenous people 33 (95% CI, 22–44) per 100 000 person-years. We found that a prospective population-based stroke incidence study in Aboriginal people was feasible, including with respect to establishing an adequate sample size, diagnostic confirmation, identification of incident stroke, confirming stroke subtypes, establishing a stable statistical population, standardising data reporting for comparison with other stroke incidence studies, and ethical research reporting that conforms to CONSIDER guidelines.

**Conclusions:** A larger, population-based study of the incidence of stroke in Aboriginal people is both feasible and needed to provide robust estimates of stroke incidence, antecedents, treatments and outcomes to help guide strategies for reducing the risk of and outcomes of stroke in Aboriginal people.

## Methods

Our prospective stroke incidence study was part of a suite of studies conceived by the South Australia and Northern Territory Stroke Study (SAINTSS) group, a partnership between Aboriginal and non-Indigenous cardiovascular researchers and an Aboriginal advisory group. As stroke incidence was defined as an area of research interest, this study was designed to determine the feasibility of conducting a large population-based stroke incidence study. We evaluated the feasibility of our approach according to the criteria of the ideal stroke incidence study design<sup>11</sup> and the Consolidated criteria for strengthening reporting of health research involving Indigenous peoples

(CONSIDER)<sup>12</sup> (Supporting Information, table 1). The reporting of our study conforms with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guideline.<sup>13</sup>

## Participants

All people aged 15 years or older who lived in postcode-defined areas of South Australia and the Northern Territory (Box 1) diagnosed with stroke for the first time during 1 October – 31 December 2015 were invited to participate in our study. The regions included Greater Alice Springs, Greater Darwin, Port Lincoln, Whyalla, Port Augusta, and northwestern and northern Adelaide, with a total population of 885 472 people, including 45 127 Aboriginal people (5.1%).<sup>14</sup> The proportions of Aboriginal people in the included areas are larger than the national mean, and these areas had previously been included in prospective and retrospective stroke incidence studies that compared Aboriginal and other Australians.<sup>3,4,15,16</sup>

Stroke was defined according to the World Health Organization clinical definition.<sup>17</sup> We included definite (neuroimaging evidence) and probable strokes (focal neurological deficit lasting at least 24 hours or leading to death) assessed independently by two neurologists; disagreements were resolved by a third vascular neurologist. Transient ischaemic attacks and possible strokes were not included.

We invited people who had been admitted to public hospitals or to stroke and transient ischaemic attack clinics. Stroke episodes not leading to hospital admission are rare<sup>15,18</sup> and there were no private emergency department admissions during the study period in the included areas. People were screened for inclusion prospectively by reviewing emergency department admission lists and retrospective review of coded cases (International Classification of Diseases, tenth revision, Australian modification [ICD-10-AM] codes I60, I61, I62.9, I63, I64). Stroke and transient ischaemic attack clinic patient records were reviewed to ensure comprehensive case ascertainment. All potential participants were then approached for consent; if they agreed, they provided written consent to participation. We did not record the number

of people excluded because they did not consent. We did not include people from the National Death Registry given previous low yield from this data source.<sup>18</sup>

## Data collection

We used an electronic data template for collecting demographic details, employment status, general practitioner, and pre-stroke functional status (modified Rankin Scale score<sup>19</sup>). We also collected information about previous diagnoses and treatment of stroke risk factors, in-hospital stroke-specific investigations, treatments and assessments, and discharge medications. At three-month follow-up, a nurse proficient in stroke care used a structured telephone protocol to collect information on smoking status, current medications, employment status, and post-stroke modified Rankin Scale score.

Clinical and radiological information was verified by stroke neurologists (authors TJK, EC) using the Trial of ORG 10172 in Acute Stroke Treatment (TOAST)<sup>20</sup> and SMASH-U intracranial haemorrhage (ICH)<sup>21</sup> criteria. Patients were deemed eligible for thrombolysis and endovascular thrombectomy if standard eligibility criteria were met.<sup>22</sup>

## Statistical analysis

The statistical significance of between-group differences was assessed in Student *t* tests (continuous variables), Mann–Whitney *U* tests (non-parametric variables), and Fisher exact tests (binary outcomes);  $P < 0.05$  was deemed statistically significant (unadjusted for multiple comparisons). Crude incidence rates (per 100 000 person-years) were calculated by Indigenous status and 10-year age group, with 95% confidence intervals (CIs) estimated using the Poisson distribution. Incidence rates (overall and for people under 55 years) were also standardised to the WHO world population, using the direct method.<sup>23</sup> Census data for the selected regions were used for denominators.<sup>14</sup> We also calculated incidence rate ratios (IRRs) with 95% CIs. All statistical analyses were performed with STATA 13.0 (Stata Corp, College Station, Texas, USA).

## Positionality

The authorship team includes senior Aboriginal and non-Indigenous researchers. Angela Dos Santos, a Gumbaynggirr and Kwiamble woman living on Wangal Country, analysed the data, and wrote and revised the draft manuscript. Senior author Alex Brown, a Wadi Wadi man of the Yuin Nation from the NSW south coast and working on Kurna Country in South Australia, provided culturally appropriate guidance on study conception, scope, framing, interpretation, and dissemination; he also prompted and guided the suite of studies on Aboriginal stroke undertaken by the author group. Luke Burchill, a Yorta Yorta and Dja Dja Wurrung man from Mooroopna, Victoria, is currently living on Dakota and Ojibwe country in the United States; provided culturally appropriate guidance on framing, interpretation, and dissemination. Edmund Cheong led data cleaning and phenotyping. Timothy Kleinig conceived the project, obtained funding, engaged sites, supervised Angela Dos Santos, and phenotyped stroke cases. All authors provided critical review of the manuscript for important intellectual content and adhered to guidelines for ethical conduct in research with Aboriginal and Torres Strait Islander Peoples.

## Community participation and governance

The study was prompted by a national stroke meeting presentation by Aboriginal researcher and senior author Alex Brown in 2013,

### 1 The regions of South Australia and the Northern Territory included in our pilot study



who co-supported a researcher and community representative meeting hosted by the Wardliparingga Aboriginal research theme at the South Australian Health and Medical Research Institute in early 2014. Researchers and community leaders confirmed stroke was a health priority and guided development of this pilot study (among other research<sup>4</sup>), which was further guided by peak Aboriginal organisations (the Council of Aboriginal Elders and Aboriginal Health Council in South Australia; the Aboriginal Medical Service Alliance in the Northern Territory) representing the communities involved. Further, local community consultation was undertaken during local visits (for instance, to the Pika Wiya Aboriginal Health Service, Port Augusta). Through their leadership, appropriate feedback structures were developed, forming strong relationships between communities and the research team. The methodology (eg, the consent process) was

refined and tailored to each community, which enabled wide applicability and dissemination of preliminary study findings. At community request, the lessons learned were promptly incorporated into developing the stroke component of the co-designed South Australian Health and Medical Research Institute-led South Australian Aboriginal Heart and Stroke plan,<sup>24</sup> instrumental in fostering early adoption of telehealth stroke services in South Australia and the Northern Territory. Finally, data analysis and interpretation were led by Angela Dos Santos. This process not only fostered relationships necessary to fulfil the CONSIDER reporting criteria but highlights the importance of adhering to principles of data sovereignty, affirming the rights of Aboriginal communities to govern the use of their data, thereby ensuring that the study respects and upholds the autonomy and cultural integrity of the people involved.<sup>25</sup>

## 2 The feasibility criteria of an ideal stroke incidence study,<sup>11</sup> and the performance of our pilot study with respect to these criteria

Feasibility criterion	Intended research design and rationale	Extent of feasibility	Implications for future study design and conduct
Incidence studies			
Sample size	Sample size calculated to allow robust estimate	HIGHLY FEASIBLE Could recruit sufficient number of participants	A study of adequate length will recruit sufficient participants
Consent	Capture all incident cases in the included areas	PARTIALLY FEASIBLE Hospital cases identified, but not all could not be included because some people did not consent to participation	Obtain ethics approval for waiver of individual consent to access minimum data (age, sex, Indigenous status, region) for incidence calculation
Diagnostic confirmation (stroke/subtype)	Assessment of imaging to define stroke subtype	HIGHLY FEASIBLE Assessment of neuroimaging completed independently by two neurologists	Essential component of prospective stroke incidence study
Ideal stroke incidence study			
Complete, community-based case ascertainment, based on multiple overlapping sources	Capture all incident cases in the included areas	NOT FEASIBLE Multiple overlapping sources not feasible because of limited funding	Funding required to enable hot pursuit of cases in hospital, including stroke deaths, general practitioners, community health clinics, and residential aged care
World Health Organization definition	Comparable with overseas incidence studies	HIGHLY FEASIBLE Clinical definition, combined with confirmatory neuroimaging used	Funding needed to support experienced personnel to assess prospective cases and the expertise to assess neuroimages
First stroke	Comparable with overseas incidence studies	HIGHLY FEASIBLE Thorough history and review of case notes to ensure participants with recurrent stroke were not included	Funding needed to support experienced personnel to evaluate cases
Large, well defined, stable population	Facilitates stable denominator	HIGHLY FEASIBLE Enrolment using pre-defined postcodes ensured an accurate population denominator	A larger study would include states to minimise missing of residents moving in and out of the study area
Reliable method for estimating denominator	Facilitates accurate denominator	HIGHLY FEASIBLE Official census statistics used	Official census statistics used
Whole years of data	Avoids confounding by seasonal variations	HIGHLY FEASIBLE Consecutive data collected during the study period	A properly funded study would have an appropriate duration of minimum three years
No combining of more than five years' data	Incidence rates can vary secularly over five-year periods	HIGHLY FEASIBLE Study duration of only three months because of funding limitations	A larger study would probably include three years' data
Men and women assessed separately	To assess differences	HIGHLY FEASIBLE Not done for the pilot study because of small sample size	A study with a larger sample size would allow meaningful comparisons of sexes
Standard mid-decade age bands (eg, 55–64 years)	Comparable with overseas incidence studies	HIGHLY FEASIBLE Data presented in this way	Data will be presented this way
Reporting of 95% confidence intervals for incidence rates	Comparable with overseas incidence studies	HIGHLY FEASIBLE Data presented in this way	Data will be presented this way

### Ethics approval

The study was approved by the Aboriginal Health Research Ethics Committee in South Australia (04-15-629), Government of South Australia Health Research Ethics Committee (HREC/15/RAH/337), the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health (HREC-2015-2440), and the Central Australia Human Research Ethics Committee (HREC-15-346).

### Results

We found that a population-based study of the incidence of stroke in Aboriginal people was specifically feasible in the following areas, required for an ideal stroke incidence study: stroke definition, defining incident events, defined population and stable denominator, consecutive data collection, and reporting of appropriate age-bands and statistical methods (Box 2). Further investment beyond that for the pilot study would be required to maximise hot and cold pursuit methods in communities to identify out-of-hospital events. With respect to the CONSIDER criteria, our approach was feasible with respect to governance, prioritisation, relationships, methodology, participation, capacity, analysis, and interpretation of data and dissemination (Box 3).

### Baseline characteristics

We enrolled 166 people in our study; 38 people with previous strokes and five who did not live in the selected areas were excluded from our analysis. Of the 123 participants with first strokes, ten were Aboriginal (8%); their median age was 45 years (interquartile range [IQR], 33–55 years) and 73 years (IQR, 62–84 years) for non-Indigenous people. Nine Aboriginal (90%) and sixteen non-Indigenous people (14.1%) were under 55 years of age (Box 4).

### Incidence of first stroke

The overall age-standardised incidence of stroke was 36 (95% CI, 25–48) per 100 000 person-years; for Aboriginal people it was 104 (95% CI, 84–124) per 100 000 person-years, for non-Indigenous people 33 (95% CI, 22–44) per 100 000 person-years. Among people under 55 years of age, the age-standardised incidence was respectively 65 (95% CI, 49–80) and seven (95% CI, 2–13) per 100 000 person-years (Box 5).

### Hospital and post-discharge management of stroke

Differences between Aboriginal and non-Indigenous people in sex distribution, stroke types, employment, general practitioner status, and cardiovascular risk factors were not statistically

### 3 The feasibility criteria of the CONSIDER guidelines,<sup>12</sup> and the performance of our pilot study with respect to these criteria

Feasibility criterion	Intended research design and rationale	Extent of feasibility	Implications for future study design and conduct
Governance	Recognise the importance of Indigenous self-determination and leadership	HIGHLY FEASIBLE Several Aboriginal organisations were involved in this study	A larger study will report on relationships built between researchers and Indigenous community and organisations
Prioritisation	Shows how research priorities reflect Indigenous health priorities	HIGHLY FEASIBLE Aboriginal organisations were consulted, and co-developed research aims	Essential component of Indigenous health research
Relationships (Indigenous participants and research team)	Describes the ethics processes, the extent to which the research involved Indigenous people, and the expertise of the research team in Indigenous health research	HIGHLY FEASIBLE All Aboriginal ethics bodies approved the study after extensive discussions with Aboriginal people and in the understanding that the team has experience and knowledge of Aboriginal histories and culture	Essential component of Indigenous health research
Methodology	Appropriate methodology for the research question	HIGHLY FEASIBLE	Essential component of prospective stroke incidence study
Participation	Relates to the use of data gathered for additional analysis outside the original ethics application and consideration of the burden shouldered by Aboriginal organisations and participants in providing their time and knowledge	HIGHLY FEASIBLE Data will be analysed only for this study; further analyses need separate ethics approval. Participants were not remunerated because data collection was standard hospital procedure	A well funded project could remunerate Aboriginal organisations and participants. If data collection is outside usual care, remuneration will be provided
Capacity	Report on the capacity building components of the research process for both Indigenous and non-Indigenous researchers	HIGHLY FEASIBLE Aboriginal researchers are part of the research team	A well funded study could allow non-Indigenous researchers to undertake cultural safety training before the study and fund positions for Aboriginal team members
Analysis and interpretation	Presentation of the data should use a strengths-based approach and incorporate cultural beliefs and values	HIGHLY FEASIBLE Data analysis and interpretation are undertaken by all researchers in the team, including Aboriginal researchers. Specific attention is paid to not affirming stereotypes or bias	A larger study could bolster the team and include more Aboriginal researchers to strengthen the data analysis and interpretation
Dissemination	Dissemination of findings should not only use usual research pathways but also to all relevant Indigenous people	HIGHLY FEASIBLE By building relationships with our Indigenous stakeholders and community groups, pilot study findings will be widely communicated	Further funding would help communication of findings to all relevant people and community groups

#### 4 Baseline characteristics of 123 people aged 15 years or older residing in selected areas of the Northern Territory and South Australia who had been diagnosed with stroke for the first time during 1 October – 31 December 2015

Characteristic*	Aboriginal people	Non-Indigenous people	P
<b>Number of people</b>	10	113	
<b>Demographic characteristics</b>			
Sex (men)	5 (50%)	67 (59%)	0.74
Age (years), median (IQR)	45 (33–55)	73 (62–84)	< 0.001
Under 55 years of age	9 (90%)	16 (14%)	< 0.001
Employed	3 (30%)	27 (24%)	0.70
<b>Stroke admission characteristics</b>			
General practitioner	9 (90%)	103 (91%)	1.0
Pre-stroke modified Rankin Scale score: 0–2	9 (90%)	74 (65%)	0.16
Initial presentation to non-primary stroke centre	5 (50%)	30 (27%)	0.14
Completed NIHSS on admission	1 (10%)	35 (31%)	0.28
NIHSS score, median (IQR)	3	6 (4–11)	0.44
<b>Stroke risk factors</b>			
Obesity	4 (40%)	22 (19%)	0.22
Hypertension	5 (50%)	77 (68%)	0.30
Treated	3 [60%]	59 [77%]	0.51
Diabetes	5 (50%)	29 (26%)	0.14
Treated	2 [40%]	22 [76%]	0.14
Hypercholesterolaemia	5 (50%)	55 (49%)	1.0
Treated	3 [60%]	45 [82%]	0.26
Ischaemic heart disease	1 (10%)	23 (20%)	0.68
Rheumatic heart disease	1 (10%)	3 (2.6%)	0.29
Peripheral vascular disease	0	6 (5.3%)	1.0
Atrial fibrillation	2 (20%)	20 (18%)	1.0
Treated with anticoagulation	0	17 [85%]	0.043
Smoked (ever)	5 (50%)	57 (50%)	1.0
Consumed alcohol	5 (50%)	53 (47%)	1.0
<b>Stroke types</b>			
Ischaemic stroke	9 (90%)	92 (81%)	0.69
Intracerebral haemorrhage	1 (10%)	19 (17%)	1.0
Subarachnoid haemorrhage	0	2 (1.8%)	1.0

IQR = interquartile range; NIHSS = National Institute of Health Stroke Scale.<sup>26</sup> \* Summary of missing data is included in the [Supporting Information](#), table 2. ♦

significant (Box 4). All three eligible Aboriginal people received intravenous thrombolysis, as did six of 24 eligible non-Indigenous people; neither of the two Aboriginal people with large vessel occlusion underwent endovascular thrombectomy, but four of ten non-Indigenous did (Box 6).

Recommended pre-stroke management of diabetes mellitus (two of five, 40% *v* 22 of 29, 76%), hypertension (three of five, 60% *v* 59 of 77, 77%), hypercholesterolaemia (three of five, 60% *v* 45 of 55, 82%), and atrial fibrillation (none of two *v* 17 of 20, 18%) was recorded for smaller proportions of Aboriginal than non-Indigenous people, but the differences were not statistically significant, with the exception of atrial fibrillation (Box 4).

On discharge, smaller proportions of Aboriginal than non-Indigenous people who had had ischaemic stroke were

prescribed a statin (four of nine, 44% *v* 69 of 92, 75%) or antiplatelet or anticoagulant therapy (eight, 89% *v* 69, 100%), but the differences were not statistically significant. Three-month follow-up was completed for a smaller proportion of Aboriginal (four, 40%) than of non-Indigenous people (97, 79%) (Box 6).

### Discussion

Our three-month prospective pilot stroke incidence study undertaken in selected regions of Australia indicated that a larger prospective study would be feasible. In particular, it would be highly feasible to define stroke, determine first ever stroke events (incident cases), confirm stroke subtype, define a stable population, and present the data in a manner that would make it comparable to other incidence studies.<sup>11</sup> Complete case ascertainment based on

### 5 Estimated age-specific annual incidence rates of stroke for people residing in selected areas of the Northern Territory and South Australia, raw and standardised to the WHO world population<sup>22</sup>

Age group (years)	Aboriginal Peoples		Non-Indigenous people		Incident rate ratio (95% CI)
	Number/ population	Rate per 100 000 (95% CI)	Number/ population	Rate per 100 000 (95% CI)	
0-14	3555	—	37 116	—	—
15-24	1/2126	47 (0-139)	1/26 397	4 (0-11)	12 (1.0-236)
25-34	2/1737	115 (0-275)	0/32 189	—	—
35-44	2/1378	145 (0-346)	8/28 084	28 (9-48)	5.1 (1.0-20)
45-54	2/1211	165 (0-394)	7/28 597	24 (6-43)	6.8 (1.0-30)
Under 55	7/10 007	70 (18-122)	16/152 383	10 (5-16)	7 (3-16)
55-64	2/768	260 (0-621)	18/24 997	72 (39-105)	3.6 (1.0-14)
65 or older	1/465	215 (0-636)	79/32 834	241 (188-294)	0.9 (0-5)
All ages	10/11 240	89 (33-144)	113/210 214	54 (44-64)	1.7 (1.0-3)
WHO world population-standardised					
All ages	—	104 (84-124)	—	33 (22-44)	2.9 (2-4)
Under 55 years	—	65 (49-80)	—	7 (2-13)	9 (4-20)

CI = confidence interval; WHO = World Health Organization. ◆

multiple overlapping sources was not feasible for our pilot study. This could be of particular importance, as people with stroke symptoms who live in remote communities (which include a larger proportion of Aboriginal Peoples than of other Australians) may not have access to hospital care. Importantly, data linkage studies of differences in stroke incidence do not include non-hospital data sources for non-fatal cases,<sup>3,4</sup> so we address this evidence gap. A larger study, funded appropriately, will have scope to ensure hot pursuit of hospital cases (including out-of-hospital deaths and people attending transient ischaemic attack clinics) and cold pursuit of cases in general practice, community health clinics, and residential aged care.

Our pilot study has helped determine the duration of a larger study; based on the current pilot results, and by expanding to include surrounding areas, we estimate that a three-year study in this population, assuming a raw incidence rate of 161 per 100 000 population to ascertain about 2300 incident strokes, including 180 in Aboriginal people. The main logistical barriers to a larger study would be informed consent and follow-up. In some Aboriginal communities, consent is a communal rather than an individual decision. The time needed to discuss and consider study enrolment can be extensive, and the acute hospital environment may not be appropriate. Governance structures that adhere to the principles of Aboriginal leadership and self-determination (such as engagement with communities at the trial design stage) could not only improve the likelihood of obtaining consent, but also approve the counting of events without explicit consent and improve health care use after stroke. This would facilitate complete ascertainment and minimise potential bias, which in our pilot study may have led to underestimation of stroke events in Aboriginal people.

Follow-up rates were lower than expected, which meant missing values at three-month follow-up were greater than anticipated (Supporting Information, table 2). Recent investments in telehealth and explicit study design, including telehealth follow-up and linkage with primary health care and Pharmaceutical Benefits Scheme data, would improve follow-up.<sup>27</sup> Further, telehealth offers the added benefit of

involving general practitioners, who can assist in promoting understanding of and adherence to secondary prevention. A larger study could incorporate an interventional component to improve secondary prevention.

For research to be beneficial to Aboriginal communities, every study should use the CONSIDER reporting principles.<sup>12</sup> Our pilot study has shown strength in all these criteria, not least in being prompted by an Aboriginal researcher, and data analysis and interpretation were undertaken by an Aboriginal researcher. Specifically, as described in our methods, an Aboriginal leader identified stroke as a health priority and guided, with community involvement, development of the pilot study. This led to engagement of the peak Aboriginal organisations that represent the communities involved, as well as local community involvement. Community wishes emphasised the importance of not just counting, but acting, which encouraged and facilitated researchers in establishing or enhancing multiple services that benefit Aboriginal people with stroke (for instance, the Alice Springs hospital stroke protocol, the South Australia/Northern Territory Telestroke service, and the SA Aboriginal Heart and Stroke plan).<sup>24</sup> Finally, data analysis and interpretation were led by Angela Dos Santos, an Aboriginal researcher in our team. A larger, better funded study would allow employment of more Aboriginal researchers, further build Aboriginal research capacity, and provide greater benefits for Aboriginal communities.

Despite small numbers limiting the statistical power of our study, we found major differences. The median age of Aboriginal people at their first stroke was 28 years lower than for non-Indigenous people, and the incident rate (standardised to the WHO world population) was almost three times as high as for non-Indigenous people. The higher rates of stroke in younger Aboriginal people with high levels of pre-stroke independence magnify the community impact. The small number of Aboriginal people with stroke precluded a detailed evaluation of predisposing factors. Finally, post-stroke follow-up for Aboriginal people may be suboptimal. All of these factors should be examined in a larger study with the statistical power to better determine priorities for primary, secondary, and tertiary intervention.

## 6 Management and follow-up of 123 people aged 15 years or older residing in selected areas of the Northern Territory and South Australia who had been diagnosed with stroke for the first time during 1 October – 31 December 2015

Characteristic*	Aboriginal Peoples	Non-Indigenous people	P
Total number of observations	10	113	
<b>Inpatient investigations</b>			
Computed tomography (CT brain)	9 (90%)	112 (99%)	0.16
Magnetic resonance imaging (MRI brain)	5 (50%)	78 (69%)	0.29
Vessel imaging <sup>†</sup>	9 (90%)	105 (93%)	0.55
Stenosis	0	20 (18%)	0.36
Echocardiography or transoesophageal echocardiography	8 (80%)	63 (56%)	0.19
Holter monitor or telemetry	8 (80%)	63 (56%)	0.19
<b>Treatment in hospital</b>			
Eligible for tissue plasminogen activator (tPA)	3 (30%)	24 (21%)	0.46
Received tPA	3 [100%]	6 [25%]	0.028
Large vessel occlusion <sup>‡</sup>	2/9 [22%]	10/92 [11%]	0.29
Endovascular thrombectomy	0	4 [40%]	0.52
Antiplatelet or anticoagulant within 48 hours <sup>‡</sup>	8/9 [89%]	89/92 [97%]	0.32
Physiotherapy assessment within 48 hours	9 (90%)	97 (86%)	1.0
Swallow screen	8 (80%)	98 (87%)	0.63
Medications prescribed on discharge from hospital			
Antiplatelet or anticoagulant <sup>‡</sup>	8/9 [89%]	92/92 (100%)	0.09
Antihypertensive medication	6 (60%)	76 (67%)	0.73
Statin <sup>‡</sup>	4/9 [44%]	69/92 (75%)	0.11
<b>Three-month follow-up</b>			
Follow-up completed	4 (40%)	97 (86%)	0.017
Smoking	0/3	8 (7%)	1.0
Prescribed medications			
Anticoagulant or antithrombotic <sup>‡</sup>	3/9 [33%]	76/92 [83%]	0.003
Antihypertensive	3 (30%)	69 (61%)	0.16
Statin <sup>‡</sup>	2/9 [22%]	52/92 [56%]	0.07
Employed	1 (10%)	11 (9.7%)	1.0
Modified Rankin Scale score: 0–2	3 (30%)	45 (50%)	0.74

\* Summary of missing data is included in the [Supporting Information](#), table 2. † CT angiogram, carotid duplex, or magnetic resonance angiogram. ‡ Denominator: people with ischaemic stroke. ◆

### Limitations

Limited funding meant that use of gold standard methodology was not feasible. Missing data rates were high, were not independently confirmed, and were deemed to indicate the absence of the characteristic, potentially introducing biases. Excluding several people who did not consent to participation will have led to underestimates of stroke incidence in both study groups.

### Conclusion

Our prospective pilot stroke study indicated that it is feasible to conduct a large population-based ideal incidence study that adheres to CONSIDER reporting guidelines, but also that further community consultation regarding consent for the use of administrative data and greater resources for local hot and cold pursuit of cases are needed to maximise case ascertainment and follow-up.

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**Data sharing:** The data underlying this report are available if appropriate Aboriginal ethics approval is sought and it is deemed appropriate by the Aboriginal Peoples who own the data. ■

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## Supporting Information

Additional Supporting Information is included with the online version of this article.