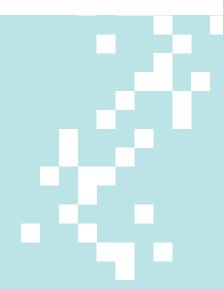
AUSCIR. Australian Stroke Clinical Registry



This publication was produced on behalf of the Australian Stroke Clinical Registry (AuSCR) Consortium partners and was approved by the AuSCR Steering Committee.

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SUMMARY

Welcome to the 2014 Annual Report of the Australian Stroke Clinical Registry (AuSCR). On behalf of the Consortium, we would like to draw your attention to some significant findings highlighted within this document.

- In 2014, 40 hospitals contributed data to the Australian Stroke Clinical Registry (AuSCR) (53% from Queensland and 30% from Victoria). The data provided in the 2014 Annual Report includes information on 8286 patients with 8625 admissions for acute stroke or transient ischaemic attack (TIA) admitted to the participating hospitals.
- To date, national averages have been used for reporting performance, but this crude method for benchmarking promotes conservative performance targets. In this report, for the first time, we have used data from the top performing hospitals in the AuSCR to establish new benchmarks to promote greater performance targets, and describe the potential benefits to patients if these targets were achieved for our national quality of care indicators. These new Australian benchmarks from the top performing hospitals are relevant to monitoring care against the Australian Acute Stroke Clinical Care Standards.* The results highlight important care gaps between the average performance and benchmark which ranged from 9% to 33% and efforts to improve care to be closer to these benchmarks are needed. For example, average national performance for access to thrombolysis for ischaemic stroke was 11%, whereas the achievable benchmark was determined to be 20% (indicating that potentially 490 patients missed out on this treatment). Hospital staff can use this data to review why underperformance is an issue and whether changes can be implemented to improve access and quality of care, where applicable.
- » Among 5485 registrants we were able to attempt to follow-up within 180 days of stroke, 3889 completed our survey (71%; 269 more

- than 2013), providing a wealth of information about recovery after stroke as reported by the patients themselves or their primary caregivers.
- In 2014, 1213 (15%) of the registrants died within 90 days of their hospital admission. This result was obtained from linking the AuSCR data with the National Death Index (NDI) data ensuring complete ascertainment of survival status. We found that patients who were treated in a stroke unit had a 59% reduced risk of death at 180 days when compared to patients not treated in stroke units when we adjusted for differences in the casemix of patients. On average, 79% of the patients were managed on stroke units during 2014, but the best performing hospitals were able to achieve 96% as the benchmark ensuring better outcomes for their patients. If all hospitals were able to achieve this target then potentially a further 1450 patients would have benefited from stroke unit care in 2014 and subsequently survival outcomes improved for three in five of these cases. These findings reinforce the need to ensure all Australians, who experience an acute stroke, have access to stroke unit care and that capacity issues of stroke units need to be reviewed to ensure access is equitable.
- We hope that these findings will create greater impetus for facilitating strong efforts to address areas of underperformance, and also provide an example for other groups that rely on reporting national average performance in efforts to guide quality improvement activity.

^{*} http://www.safetyandquality.gov. au/our-work/clinical-care-standards/ acute-stroke-clinical-care-standard/

PUBLICATIONS

Relevant publications (peer-reviewed journals or other) highlighting the AuSCR program or data:

PUBLISHED ABSTRACTS

Cadilhac D, Andrew N, Kilkenny M, Hill K, Grimley R, Middleton S, Lannin N, Anderson C, Donnan G. Piloting the establishment of performance benchmark methods for acute stroke care in Australian hospitals. International Journal of Stroke 2014; 9(S3):257-258.

Cadilhac D, Lannin NA, Kilkenny M, Kung F, Grabsch B, Donnan G, Levi CR, Dewey H, Hill K, Faux S, Middleton S, Anderson C. Stroke data collection in the Australian Stroke Clinical Registry – progress with a purpose. International Journal of Stroke 2014; 9(S2):18.

Lannin NA, Cadilhac D, Kilkenny M, Kung F, Grabsch B, Donnan G, Levi CR, Dewey H, Hill K, Faux S, Middleton S, Anderson C. Life after stroke – a reflection on patients' experience using data from the Australian Stroke Clinical Registry (AuSCR). International Journal of Stroke 2014; 9(S2):19-20.

Cadilhac D, Lannin NA, Kilkenny MF, Churilov L, Kung F, Grabsch B, Donnan G, Levi C, Dewey H, Hill K, Faux S, Middleton S, Anderson C. Variances in hospital death mortality: experiences from the Australian Stroke Clinical Registry (AuSCR). International Journal of Stroke 2014; 9(S1):19-20.

Kilkenny MF, Dewey H, Andrew N, Lannin NA, Anderson C, Donnan GA, Cadilhac DA. Quality of life and readmission after stroke: the Australian Stroke Clinical Registry experience. International Journal of Stroke 2014; 9(S1):21.

Cadilhac D, Lannin NA, Kilkenny MF, Kung F, Grabsch B, Donnan G, Levi C, Dewey H, Hill K, Faux S, Grimley R, Middleton S, Anderson C. The Australian Stroke Clinical Registry – a national tool responsive to state needs. International Journal of Stroke 2014; 9(S1):21-22.

Cadilhac DA, Lannin NA, Kilkenny MF, Kung F, Grabsch B, Donnan GA, Levi CR, Dewey HM, Hill K, Faux S, Middleton S, Anderson CS. Variances in hospital mortality following stroke: experiences from the Australian Stroke Clinical Registry (AuSCR). (B1710) Cerebrovascular Diseases 2014; 37(suppl 1):452.

ANNUAL REPORT PUBLICATION

Cadilhac DA, Lannin NA, Anderson CS, Andrew N, Kim J, Kilkenny M, Kung F, Grabsch B, Levi C, Faux S, Dewey H, Hill K, Donnan G, Middleton S on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Annual Report 2013. The Florey Institute of Neuroscience and Mental Health; November 2014, Report No 5, pages 59.

PUBLIC PRESENTATIONS

(INVITED OR PEER REVIEWED)

In 2014, the following presentations about the Australian Stroke Clinical Registry were given:

Middleton S, on behalf of the AuSCR Management Committee. Australian Stroke Clinical Registry: an Update. National Stroke Workshop, Melbourne, 17th March 2014.

Cadilhac D, on behalf of the AuSCR Management Committee. Variances in hospital mortality: experiences from the Australian Stroke Clinical Registry (AuSCR). European Stroke Conference, France, May 2014. [Poster]

Moss K, on behalf of the AuSCR team. Followup telephone interviews – processes and outcomes for the Australian Stroke Clinical Registry. Stroke Division seminar, The Florey Institute of Neuroscience and Mental Health, 16th May 2014.

Grabsch B, on behalf of the AuSCR Management Committee. An overview of the Australian Stroke Clinical Registry. Presentation to undergraduate Health Information Systems students, La Trobe University, 29th May 2014.

Grabsch B, on behalf of the AuSCR Management Committee. Getting the most out of the Australian Stroke Clinical Registry. Queensland Statewide Stroke Clinical Network Forum, Toowoomba, 13th June 2014.

Cadilhac D, on behalf of the AuSCR Management Committee. Variances in hospital mortality: Experiences from the Australian Stroke Clinical Registry (AuSCR). Stroke Society of Australasia Annual Scientific Meeting, Hamilton Island, August 2014

Grimley R, Rowley D, Trinder J, Casey M. Monitoring of clinical indicators utilising the Australian Stroke Clinical Registry enables early response to declining performance in quality of stroke care. Stroke Society of Australasia Annual Scientific Meeting, Hamilton Island, August 2014. [Poster]

Anderson C, on behalf of Cadilhac D, Lannin N, Kilkenny M, Kung F, Grabsch B, Donnan G, Levi C, Dewey H, Hill K, Faux S, Grimley R, Middleton S representing the AuSCR Project, Management and Steering Committees. Australian Stroke Clinical Registry: a national tool that is responsive to state needs. Stroke Society of Australasia Annual Scientific Meeting, Hamilton Island, August 2014.

Cadilhac D, on behalf of the AuSCR Management Committee. Stroke data collection in the Australian Stroke Clinical Registry – progress with a purpose. SmartStrokes 10th Australasian Nursing and Allied Health Stroke Conference, Sydney, August 2014.

Lannin NA, Cadilhac DA, Kilkenny M, Kung F, Grabsch B, Donnan G, Levi C, Dewey H, Hill K, Faux S, Middleton S, Anderson CS. Life after stroke – a reflection on patients' experience using data from the Australian Stroke Clinical Registry (AuSCR). SmartStrokes 10th Australasian Nursing and Allied Health Stroke Conference, Sydney, August 2014.

Grabsch B, on behalf of the AuSCR Management and Steering Committees. Australian Stroke Clinical Registry: progress and future plans. Registry Special Interest Group, 19th September 2014.

Cadilhac DA, Lannin NA, Kilkenny M, Churilov L, Kung F, Grabsch B, Donnan G, Levi C, Dewey H, Hill K, Faux S, Middleton S, Anderson CS. Variances in hospital mortality: experiences from the Australian Stroke Clinical Registry (AuSCR). Austin Research Week, Heidelberg, October 2014. [Poster]

Cadilhac D, Andrew N, Kilkenny M, Hill K, Grimley R, Middleton S, Lannin N, Anderson C, Donnan G on behalf of the Stroke123 investigators. Reviewing the options for performance benchmarks for acute stroke care in Australia. NHMRC Translation Conference, December 2014.

Grabsch B, Salama E. AuSCR live reports. Queensland Statewide Stroke Clinical Network Forum, Brisbane, December 2014.

ACKNOWLEDGMENTS

We gratefully acknowledge contributions made by the AuSCR staff at the Florey Institute of Neuroscience and Mental Health (The Florey): Karen Moss, Adele Gibbs, Alison Dias, Gary Eaton, Robin Armstrong, Enna Salama, Kasey Wallis and Kate Paice. We also appreciate the expert statistical advice from Professor Leonid Churilov (The Florey) and contributions from the Information Technology team at The Florey in supporting the AuSCR server hosting and other technical processes.

We acknowledge the generous financial support of the AuSCR operations in Victoria by the Victorian Stroke Clinical Network, through State Government Victoria. The National Health and Medical Research Council (NHMRC), Monash University, Queensland Health and the National Stroke Foundation have also provided financial support through the Stroke 123 Better Health Partnerships grant.

The Florey Institute of Neuroscience and Mental Health acknowledges the strong support from the Victorian Government and in particular the funding from the Operational Infrastructure Support Grant.

We also acknowledge the staff at the Australian Institute of Health and Welfare for their role in linking the AuSCR data to the National Death Index.

CONTRIBUTION TO ANNUAL REPORT

Florey AuSCR Office: Brenda Grabsch is responsible for overall coordination of the AuSCR program and provides invaluable support to participating hospitals and other AuSCR program staff and collaborators.

Francis Kung was the National Data Manager (until January 2015) when Sam Shehata was employed in this role. Both have been essential in maintaining the integrity of the database, facilitating data quality checks and providing information for the completeness of data, opt-out and case ascertainment tables.

Monash University: Joosup Kim, Nadine Andrew, and Monique Kilkenny (Stroke and Ageing Research Centre, Monash University) conducted the AuSCR data analyses for this report and as required throughout 2014. We are most appreciative of their contributions. The majority of analyses presented in this report were undertaken by Dr Joosup Kim, Research Fellow, under the supervision of Associate Professor Dominique Cadilhac using de-identified data supplied securely by Mr Sam Shehata (AuSCR Data Manager [2015]). Dr Monique Kilkenny (Senior Research Officer) was responsible for the analysis of the risk adjusted mortality data (in consultation with Associate Prof Leonid Churilov from the Florey).

We are grateful to the National Stroke Foundation for the compilation and mail out of the AuSCR follow-up questionnaires. This report would not have been possible without the efforts of doctors, nurses, ward clerks and other staff from participating hospitals who have contributed data to the AuSCR. Lead clinical staff for the AuSCR in 2014 and participating hospitals are gratefully acknowledged below.

New South Wales Nisal Gange Lyndell Scott Sharan Ermel Craig Anderson Richard Geraghty Robert Scott Tanya Frost Christie Bithrey Rohan Grimley Amanda Siller Patrick Groot Nadia Burkolter Graham Hall Rebecca Sjodin Casey Hair Melissa Gill Nicola Hall Ella Stanfield Peter Hand James Hughes Thomas Kraemer Dawn Harwood Chris Staples Leah Thompson Fiona Ryan Joel Iedema Mark Mackay Amanda Styles Richard White Tracy Johnson Nerylee Morris Ian Wilson Peter Jones Marie Williams Kate Nolan Queensland Sarah Kuhle Raylene Williams Penny Pendrey Pamela Atkinson Paul Laird Andrew Wong Anne Rodda Pradeep Bambery Graham Mahaffev Jerry Wong Zofia Ross Merv McAllister Lillian Wong Kristen Rowe Haylee Berrill Gai Meade Ann Woolcock Mary-Ellen Booker Margaret Stevenson Joanne Branch Ian Meade Victoria Belinda Stojanovski Carolyn Beltrame Vicki Thomas Mildred Chitawaba Suzana Milosevic Damiane Clifford Mandy Parrish Kate Birch Lyndsay Trewhella Deirdre Cooke Timothy Richardson Chris Bladin Louise Weir Ernie Butler Dijana Cukanovic-Krebs Linda Roche Western Australia Rachel De Monte Juan Rois-Gnecco Chris Charnley Timothy Bates Martin Dunlop Linda Roper Douglas Crompton Cathy Forrester Paula Easton Donna Rowley Vanessa Crosby Tasmania Alyssia Economidis Arman Sabet Helen Dewey Helen Castley Linda Edwards **Noel Saines** Allison Easden

PARTICIPATING HOSPITALS

New South Wales Ipswich Royal Brisbane & Women's Northern Armidale Rural Referral Logan Toowoomba Peninsula Health (Frankston) Townsville Bathurst Base Mackay Base Royal Children's Orange Health Service Mater Adult Wesley Royal Melbourne Royal Prince Alfred Nambour Victoria Warrnambool Base Hospital Tamworth Rural Referral Prince Charles Albury Base Hospital Western Australia Queensland Princess Alexandra Austin Health Swan District Bundaberg Queen Elizabeth II Jubilee Ballarat Health Services **Tasmania** Redcliffe Cairns Bendigo Health Royal Hobart Redland Gold Coast Eastern Health (Box Hill) Gympie Robina Goulburn Valley Health Hervey Bay Rockhampton Latrobe Regional

CHAIRPERSONS' REPORTS

STEERING COMMITTEE



The Australian Stroke
Clinical Registry (AuSCR)
Steering Committee
members are representative of stakeholders from
the wider professional
and consumer stroke
community across
Australia. Their role is to
oversee the governance

and strategic direction of the AuSCR. Their commitment to this important task is evidenced by all members' continued involvement from 2013 into 2014; we are grateful for their ongoing contribution and support.

Following on from the substantial growth in AuSCR participation in Queensland over 2012-2013, funding from the Victorian Stroke Clinical Network has enabled increased AuSCR activity in Victoria in 2014 with the aim of bringing on board all major hospitals with 100 or greater stroke admissions per annum over 2014-2015. The prospect of yet another state with near universal AuSCR participation is gratifying.

In 2013, the Australian Stroke Coalition (ASC) acknowledged the significant gaps that existed between recommended stroke care and the actual care delivered to patients. The ASC recognised the important role that data can have in facilitating improvements to the quality of care and acknowledged that, whilst stroke data are valued and collected across many Australian hospitals, there were multiple data collection tools being used and inconsistent participation. Consequently, the ASC endorsed the development of an integrated technological solution capable of collecting data through a

single portal across multiple programs. Under the governance of the ASC Data and Quality Working Group (now Committee), a new online integrated data management system (the Australian Stroke Data Tool – AuSDaT) is being developed. The AuSCR is a major partner in this project.

The data collected in the AuSCR are not systematically and routinely available elsewhere, and the analyses presented in this report are a testament to the power of the data for informing quality improvement activities. However, the realities of sustainable funding are never out of sight since only short term (1-4 years) commitments have been made. We continue to explore options that might contribute to the ongoing sustainability of the AuSCR.

I would like to express my appreciation to all AuSCR Management and Steering Committee members, the AuSCR Research Task Group and AuSCR staff/ analysts who have contributed in so many ways to the consolidation and expansion of the AuSCR. In particular, Dominique Cadilhac (Data Custodian), Craig Anderson (Chair, Management Committee) and Brenda Grabsch (AuSCR National Coordinator) who continue to play pivotal roles in ensuring the success of the Registry; I thank them for their long-standing efforts. I also pay tribute to the hospital staff, most of whom have heavy clinical loads, who participate in the AuSCR and whose commitment has helped make the Registry what it is today.

Professor Sandy Middleton

MANAGEMENT COMMITTEE



Over 2014, the number of hospitals with ethics approval for AuSCR participation has increased. Operations have consolidated in Queensland and we have expanded sites in Victoria. Nationally, however, several approved hospitals have been

unable to actively contribute data to the Registry for various reasons, in particular due to limited staff resources. We are optimistic that, over time, such barriers impeding participation will be overcome so that the AuSCR can be a truly national registry. Importantly, the merits of the large scale collection and analysis of data on stroke and TIA care have once again been evidenced by the findings presented at national and international conferences.

The Management Committee members, through their contribution to various committees and decision-making processes, have made valuable contributions to the development of the new Australian Stroke Data Tool (AuSDaT). This innovative project is the most significant development for the AuSCR since its inauguration in 2009 and we look forward to the new streamlined and harmonised data collection facility.

Once again we express our appreciation to the National Stroke Foundation for its critical role in the follow-up mail out processes. We also appreciate the support provided by Smart Strokes at its annual conference through the provision of a trade table for the AuSCR.

Achievements in 2014 included:

- We will a work with a work
- » AuSCR Research Task Group review and approval of two external projects, and one core AuSCR project approved
- » AuSCR exhibit at the Smart Strokes (Sydney) conference
- » Presenting AuSCR data at the Queensland Statewide Stroke Clinical Network meetings
- » Receipt of a further year's funding from the Victorian Stroke Clinical Network to consolidate and expand AuSCR participation in Victoria
- » Signing of a Memorandum of Understanding with the Victorian Stroke Telemedicine Project for them to share three month follow-up data that they collect from patients common to both projects, thereby reducing participant burden
- » National Stroke Workshop (March 2014) held with a focus on data quality, performance monitoring, quality improvement and telemedicine
- » The AuSCR Data Dictionary was used as a guide to creating the first National Stroke Data Dictionary to be used with the AuSDaT
- » The AuSCR data were linked with the National Death Index at the Australian Institute for Health and Welfare
- » I would like to thank the Management Committee, Research Task Group members and staff for their ongoing commitment to the AuSCR in 2014.

Professor Craig Anderson

DATA CUSTODIAN REPORT

The Australian Stroke Clinical Registry continues to operate under the data custodianship of the Florey Institute of Neuroscience and Mental Health (The Florey), with direction provided by the AuSCR Management and Steering Committees. In 2014, the Florey AuSCR program team included nine staff who work for the Public Health and Epidemiology Unit of the Stroke Division.



Data analyses for the annual report, or conference presentations and papers, are conducted using de-identified data by experienced epidemiologists, Dr Monique Kilkenny, Dr Nadine Andrew and Dr Joosup Kim, from the Stroke and Ageing Research Centre, School of Clinical Sciences, Monash University under my supervision and, as required, by Prof Leonid Churilov (Head of Statistics, The Florey) and Prof Amanda Thrift (AuSCR Steering Committee member and epidemiologist based at Monash University).

Over 2014, we implemented the addition of a number of new variables to the web tool, all of which required ethics/governance approvals in all participating hospitals:

- » 'Arrival by ambulance' (Victoria)
- » Victorian Stroke Telemedicine (VST) variables sub-set (VST hospitals)
- » 'NIHSS (National Institutes of Health Stroke Scale) on presentation' (national)
- » 'Modified Rankin Scale' at 3 month follow-up (national)

The value of a registry is in the quality of its data and, as the AuSCR continues to grow, we are constantly reviewing processes to ensure that we maintain the quality, integrity and security of the data. I have been ably supported in this important aspect of the AuSCR operations by the National Data Manager (Francis Kung), Victorian Data Manager (Kate Paice) and Information Technology Project Officer (Gary Eaton). Processes for enhancing data quality, completeness and timely data entry include:

- » Data quality checks including case ascertainment reports
- » Regular newsletters with reminders and clarification about data-related issues
- » Ongoing training at hospitals e.g. for new staff
- » Medical record audits of randomly selected registrants
- » Training hospital staff in the use of their live reports
- » Contribution to a national workshop on data and quality to share our experience

To ensure that the AuSCR data continue to facilitate quality improvement we now provide achievable benchmarks derived from the top performing hospitals that provide 15% of the data. This work supplements the standard reporting of national average performance, and highlights what is possible to achieve providing greater motivation to improve care.

With the advent of the Australian Stoke Data Tool, it has been incumbent on the AuSCR Data Custodian to ensure that this new online, integrated data management system is compliant with all processes that safeguard AuSCR data to the same standards as have been in place to date. Each aspect of the build has been designed and reviewed to ensure our confidence in the system, to which we anticipate the AuSCR's transition will be in mid-2016.

I wish to thank all the AuSCR and data analysis staff for their contribution to the AuSCR and this report, as well as the AuSCR Steering and Management Committees for their support. Additionally I thank the NSF who support patient follow-up, as well as the hospital staff who contribute and use the data.

Associate Professor Dominique Cadilhac
Data Custodian (The Florey)

FUNDING 2014

In 2014, the AuSCR Office was supported by funds from The Florey, consumer donations, industry, and allocations from the NHMRC Stroke123 Partnership grant to support the AuSCR activities including expansion in Queensland. Support for senior researchers by the NHMRC, which provides salary via fellowship awards, has assisted with containing staff costs. Further, substantial savings to the AuSCR Office in staff resources have been made possible through the National Stroke Foundation (NSF) that provides significant in-kind support by collating and mailing the AuSCR follow-up questionnaires.

The support from the NSF represents an in-kind contribution of approximately \$13,300. The Smart Strokes Conference organising committee generously provided exhibition display resources at their conference. This support provided an important opportunity to promote the AuSCR and also to interact with participating hospital staff attending these conferences. Members of the Management Committee and Steering Committee and Research Task Group also provide their time 'in-kind'.

During 2014, members of the Management Committee (Dominique Cadilhac, Craig Anderson and Chris Levi) were supported by National Health and Medical Research Council (NHMRC) Fellowships that provided them with salary support to contribute to initiatives such as the AuSCR. Dominique Cadilhac's Fellowship was co-funded by the National Heart Foundation.

| ORGANISATION | AMOUNT |
|--|-----------|
| Florey (via NHMRC grant) | \$168,300 |
| Florey (other) | \$35,484 |
| Queensland Health (Partnership grant) | \$30,000 |
| Monash University* | \$82,019 |
| National Stroke Foundation (Partnership Grant) | \$45,000 |
| Industry (Ipsen and Boehringer Ingelheim) | \$20,500 |
| Consumer donations | \$0 |
| Victorian government | \$250,000 |
| Other** | \$7,634 |
| Total Funding received | \$638,937 |

^{*}NHMRC Partnership grant contribution; staff costs to cover analytic work data reports and follow-up data collection from Heart Foundation/Stroke Foundation Future Leader grant awarded to D. Cadilhac.

^{**}Includes income from projects approved by the Research Task Group to access the AuSCR data.

INTRODUCTION

The Australian Stroke Clinical Registry (AuSCR) Consortium and staff have great pleasure in presenting the 2014 Annual Report covering data collected for patients admitted to participating hospitals between 1 January 2014 and 31 December 2014.

The AuSCR was established in 2009 to provide national data on the process of care and outcomes for patients admitted to hospital with acute stroke or transient ischaemic attack (TIA). The registry was designed to be used in public and private hospitals and is also applicable to adults and children. Therefore, follow-up data collection includes age-appropriate questionnaires for different age groups. Further information about the AuSCR and its development is available online at http://www.auscr.com.au, or in our publications. The provided in the process of the provided in the strong provided in the process of the provided in the process of the provided in the process of the process of the provided in the process of the proce

The purpose of clinical quality registries is to measure quality of care.3 The AuSCR adheres to the national guidelines for best-practice in clinical quality registries.4 The overall goal of the AuSCR is to provide reliable and representative data that can be used to improve the quality of stroke care nationally. Presently, very few registries in Australia have national coverage.⁵ The primary aim of the AuSCR is to provide a mechanism to routinely and prospectively monitor the quality of acute stroke care in hospitals.1 Fundamental to this aim is the registration of all eligible stroke, or TIA, cases admitted to the participating hospitals. In this way, selection bias is minimised. A second aim of the AuSCR initiative is to provide a database that will enable future stroke research in large numbers of people, or in those with certain characteristics, which might otherwise have not been possible. Presently, each hospital has access to their own data and summary 'live' reports which the staff can download from the AuSCR to enable regular quality of care reviews.

In 2014, research to better understand the factors that impact on the quality of care and delivery of evidence-based stroke care through an NHMRC

Partnerships for Better Health grant (Stroke123 Project) remained a major focus, with ongoing work in our Queensland Quality Improvement substudy as well as progressing data linkage approval and ethics applications. Our Nancy and Vic Allen Foundation funded small project undertaken in Queensland with a focus on secondary prevention and improved discharge care planning was also successfully completed. This work permitted us to develop and test the value of using the Achievable Benchmarks of Care (ABCTM)6 method, an approach validated by Hall et al, 2013 using data for stroke,7 whereby the average benchmark of the hospitals with the greatest adjusted adherence representing at least 15% of the data is used. The results of this small project were initially reported at the annual National Stroke Workshop, as part of the Policy and Practice Translation activities for the Stroke123 project (see Partnerships and Collaborations), and this benchmark method has now been incorporated as part of the national performance results provided in this annual report. For the first time, we report achievable national

benchmarks for our national quality of care indicators that represent four of the seven recently released Acute Stroke Clinical Care Standards.⁸

In this 2014 Annual Report, data collected from 40 contributing hospitals for 8625 episodes of care, and the outcomes for 5485 registered patients who were eligible to be followed up between 90 to 180 days are presented. In addition to providing comprehensive graphs of performance and casemix adjusted comparisons of patient outcomes for hospitals we also highlight, for the first time, issues related to incomplete and discrepant data observed during quality checking of data using random medical record audits by the AuSCR Office staff.

PARTNERSHIPS AND COLLABORATIONS

The AuSCR initiative is undertaken by a consortium of two leading academic research institutes, The Florey Institute of Neuroscience and Mental Health (Stroke Division) and The George Institute for Global Health, and two leading non-government organisations, the National Stroke Foundation (NSF) and the Stroke Society of Australasia (SSA). Collectively, these organisations represent a broad section of the Australian clinical and scientific stroke community.

Significant sanction from clinicians and professional associations for the AuSCR initiative has occurred through the AuSCR Consortium partners and the Australian Stroke Coalition (ASC), a network of clinicians and professional associations (www.australianstrokecoalition.com.au). There has also been highly valued support from the Victorian Stroke Clinical Network and the Queensland Statewide Stroke Clinical Network.

In 2014, our NHMRC Partnerships for Better Health grant collaborations through the Stroke123 project have continued with Monash University and Queensland Health contributing funding, along with our existing partner the National Stroke Foundation. Additionally, there is significant in-kind support from various state stroke clinical networks to explore the potential to better understand the quality of care in hospitals using data linkage between the AuSCR and government data. Collaborations are continuing with staff from the Australian Institute of Health and Welfare, the Population Health Research Network and data linkage units based in health departments within various states (including Victoria, Western Australia, Queensland and New South Wales) to work through the processes to enable the linking of the AuSCR data with government data such as the National Death Index and state level admitted episode data and emergency department admissions.

We are also collaborating with the Australian Catholic University, through Professor Sandy Middleton, to ensure that the AuSCR registrants are not followed up twice at 90 days when they are also part of a stroke clinical trial (the T³ Trial) being conducted in several hospitals that also use the AuSCR. In Victoria, we have continued our collaboration with the Victorian Stroke Telemedicine (VST) program. This approach is mutually beneficial since the VST is required to report to government funders on the rates of intravenous thrombolysis use, and the AuSCR provides a system that can be embedded as part of routine health care monitoring to reliably obtain these data.

Once again in 2014, we were supported from industry (Boehringer Ingelheim and Ipsen) in conducting a national workshop on stroke data in March that was co-convened with the National Stroke Foundation. Such events provide additional opportunities for clinicians and academics to be involved in translational activities to further enhance stroke care and outcomes.

A significant collaboration has been that of working closely with the NSF and the ASC to develop and commence the build of the Australian Stroke Data Tool (AuSDaT). AuSDaT, when fully implemented, will provide an integrated data management system for several national stroke programs (AuSCR, NSF audits, SITS [Safe Implementation of Treatments in Stroke] and INSPIRE [International Stroke Perfusion Imaging Registry]). The advantage will be that hospitals need only enter patient data once for it to be available for any of these programs in which they are participating. A significant investment of time, effort and goodwill result in a more efficient, standardised approach to stroke data collection in Australia (see page 53 for further details).

These partnerships and collaborations highlight the close cooperation that exists within the stroke community.

GOVERNANCE STRUCTURE

Accountability and transparency are cornerstones for governance of a clinical registry program. This is particularly important when the data set contains personal identifying information.

The AuSCR has a Steering Committee whereby members agree to participate for a two-year period. The Steering Committee was chaired in 2014 by Professor Sandy Middleton. The members of the Steering Committee in 2014 are listed in Appendix A. The purpose of the Steering Committee is outlined in agreed Terms of Reference and its primary role is in providing the AuSCR governance, maintaining the confidence of all parties involved, and providing contributions to strategic direction. The committee has representatives from

most states in Australia, as well as representation from clinicians, health informatics, epidemiology, consumers, the President of the SSA, the Chair of the Management Committee and the AuSCR Data Custodian. This committee meets three times per year including one joint, face-to-face meeting with the Management Committee.

The Management Committee includes representatives from the consortium partner organisations: all members having clinical backgrounds in medicine, nursing or allied health. The Management Committee is responsible for the day-to-day operation of the AuSCR, with oversight from the Steering Committee, and works with the AuSCR Office to manage the ongoing operations of the registry. This committee meets monthly, including a joint face-to-face meeting with the Steering Committee. For 2014, the Management Committee membership was as follows:

| Professor Craig Anderson (Chair) | The George Institute for Global Health |
|----------------------------------|---|
| A/Professor Dominique Cadilhac | The Florey Institute of Neuroscience and Mental Health/ Monash University |
| Professor Geoffrey Donnan | The Florey Institute of Neuroscience and Mental Health |
| A/Professor Steven Faux | St Vincent's Hospital, Sydney |
| A/Professor Natasha Lannin | La Trobe University and Alfred Health |
| Professor Chris Levi | Hunter Medical Research Institute |
| Professor Helen Dewey | Stroke Society of Australasia |
| Mr Kelvin Hill | National Stroke Foundation |

RESEARCH TASK GROUP

The Research Task Group is independent of the AuSCR Management Committee. The primary purpose of this Research Task Group is to ensure appropriate use and protection of the Australian Stroke Clinical Registry data when it is to be used for research purposes by third parties. The reviews of applications are conducted via email. In 2014, the members of the Research Task Group are listed below.

| Dr Sue Evans (Chair) | Department of Epidemiology and Preventive Medicine, Monash University |
|-------------------------------|---|
| Professor Richard Lindley | The George Institute for Global Health, University of Sydney |
| Professor Ian Cameron | Rehabilitation Studies Unit, University of Sydney |
| Dr Coralie English | Hunter Medical Research Institute |
| Professor Leeanne Carey | The Florey Institute of Neuroscience and Mental Health |
| Professor John McNeil | Department of Epidemiology and Preventive Medicine, Monash University |
| A/Professor Velandai Srikanth | School of Clinical Sciences at Monash Health, Monash University |

METHODS

The AuSCR is a secure online database that enables the collection of a standardised data set (Box 1) that can be used to describe stroke care and outcomes in Australia and permit comparisons of performance within, and between, hospitals. The AuSCR is based on an 'opt-out' model, whereby patients are distributed information outlining the nature and purpose of the information collected, offered an opportunity to ask questions, and are provided with the various options available should they wish to withdraw all, or part, of their data. These options include: submission of an opt-out form to the AuSCR Office; calling the 1800 telephone number (free); emailing the AuSCR administrative email; or directly via hospital staff who use the opt-out function in the AuSCR database. This approach is promoted for registries to reduce the likelihood of selection bias (see http://www.registries.org.au/ reports-publications/guidelines-registries.pdf). To this end, the AuSCR Office has provided a Patient Information Sheet for each participating hospital to use (or a locally modified version to meet ethics committee requirements) to inform patients of their rights. If patients are discharged before receiving the information sheet, the hospital has a specific cover letter that is posted with the information sheet. This Patient Information Sheet is also provided with the follow-up questionnaire at 90 days post-stroke/TIA. At the time of data collection, each hospital is asked to comply with the conditions of the ethical approval and relevant privacy guidelines for the project. As part of record management, the AuSCR Office staff also keep track of the number of

registrants 'opting-out' of the registry. Further information about the opt-out process in the AuSCR is available in the Hospital User Manual: (http://www.auscr.com.au/health-professionals/forms-manuals/hospital-user-manual/).

Staff from participating hospitals enter data on all eligible patients either manually via the web-tool, or by using a data import process, or a combination of both. Clinical staff, who have user access privileges, can view and download standard performance reports for any specified date range. The AuSCR Office staff, with the assistance of the National Stroke Foundation, are responsible for contacting patients 90 to 180 days after their stroke as long as they are known to be alive, have not refused follow-up at the outset or 'opted-out' of the registry. For registrants who are unable to be contacted, survival status is determined using annual data linkage with the National Death Index data made available, through an ethically approved process, by the Australian Institute of Health and Welfare. The AuSCR Office staff also provide: five day helpdesk support for registrants; assistance to hospital staff with completing ethics applications, amendments and annual ethics progress reporting; training for new staff; quality control assessments to ensure hospital data are reliably obtained; as well as coordination of the committee meetings necessary for the governance of the AuSCR.

The general AuSCR website available to the public is: www.auscr.com.au.

BOX 1: THE AUSCR MINIMUM VARIABLE DATA SET USED IN 2014

| IDENTIFYING INFORMATION | PROCESS INDICATORS OF EVIDENCE-BASED CARE |
|--|--|
| » date of birth » sex » address » telephone number » hospital name » contact details for: next of kin (x 2); general practitioner | use of intravenous thrombolysis (tPA) if an ischaemic stroke access to a stroke unit (geographically defined ward area) discharged on an antihypertensive agent care plan provided at discharge (any documentation in the medical record) |
| CLINICAL INFORMATION FOR RISK ADJUSTMENT AND MEASURING TIMELINESS OF CARE DELIVERY | HOSPITAL OUTCOMES DATA |
| » ICD10 codes (diagnosis, medical condition, complications and procedures) » country of birth » language spoken | » date of discharge or » date of death » discharge destination |
| » aboriginal and Torres Strait Islander status» type of stroke | 90 DAY OUTCOME DATA |
| » date & time of stroke onset » date & time of arrival to emergency department » date of admission and inpatient stroke status » transferred from another hospital status | » survivor status » place of residence » living alone status » recurrent stroke episodes since discharge |
| ability to walk independently on admission first-ever (incident) episode status | readmission to hospital quality of life (EuroQoL5D adults/ PedsQoL children up to 18 years old) |

BOX 2: ADDITIONAL QUALITY INDICATORS COLLECTED IN QUEENSLAND AS PART OF THE AUSCR MINIMUM DATA SET

PROCESS INDICATORS OF EVIDENCE-BASED CARE (QUEENSLAND ONLY)

- » mobilisation during admission
- » swallow assessment and formal speech pathologist review
- » aspirin administration <48 hours
- » discharged on anti-platelets or antithrombotics

METHODS FOR ENSURING DATA QUALITY

In 2014, data quality in the AuSCR was assessed via missing and discrepant data reports which were sent to hospitals by the AuSCR Office staff.

The online AuSCR database has built-in logic checks and variable limits to reduce the likelihood of inaccurate data being entered. Mandatory fields have also been created to reduce missing data. In-built functions within the database are used to identify duplicate entries and multiple patient records, which may be merged if necessary (for example, if a patient had more than one admission in the same or different hospitals).

Each new site is also subjected to a 10% random audit of medical records conducted by the AuSCR Office staff after approximately 50 patients are entered in the registry. Following the audit, the site is given a data quality report and suggested ways of improving data quality are discussed and may include additional training or amendments being made to data dictionary items which are found to be ambiguous (findings from this data quality assurance process are reported on pages 26-27).

At the end of 2014, hospitals were requested to provide a list of all admissions based on the AuSCR's ICD10 stroke codes to enable a process of assessing case ascertainment by matching this list to the data in the AuSCR. This process also permits missing data in the AuSCR for ICD10 codes to be obtained.

RESEARCHERS REQUESTING TO USE DATA FROM THE AUSCR

In 2014, there were two applications approved by the Research Task Group:

The impact of discharge planning on post-discharge stroke outcomes (PI: Dr Nadine Andrew, Stroke and Ageing Research Centre, Monash University; Approved: 4th June 2014). This project involved recruiting AuSCR registrants, and their carers, for an exploration of the impact of discharge planning on quality of life and hospital readmissions within the first 3-6 months following stroke.

Health risk behaviours of stroke and TIA survivors and their informal carers (PI: A/P Billie Bonevski, Centre for Translational Neuroscience and Mental Health, University of Newcastle; Approved: 25th November 2014). This project involved recruiting AuSCR registrants for measuring risk behaviours in recent stroke and TIA survivors and exploring their preferences in regard to health behaviour change strategies.

Four AuSCR projects, submitted by AuSCR team members, were also reviewed and approved by the Chairs of the Management Committee, Steering Committee and Research Task Group.

Telephone follow-up interviewing in a national stroke registry – a process evaluation of respondent comments (PI: Ms Karen Moss; Approved: 23rd February, 2014). The aim of this project was to illustrate the strengths and limitations of telephone interviewing in a health registry for people who choose not to return mailed surveys.

The association between discharge planning and post discharge outcomes for patients admitted to acute care hospitals following stroke or transient ischaemic attack. (PI: Dr Nadine Andrew; Approved: 23rd February, 2014). The aim of this project was to understand the association between documented provision of a discharge care plan and secondary prevention medication with outcomes post-discharge.

Hospital readmissions and quality of life after stroke (PI: Dr Monique Kilkenny; Approved: 23^{rd} February, 2014). The aim of this project was to understand the factors associated with hospital readmissions including quality of life.

Understanding the variations in acute care to reduce disparities in outcomes for stroke: what has been learnt from four years of collecting data in the Australian Stroke Clinical Registry (AuSCR) (PIs: Assoc Prof Dominique Cadilhac, Assoc Prof Natasha Lannin; Approved: 26th June, 2014). This project was to cover a range of publications to be prepared in relation to: health outcomes for people who suffer stroke/TIA; factors associated with poor health outcomes; benchmarking of Australian clinical performance; and methods related to registries.

2014 DATA ANALYSIS METHODS

The majority of data presented in this annual report includes all patients registered in the AuSCR database and admitted to the participating hospitals between 1 January and 31 December, 2014.

Data entry for acute stroke/TIA episodes were closed off on the 1st July 2015 and data extracted on 14th August 2015. Follow-up assessments of registrants admitted in 2014 were closed off on 14th August 2015. Data for these analyses were extracted from the AuSCR database on 14th August 2015.

Statistical analyses were performed using STATA software (version 12.1 for windows, Stata Corporation PL). The presentation of data was principally based on formats used in the 2009-2013 annual reports as developed by Natasha Lannin and Dominique Cadilhac and the AuSCR Management Committee.

For the purpose of data cleaning, duplicate data were checked by the AuSCR Data Manager using the registrants' identifiers (name, date of birth, Medicare number or hospital medical record number) and date of stroke onset, arrival, admission or discharge. Data cleaning was undertaken by the AuSCR Florey staff before the de-identified raw data were extracted. A second level of data checking was then performed by the Monash University analytic staff.

In the *final* raw data extract, there were 8286 patient records and 8625 acute stroke/TIA episodes. A description of the methods for analysing adherence to the process of care (quality indicator) variables is provided in Appendix B. Several changes were made to the way that some of the variables were derived. The major change was that all processes of care presented in this report *have episodes with missing information including in*

the denominator. This is because, if the data were not provided, we assumed that care related to that indicator was not offered in those circumstances.

Hospital postcodes were mapped to the Accessibility/Remoteness Index for Australia 2011 (ARIA+). The ARIA+ is used to calculate remoteness as accessibility, based on road distance, to 'service centres' (defined as populated localities where the population is greater than 1,000 persons, of which there are 201). For this report ARIA+ category 1 was defined as a major city and ARIA categories 2 and 3 were combined to indicate a regional location. Paediatric cases were not included in the overall patient characteristic, clinical and outcome data analyses and are presented separately.

To evaluate the *completeness of case ascertain-ment*, each 2014 participating hospital was requested to send us a hospital report of patients who were admitted to the hospital during 2014 with ICD10 codes of stroke/TIA (i.e. I61.0 – I61.6, I61.8, I61.9, I62.9, I63.0 – I63.6, I63.8, I63.9, I64, G45.9). Hospital reports were then matched to the AuSCR database to detect potentially missing episodes of stroke or TIA.

Once the data verification was finalised following these reviews, the proportion of completeness for case ascertainment was estimated using the following formula A/(A+B) where 'A' was the number of episodes which were registered in the AuSCR and 'B' was the missed episodes in the AuSCR database. The proportion of completeness for case ascertainment did not differ between stroke and TIA.

Benchmarks for the four AuSCR national indicators were calculated based on a modified version of the Achievable Benchmark of Care (ABC™) methodology9 which has been used and validated by Hall et al, 2013.7 Only sites that had contributed data to the AuSCR for more than six months, and had submitted at least 50 cases, were eligible for inclusion (n = 34). An Adjusted Performance Fraction (APF) score was calculated for each site for each of the four indicators. This allowed adjustment for under or over inflation due to small numbers present at some sites. The benchmarks were calculated as the mean APF scores of the top performing hospitals that represented at least 15% of the sample of eligible patients. We also report national averages and adherence achieved by the top ranked hospitals from the sample of hospitals that had registered at least 50 episodes of care.

Unless otherwise stipulated, the follow-up data were analysed using descriptive statistics and multivariable logistic regression with adjustment for patient casemix using age, sex, stroke type, ability to walk on admission, inpatient stroke or patient transferred from another hospital as appropriate. Since each individual patient is only followed-up once, based on their first registered episode of care, these analyses only include registrants eligible for follow-up in 2014. In addition, the registrants were required to have their data entered, by hospital staff, in the AuSCR within approximately 180 days of the index stroke onset in order to be eligible for follow-up.

Casemix adjusted survival analysis for deaths up to 180 days following admission was performed for those who had experienced an episode of care in 2014. It was possible to undertake these analyses for the whole registrant cohort since we had access to NDI data. Cox proportional-hazards regression comparing survival status for those who did and did not receive stroke unit care, adjusted for age, gender, stroke type, inpatient stroke, transferred from another hospital and ability to walk on admission, was also performed.

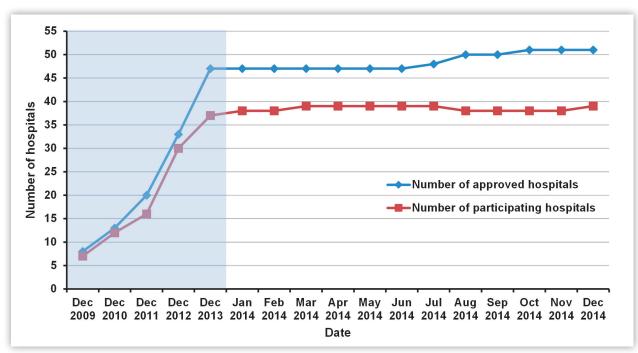
FINDINGS FROM DATA COLLECTED IN 2014

HOSPITALS

In 2014, 40 hospitals provided data for the AuSCR, three more than in 2013. During 2014, four new hospitals joined the AuSCR and four hospitals stopped contributing data due to a lack of capacity. Three hospitals that received ethics approval in 2014 had

not commenced data collection by December 2014. One Victorian hospital, approved in 2013, was also not yet collecting data. Figure 1 shows the incremental shift in numbers of hospitals participating in the AuSCR.

FIGURE 1: NUMBER OF APPROVED AND PARTICIPATING HOSPITALS IN THE AuSCR OVER 2009-2014



The characteristics of the 2014 participating hospitals are shown in Table 1. In 2014, there were five hospitals located in New South Wales (NSW), 21 in Queensland (QLD), 12 in Victoria (VIC), one in Western Australia (WA), and one in Tasmania (TAS). There were 28 hospitals that had 100 or more episodes of stroke/TIA registered during 2014. There were 20 hospitals located in a major city, 39 that had stroke units and 33 that provided thrombolytic therapy using tissue plasminogen activator (tPA).

Two of the 37 hospitals were private hospitals, located in Queensland and one was a children's hospital in Victoria.

TABLE 1: CHARACTERISTICS OF PARTICIPATING HOSPITALS.

| | | 2009 | 2010 | 2011 | 2012 | 2013 | TOTAL | 2014 | | | | |
|--|-------------------------------|------|------|------|------|------|-------|------|-----|-----|----|-----|
| YEAR | | 2009 | 2010 | 2011 | 2012 | 2013 | IOIAL | NSW | QLD | VIC | WA | TAS |
| NUMBER OF H | OSPITALS | 6 | 12 | 16 | 31 | 37 | 40 | 5 | 21 | 12 | 1 | 1 |
| ANNUAL | Low (<33 episodes) | - | 1 | 4 | 11 | 2 | 5 | 2 | 1 | 2 | 0 | 0 |
| NUMBER OF EPISODES | Medium (33-99 episodes) | 1 | 5 | 2 | 6 | 8 | 6 | 2 | 3 | 1 | 0 | 0 |
| IN THE Auscr* | High (≥100 episodes) | 5 | 6 | 10 | 14 | 27 | 29 | 1 | 17 | 9 | 1 | 1 |
| | Major city (Metro) | 6 | 10 | 11 | 16 | 28 | 20 | 1 | 12 | 6 | 1 | 0 |
| EPISODES IN THE AUSCR* LOCATION# STROKE UNIT INTRAVENOUS | Regional (Rural) | - | 2 | 5 | 15 | 9 | 20 | 4 | 9 | 6 | 0 | 1 |
| STROKE UNIT | | 6 | 10 | 14 | 28 | 35 | 39 | 5 | 21 | 11 | 1 | 1 |
| INTRAVENOUS THROMBOLYSI UNDERTAKEN | | 6 | 9 | 10 | 22 | 31 | 33 | 2 | 18 | 11 | 1 | 1 |

 $^{{}^*} Hospital\ categories\ as\ per\ the\ definitions\ used\ in\ registry\ of\ the\ Canadian\ Stroke\ Network.$

NUMBER OF REGISTRANTS

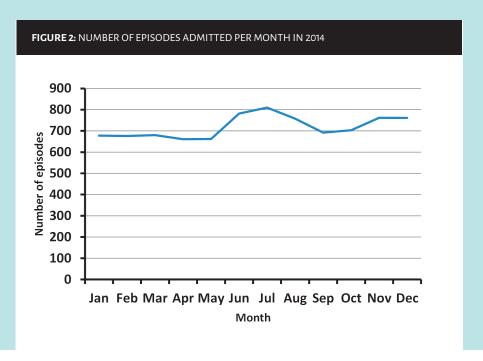
In 2014, there were 8286 patients registered in the AuSCR (Table 2). During a calendar year, patients may have multiple admissions for stroke or TIA that are also eligible to be included in the AuSCR. In 2014, there were 8625 episodes of acute hospital care entered in the AuSCR for the 8286 individuals registered. There were 339 patients (4%) who had multiple episodes registered in 2014. Among these,

315 had two episodes, 21 had three episodes and 3 had four episodes. The minimum number of episodes registered for any particular site was three at a metropolitan Victorian hospital and the maximum number registered was at a metropolitan Victorian hospital (n = 623). The median number of episodes per hospital was 193 (Q1, Q3: 84, 277).

| Number of hospitals contributing data | 40 |
|--|----------|
| Number of episodes submitted | 8625 |
| Number of patients | 8286 |
| Number and percentage of multiple episodes | 339 (4%) |

TABLE 2: NUMBER OF HOSPITALS, PATIENTS AND EPISODES IN 2014

^{*}Location categorised using Accessibility/Remoteness Index for Australia 2011 (ARIA+). Major city = category 1, Regional = categories 2 and 3



CASES ADMITTED PER MONTH

Figure 2 shows the number of episodes (including multiple episodes) entered per month based on date of admission. The median number was 698 per month. The minimum was 661 in April and the maximum was 810 in July. These data provide evidence of increased activity for AuSCR whereby in 2013 the median number of episodes per month was 645, while in 2012 it was 372 per month.

TIME TO CREATION OF REGISTRANT RECORDS BY HOSPITALS

Among the 8625 episodes of care, the median number of days from the admission to the creation of the patient record in the AuSCR was 77 days (Q1 to Q3: 33 to 129 days) consistent with performance in 2013 (but an improvement from 2012 whereby the median was 83 days to patient record creation). By hospital, the shortest median number of days was two days, and the longest median number of days was 271 days. These data at a hospital level may be influenced by several factors such as numbers of eligible admissions, as well as the method of data collection.

OPT-OUT REQUESTS AND IN-HOSPITAL REFUSAL TO 90 DAY FOLLOW-UP

As previously highlighted, registrants are informed by hospital staff that they are able to opt-out some, or all, of their data from the AuSCR database (e.g. personal identifying information). During 2014, 211 (2.5%) opt-out requests were received from hospital staff or patients (Table 3). Overall, 148 (1.8%) of registrants wanted all of their personal and episode information removed from the registry. The total number of opt-out requests varied, ranging from 0 to 67 per hospital. The breakdown of opt-outs for either personal or episode data or follow-up refusal (at the time of hospitalisation) is shown in Table 3.

TABLE 3: OPT OUT REQUESTS AND FIELDS

| Total opt-out cases | Complete episode and personal data to be removed | Complete episode data only to be removed | Personal data only to be removed | Refused 90 day follow-up partic- ipation at time of hospitalisation |
|------------------------|--|--|-------------------------------------|--|
| 211 | 148 | 7 | 56 | 223 |

DATA COMPLETENESS

A summary of the completeness of hospital collected data for the majority of fields within the registry for the 8625 episodes, from 8286 patients, in 2014 is presented in Table 4. These estimates represent the proportion of data completeness for applicable cases only, since not all variables are relevant to every patient, such as use of intravenous thrombolysis.

TABLE 4: COMPLETENESS OF FIELDS IN THE AUSCR DATABASE BY YEAR OF REGISTRY BEING OPERATIONAL

| FIELD | 2009 # % COMPLETE | 2010 % COMPLETE | 2011 % COMPLETE | 2012 % COMPLETE | 2013 % COMPLETE | 2014 n (% COMPLETE) | | | | |
|---|-----------------------------|---------------------------|---------------------------|---------------------------|---------------------------|-------------------------------|--|--|--|--|
| PERSON DETAILS (N=8286) | | | | | | | | | | |
| First name | 100 | 100 | 100 | 100 | 100 | 8230/8286 (99) | | | | |
| Surname | 100 | 100 | 100 | 100 | 100 | 8230/8286 (99 | | | | |
| Date of birth | 100 | 100 | 100 | 99 | 100 | 8230/8286 (99) | | | | |
| Medicare number | 67 | 90 | 92 | 92 | 91 | 7337/8286 (89) | | | | |
| PATIENT CONTACT (N=8286) | | | | | | | | | | |
| Available (complete or partial for street address, suburb and state) | 95 | 99 | 99 | 100 | 98 | 7814/8286 (94) | | | | |
| Complete (street address, suburb, state) | 97 | 55 | 93 | 100 | 97 | 7041/8286 (85) | | | | |
| Telephone for patient (land- line or mobile) | 90 | 96 | 94 | 95 | 94 | 6136/8286 (74) | | | | |
| EMERGENCY AND ALTERNATE CO | NTACTS (N=828 | 6) | | | | | | | | |
| Address for one or both of emergency and alternate contacts | 71 | 47 | 78 | 75 | 75 | 6355/8286 (77) | | | | |
| Address for one contact | 62 | 40 | 69 | 66 | 64 | 5520/8286 (67) | | | | |
| Address for both contacts | 10 | 7 | 9 | 9 | 11 | 835/8286 (10) | | | | |
| Telephone for emergency and/or alternate contact (landline or mobile) | 92 | 94 | 90 | 54 | 81 | 6848/8286 (83) | | | | |

TABLE 4: CONT'D

| FIELD GENERAL PRACTITIONER CONTA Address Telephone for general prac- | 73 | % COMPLETE | % COMPLETE | % COMPLETE | % COMPLETE | N (% COMPLETE) | | | | | | | | |
|---|-----------------|------------|--|------------|------------|-----------------|--|--|--|--|--|--|--|--|
| Address | 73 | 46 | | | | | | | | | | | | |
| | | 46 | GENERAL PRACTITIONER CONTACTS (N=8286) | | | | | | | | | | | |
| Telephone for general prac- | | | 84 | 65 | 74 | 6331/8286 (76) | | | | | | | | |
| titioner (landline or mobile) | 75 | 71 | 82 | 63 | 63 | 5346/8286 (65) | | | | | | | | |
| PATIENT CHARACTERISTICS (N=8 | 286) | | | | | | | | | | | | | |
| Title | 99 | 97 | 100 | 100 | 100 | 8177/8286 (99) | | | | | | | | |
| Hospital medical record number | 100 | 100 | 100 | 100 | 100 | 8282/8286 (100) | | | | | | | | |
| Sex | 99 | 98 | 100 | 100 | 100 | 8165/8286 (99) | | | | | | | | |
| Country of birth | 92 | 98 | 95 | 97 | 94 | 7877/8286 (95) | | | | | | | | |
| Language spoken | 97 | 84 | 96 | 86 | 84 | 7427/8286 (90) | | | | | | | | |
| Indigenous status | 100 | 100 | 100 | 99 | 100 | 8098/8286 (98) | | | | | | | | |
| Interpreter needed | 100 | 84 | 100 | 96 | 98 | 8219/8286 (99) | | | | | | | | |
| PISODE DATA (INCLUDING MULT | TIPLE EPISODES) | (N=8625) | | | | | | | | | | | | |
| Date of arrival | 100 | 100 | 100 | 95 | 95 | 8231/8625 (95) | | | | | | | | |
| Date of admission | 100 | 100 | 100 | 100 | 100 | 8625/8625 (100) | | | | | | | | |
| Transfer from another hospital | 100 | 100 | 99 | 98 | 98 | 8500/8625 (99) | | | | | | | | |
| Stroke occurs while in hospital | 100 | 99 | 99 | 98 | 97 | 8501/8625 (99) | | | | | | | | |
| Able to walk independently on admission | 100 | 95 | 91 | 90 | 88 | 7791/8625 (90) | | | | | | | | |
| Documented evidence of a previous stroke | 100 | 98 | 92 | 92 | 92 | 8136/8625 (94) | | | | | | | | |
| Treated in a stroke unit | 100 | 99 | 100 | 99 | 98 | 8326/8625 (97) | | | | | | | | |
| Type of stroke | 100 | 100 | 100 | 100 | 100 | 8624/8625 (100) | | | | | | | | |
| Use of intravenous throm- bolysis (if ischaemic stroke) | 100 | 98 | 97 | 95 | 95 | 5296/5466 (97) | | | | | | | | |
| Cause of stroke | 100 | 100 | 100 | 82** | 98 | 8590/8625 (100) | | | | | | | | |
| CD10 CODING (INCLUDING MULT | TIPLE EPISODES) | (N=8625)* | | | | | | | | | | | | |
| Diagnosis code | 63 | 66 | 96 | 95 | 95 | 7719/8625 (89) | | | | | | | | |
| Medical conditions | 1 | 14 | 36 | 40 | 40 | 3943/8625 (46) | | | | | | | | |
| Complications | 0 | 4 | 7 | 26 | 13 | 962/8625 (11) | | | | | | | | |
| Procedures | 9 | 23 | 25 | 60 | 35 | 3688/8625 (43) | | | | | | | | |

TABLE 4: CONT'D

| DISCHARGE INFORMATION (INCLUDING MULTIPLE EPISODES) (N=8625) | | | | | | | | |
|--|-----|-----|-----|------|-----|-----------------|--|--|
| Deceased status† | 100 | 100 | 100 | 100 | 100 | 8625/8625 (100) | | |
| Date of death (if deceased status is yes) † | 100 | 100 | 100 | 100 | 100 | 1036/1037 (100) | | |
| Date of discharge (if not deceased while in hospital)† | 87 | 97 | 98 | 96 | 95 | 7493/7588 (99) | | |
| Discharge destination (if not deceased while in hospital)† | 87 | 97 | 97 | 97 | 98 | 7531/7588 (99) | | |
| Discharge on antihypertensive agent (if not deceased while in hospital)† | 87 | 92 | 90 | 97 | 86 | 7052/7588 (93) | | |
| Evidence of care plan on discharge (if discharged to the community)## | 87 | 91 | 91 | 78** | 86 | 3974/4355 (91) | | |

Incomplete: coded as unknown or missing *Note that not every patient will have other medical conditions, complications and procedures coded, therefore the denominator is unknown #Only approximately six months of data were collected during 2009, the pilot year. †Deceased status and date of death determined using the AuSCR data. **Data completeness was lower for these variables in 2012 compared to other years due to technical issues with the AuSCR database. ##Previously the denominator was those not deceased while in hospital

DATA DISCREPANCIES FROM DATA QUALITY AUDITING

Auditors from the AuSCR Office undertook site visits at six hospitals where 50 medical records were reviewed. Data recorded in the AuSCR data collection tool were compared with information recorded in the medical record. A summary of the discrepancies for the AuSCR data fields for audits completed, in 2014 are presented below (Table 5). Variables with >5% disagreements are bolded within the table. These disagreements represented either incorrect or missing data.

TABLE 5: DISCREPANCIES OF FIELDS IN THE AUSCR DATABASE NOTED DURING THE AUSCR OFFICE DATA QUALITY AUDITS

| FIELDS | 2014 | | |
|--|-----------------------------------|----------------------|-----|
| N=50 AUDITS FROM 6 HOSPITALS UNDERTAKEN IN 2014# | | DISCREPANT NUMBER | %* |
| | First name | 2 | 3.9 |
| | Surname | 2 | 3.9 |
| | Date of birth | 0 | 0.0 |
| Patient Details | Medicare number | 4 | 7.8 |
| | Patient contact details available | 0 | 0.0 |
| | Patient contact details complete | 2 | 3.9 |
| | Patient phone number | 4 | 7.8 |

TABLE 5: CONT'D

| FIELDS | 2014 | 2014 | |
|--------------------------------|--|----------------------|------|
| N=50 AUDITS FROM 6 HOSPITALS U | INDERTAKEN IN 2014# | DISCREPANT NUMBER | %* |
| | Address for one, or both, emergency and alternate contacts | 5 | 9.8 |
| Emergency and Alternate | Address for one contact | 5 | 9.8 |
| Contacts | Address for both contacts | 0 | 0.0 |
| | Alternate contact phone number | 1 | 2.0 |
| Consul Describing Contracts | GP address | 1 | 2.0 |
| General Practitioner Contacts | GP phone number | 1 | 2.0 |
| | Patient title | 0 | 0.0 |
| | Patient MR number | 0 | 0.0 |
| | Sex | 0 | 0.0 |
| Patient Characteristics | Country of birth | 2 | 3.9 |
| | Language spoken | 0 | 0.0 |
| | Aboriginal and Torres Strait Islander status | 4 | 7.8 |
| | Interpreter needed | 0 | 0.0 |
| | Date of arrival | 7 | 13.7 |
| | Time of arrival | 9 | 17.6 |
| | Date of stroke onset | 12 | 23.5 |
| | Date of admission | 5 | 9.8 |
| | Transfer from another hospital | 0 | 0.0 |
| | Stroke occurred while in hospital | 0 | 0.0 |
| Episode Data | Able to walk independently on admission | 7 | 13.7 |
| | Documented evidence of a previous stroke | 1 | 2.0 |
| | Treated in stroke unit | 0 | 0.0 |
| | Time of stroke | 22 | 43.1 |
| | Type of stroke | 4 | 7.8 |
| | Use of IV thrombolysis (if ischaemic) | 1 | 2.0 |
| | Cause of stroke | 1 | 2.0 |
| | Diagnosis code | 2 | 3.9 |
| ICD to and it. | Medical conditions | 0 | 0.0 |
| ICD-10 coding | Complications | 0 | 0.0 |
| | Procedures | О | 0.0 |

TABLE 5: CONT'D

| FIELDS | 2014 | | |
|--|-------------------------------------|----------------------|-----|
| N=50 AUDITS FROM 6 HOSPITALS UNDERTAKEN IN 2014# | | DISCREPANT NUMBER | %* |
| Discharge Information | Deceased status | 0 | 0.0 |
| | Date of death | 1 | 2.0 |
| | Date of discharge | 1 | 2.0 |
| | Discharge destination | 3 | 5.9 |
| | Discharge on antihypertensive agent | 3 | 5.9 |
| | Evidence of care plan on discharge | 5 | 9.8 |
| Average | | | 5.3 |

[#]Although audited in 2014, the case may have been submitted prior to 2014

COMPLETENESS OF CASE ASCERTAINMENT

Among the 40 hospitals contributing data, 22 (55%) of them sent us case ascertainment information (by the due date) for 2014 stroke and TIA admissions (methods described on page 17) and, 31 (78%) hospitals had participated in the AuSCR for a full year. Table 6 shows the number of episodes that were registered (A) or missed (B) in the AuSCR database, and the proportion of completeness for case ascertainment. From the hospitals that provided data for this review, case-ascertainment ranged from 29% to 100%. Comparative percentages for 2013 are provided in the last column. The case ascertainment results were partly influenced by data quality issues where manual data entry of names or unit record numbers by hospital staff are recorded incorrectly and then do not match the data provided by hospitals for case ascertainment checking. Processes to improve these aspects of quality control for the registry continue to be a focus of the AuSCR Office. The other main reason for the low level of data completeness for some sites was that, due to resource limitations, only part of the data were entered into the AuSCR for the reporting period.

TABLE 6: SUMMARY OF THE CASE ASCERTAINMENT IN 2014 (IN COMPARISON WITH 2013)

| HOSPITAL | EPISODES IN THE DATABASE (N) | EPISODES MISSED IN THE DATABASE (N) | COMPLETENESS (2014) | COMPLETENESS (2013) |
|-----------------|---------------------------------|-------------------------------------|------------------------|---------------------|
| 9 [†] | 194 | Not provided | | 82% |
| 10 [†] | 257 | 286 | 47% | Not provided |
| 11 [†] | 268 | 201 | 57% | 66% |
| 12*† | 623 | 568 | 52% | 79% |
| 15 | 34 | Not provided | | 43% |
| 16 | 59 | Not provided | | Not provided |
| 19 [†] | 6 | 8 | 42% | 42% |
| 20^{\dagger} | 188 | 40 | 82% | 55% |
| 21 [†] | 127 | Not provided | | 82% |

^{*}Variables with >5% disagreements are bolded within the table

TABLE 6: CONT'D

| | HOSPITAL | EPISODES IN THE DATABASE (N) | EPISODES MISSED IN THE DATABASE (N) | COMPLETENESS (2014) | COMPLETENESS (2013) |
|-------|------------------|---------------------------------|-------------------------------------|------------------------|------------------------|
| | 22 [†] | 475 | Not provided | | Not provided |
| | 23*† | 563 | 8 | 99% | 100% |
| | 25 | 19 | Not provided | | 26% |
| | 26 | 13 | Not provided | | Not active |
| | 28 [†] | 352 | Not provided | | 100% |
| | 29*† | 508 | Not provided | | 79% |
| | 30 [†] | 79 | 192 | 29% | 13% |
| | 31*† | 205 | 44 | 82% | Not provided |
| | 32 ^{*†} | 487 | 492 | 50% | 75% |
| | 34 ^{*†} | 158 | 241 | 40% | Not provided |
| | 35 [†] | 180 | Not provided | | 34% |
| | 36 [†] | 213 | 261 | 45% | Not provided |
| | 37 [†] | 25 | Not provided | | Not provided |
| | 39 [†] | 69 | 112 | 38% | Not provided |
| | 40 [†] | 250 | Not provided | | 66% |
| | 41*† | 325 | 113 | 74% | 100% |
| | 43 [†] | 193 | 108 | 64% | Not provided |
| | 44*† | 203 | 12 | 94% | 100% |
| | 45 [†] | 251 | 0 | 100% | 81% |
| | 46 [†] | 194 | 286 | 40% | 38% |
| | 47 [†] | 248 | Not provided | | Not provided |
| | 48 [†] | 120 | Not provided | | 36% |
| | 49 [†] | 303 | 4 | 99% | Not provided |
| | 50 ^{*†} | 355 | 508 | 41% | 18% |
| | 51 | 75 | 95 | 44% | New |
| | 53 | 144 | Not provided | | New |
| | 54 [†] | 88 | 32 | 73% | 38% |
| | 55 [†] | 121 | Not provided | | Not provided |
| | 56 | 564 | Not provided | | New |
| | 57 | 86 | 141 | 38% | New |
| | 62 | 3 | Not provided | | New |
| Total | | 8625 | - | - | |

Patients who opted out of participation in the AuSCR do not appear in the above table Not provided: data are not available as not provided by hospital *These 9 hospitals used the data import function †These 31 hospitals participated in the AuSCR for the full 2014 year

REGISTRANT CHARACTERISTICS

Table 7 provides the baseline characteristics for patients and information related to their episodes of care. Adult and paediatric cases of stroke are presented separately. There were 11 hospitals that admitted paediatric (patients aged < 18 years) cases of stroke.

Among the 8265 adult patients, the most common country of birth was Australia (70%) followed by the United Kingdom (8%) and Italy (4%). The remainder were from a range of mainly European or Asian nations. There were 165 adult patients (2%) who identified as having an Aboriginal or Torres Strait Islander background. The majority of the registered adult patients spoke English (93%). The adult registrants comprised 3752 (46%) females and the mean age was 73 years. There were 1001 patients (12%) aged less than 55 years and 1149 patients (14%) were aged between 55 and 64 years.

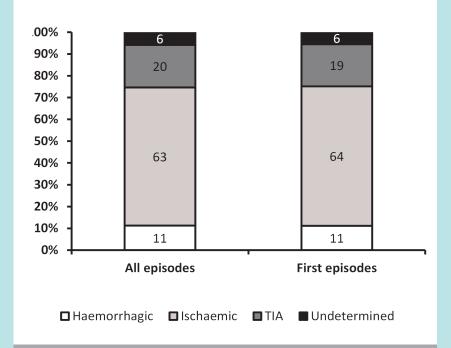
TABLE 7: BASELINE CHARACTERISTICS BY PATIENTS (ADULTS AND PAEDIATRICS) AND EPISODES

| | | ADULTS (N=8265) | PAEDIATRICS (N=21) | |
|--|----------------------------|---|-------------------------------|--|
| PATIENTS (N=7325) | | | | |
| Age, years, mean (SD) | | 73 (14) | 8 (7) | |
| Age, years, median (Q1 to C | (3) | 75 (64 to 84) | 7 (2 to 17) | |
| Female, n (%) | | 3752/8145 (46%) | 8/21 (38%) | |
| | Australia | 4714/7761 (70%) | 17/19 (89%) | |
| | United Kingdom | 592/7761 (8%) | 0/19 (0%) | |
| County of high n (0/) | Italy | 296/7761 (4%) | 0/19 (0%) | |
| Country of birth, n (%) | Other European countries | 686/7761 (9%) | 0/19 (0%) | |
| | Asia | 265/7761 (3%) | 0/19 (0%) | |
| | Others | 488/7761 (6%) | 2/19 (11%) | |
| Aboriginal and/or Torres S | trait Islander, n (%) | 165/8209 (2%) | 1/20 (5%) | |
| English spoken, n (%) | | 6887/7410 (93%) | 19/19 (100%) | |
| EPISODES (INCLUDING MULTIPLE EPISODES) (N=7614) | | ADULT EPISODES (INCLUDING MULTIPLE EPISODES) (n=8604) | PAEDIATRIC EPISODES (n=21) | |
| | Ischaemic | 5449/8603 (63%) | 16/21 (76%) | |
| Type of strake n (9/) | Haemorrhagic | 970/8603 (11%) | 2/21 (10%) | |
| Type of stroke, n (%) | Transient ischaemic attack | 1678/8603 (20%) | 1/21 (5%) | |
| | Undetermined | 506/8603 (6%) | 2/21 (10%) | |
| Able to walk on admission^, n (%) | | 3071/7773 (40%) | 4/18 (22%) | |
| Length of hospital admission (days), median (Q1 to Q3) | | 4 (2 to 7) | 7 (2 to 11) | |
| Cause of stroke known, n (%) | | 4642/8569 (54%) | 13/21 (62%) | |

SD: standard deviation Q1: 25th percentile Q3: 75th percentile ^Used as an indicator of stroke severity Paediatric cases were those admitted to the participating paediatric hospital

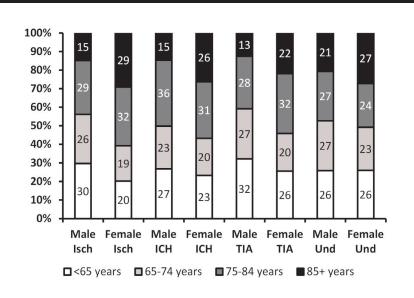
From the total 8604 adult episodes, the clinicians indicated that there were 5449 ischaemic strokes, 970 intracerebral haemorrhages (ICH), 1678 TIAs, 506 episodes of undetermined stroke type and one episode with missing stroke type data. The proportion of stroke episodes, according to the clinician-based classification of stroke sub-type for all episodes and first registered episodes, is provided in Figure 3. Stroke sub-type according to sex and age is presented in Figure 4. Among the 8604 adult episodes, the patient was noted as being able to walk at the time of admission in about 40% of admissions. For the paediatric cases, the median age was seven years with nearly two thirds of the patients being male. In three quarters of the episodes, the stroke type was ischaemic.

FIGURE 3: DISTRIBUTION OF STROKE SUB-TYPES IN ALL AND THE FIRST EPISODES



Excludes paediatric cases and an episode with missing stroke type All episodes n=8603, First episodes n=8264

FIGURE 4: DISTRIBUTION OF STROKE SUB-TYPES BY SEX AND AGE GROUPS (INCLUDING MULTIPLE EPISODES)



Excludes paediatric cases and episodes with missing stroke type and/or gender lsch: lschaemic stroke, ICH: intracerebral haemorrhage, TIA: transient ischaemic attack, Und: undetermined stroke

Male Isch n=2949, Female Isch n=2427, Male ICH n=514, Female ICH n=442, Male TIA n=871, Female TIA n=776, Male Und n=247, Female Und n=250

PROCESSES OF HOSPITAL CARE

Of the 8625 episodes, there were 1077 episodes (12%) transferred from another hospital and 405 episodes (5%) of inpatient stroke whilst patients were already in hospital for another condition. The majority of the inpatient strokes were ischaemic (n = 300, 74%) and most of these (n = 125, 31%) occurred among patients aged between 75 and 84 years. The median length of stay was longer for patients who had a stroke while already in hospital for another condition (inpatient median 9 days [Q1 to Q3: 4 to 16 days] vs. median 4 days [2 to 7 days] for non-inpatient events (presented from the community), p < 0.001).

OVERALL ADHERENCE TO QUALITY INDICATORS

Table 8 provides the average adherence results for the process of care indicators collected nationally in the AuSCR and the number of patients who were discharged from hospital. Most patients registered in the AuSCR were treated in a stroke unit and about half received a care plan at the time of discharge if they were discharged home or to an aged care facility. Adherence to each of these quality indicators by participating hospitals is presented in a de-identified format in Appendix C.

TABLE 8: STROKE EVALUATION AND THERAPY (INCLUDING MULTIPLE EPISODES)

| QUALITY INDICATORS OF HOSPITAL CARE | ALL EPISODES | ISCHAEMIC | TIA |
|--|-----------------|-------------------|-----------|
| Patients admitted to a stroke unit | 6792/8604 | 4736/5449 | 1077/1678 |
| | (79%) | (87%) | (64%) |
| Patients who received intravenous thrombolysis (tPA) if an ischaemic stroke | n/a | 599/5449 (11%) | n/a |
| Patients discharged (not deceased while in hospital) | 7788/8449 | 4981/5369 | 1666/1671 |
| | (92%) | (93%) | (99.7%) |
| Patients discharged on an antihypertensive agent (if not deceased while in hospital) | 5554/7788 | 3671/4981 | 1172/1666 |
| | (71%) | (74%) | (70%) |
| Patients who received a care plan at discharge (if discharged home or to RACF) | 2316/4330 | 1417/2333 | 671/1497 |
| | (53%) | (61%) | (45%) |

n/a: not applicable, RACF: Residential Aged Care Facility
Unknowns coded as no, inpatient death determined using National Death Index (NDI) data, excludes paediatric cases

There was no difference in the age of patients admitted to stroke units among the hospitals (mean age if managed in a stroke unit 73 years (SD 14) and non-stroke unit mean age 72 years (SD 15), p = 0.108) (Figure 5). However, there were more patients with ischaemic stroke treated in a stroke unit than the other types of stroke (p < 0.001) (Figure 6).

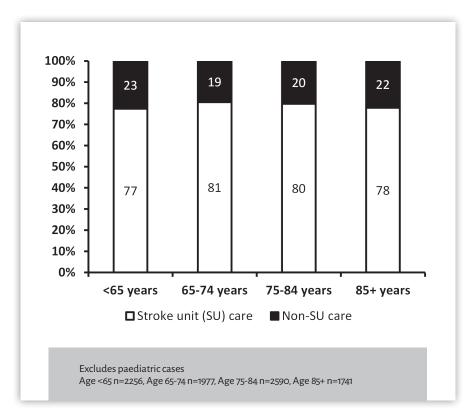
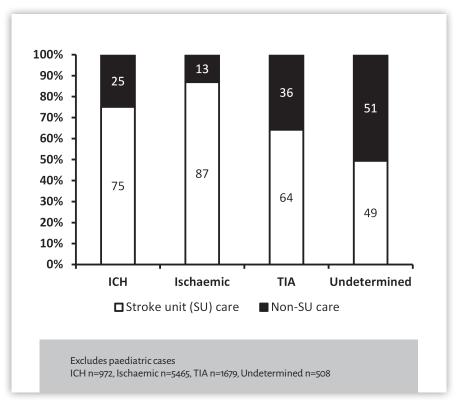


FIGURE 5: MANAGEMENT IN A STROKE UNIT ACCORDING TO AGE GROUP (INCLUDING MULTIPLE EPISODES)

FIGURE 6 (BELOW): MANAGEMENT IN A STROKE UNIT ACCORDING TO STROKE SUB-TYPE (INCLUDING MULTIPLE EPISODES)



BENCHMARKS FOR QUALITY INDICATORS

The AuSCR benchmarks for the quality indicators compared to other commonly used performance metrics i.e. adherence achieved by top performing hospitals or average adherence rates are shown in Table 9. If the achievable benchmarks were able to be achieved by all AuSCR hospitals relative to the overall average adherence then it is estimated that a further 1463 patients would have benefited from care in a stroke unit; an extra 490 from intravenous thrombolysis if an ischaemic stroke; 1090 from secondary prevention with antihypertensive medication; and 1429 being provided with a care plan if discharged into the community.

TABLE 9: ACHIEVABLE PERFORMANCE BENCHMARKS FOR NATIONAL CARE PROCESSES AND CORRESPONDING AVERAGE PERFORMANCE

| PROCESS OF CARE | BENCHMARK* (%) | TOP ADHERENCE** (%) | AVERAGE PERFORMANCE# (%) | OVERALL AVERAGE ADHERENCE^ (%) |
|---|----------------|---------------------|--------------------------|---|
| Received stroke unit care | 96 | 98 | 79 | 79 |
| Received intravenous throm- bolysis if an ischaemic stroke | 20 | 21 | 11 | 11 |
| Discharged on antihypertensive medication | 88 | 93 | 71 | 74 |
| Care plan provided if discharged to the community | 86 | 90 | 53 | 53 |

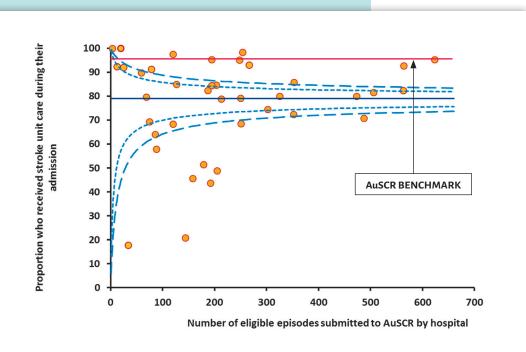
^{*}Only sites that had contributed data for >6 months and had >50 cases were eligible for inclusion (n=34). Benchmarks were calculated based on a modified ABCTM method.^{7,9} **The top performer adherence results are the unadjusted scores for a single hospital in this sample. *The average performance results were calculated as the sum of the unadjusted adherence score for each hospital in this sample divided by the total number of hospitals (n=34). ^Average adherence results from all hospitals (n=40) providing data in 2014.

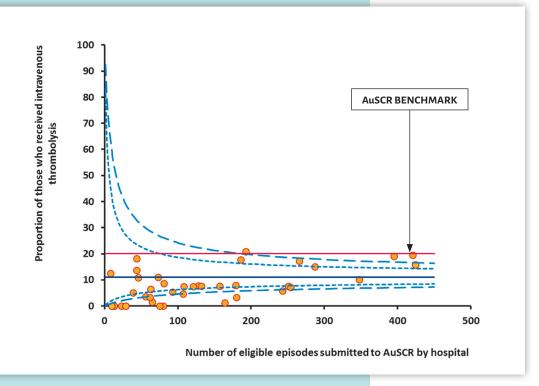
ADHERENCE TO QUALITY INDICATORS BY NUMBER OF ADMISSIONS PER HOSPITAL IN 2014

Adherence to quality indicators by number of episodes registered in 2014 for each hospital is shown in funnel charts in Figures 7-10. The summary data from each hospital used for these funnel charts are available in Appendix C.

EXPLANATION OF FUNNEL CHARTS

Funnel charts can be used to display deviations from the average achievement of quality of care. 10 The horizontal axis (line across the page from left to right) in these funnel charts indicates the number of episodes (volume) per hospital eligible to be included in the analysis. The larger number of episodes (volume) submitted to the AuSCR, the further to the right a hospital result will be as represented by a circle. The smaller the patient admission volume, the further to the left a hospital's circle will be located. The **vertical axis** indicates the adherence to quality indicators, expressed as a proportion (%). The circles show each individual hospital's adherence; and the horizontal centre line shows the overall (all hospitals combined) average adherence. The thicker red line, labelled as 'AuSCR benchmark', indicates the achievable performance benchmark derived from 34 hospitals providing a minimum of data over six months and with at least 50 episodes of care based on the ABC™ Benchmark methodology.6 Using Figure 7 as an example, the overall proportion of patients admitted to a stroke unit was 77%. The dashed lines constitute the funnel or 'control limits'. These represent the number of standard deviations (SD; either 2 or 3 SDs) from the overall average result. Hospitals within the 2 SD limits are considered to be within 'normal variation' while those outside are not within 'normal variation'. Those outside the 3 SD limits are considered to have 'special cause variation'. This means that hospitals above the 3 SD limits line may be considered as having 'good performance', while those below the 3 SD limits line may be considered as having 'poor performance', relative to the sample average performance. Care must be taken in interpreting these data when they are skewed because the control limits rely on the assumption that the distribution of data follows a bell curve or 'normal distribution'.





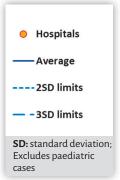


FIGURE 7: MANAGEMENT IN A STROKE UNIT BY HOSPITAL

FIGURE 8 (BELOW): RECEIVED INTRAVENOUS THROMBOLYSIS BY HOSPITAL

FIGURE 9 (OPPOSITE TOP): DISCHARGED ON ANTIHYPERTENSIVE MEDICATIONS BY HOSPITAL

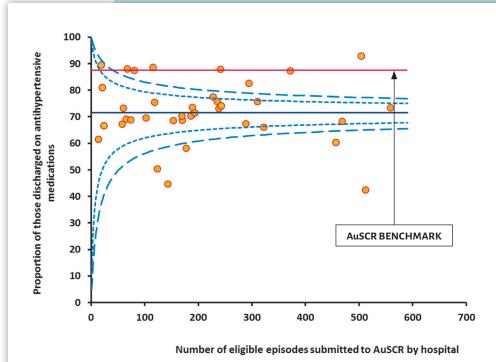
FIGURE 10 (OPPOSITE BELOW): CARE PLAN PROVIDED BY HOSPITAL IF DISCHARGED HOME OR TO A RESIDENTIAL AGED CARE FACILITY BY HOSPITAL

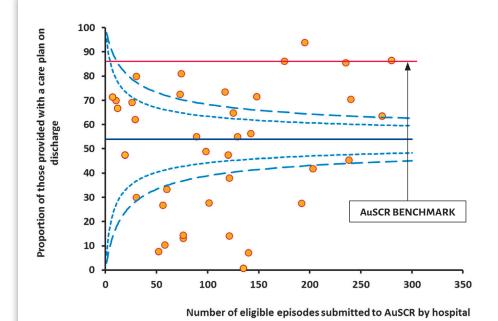
Variance existed in the proportion of patients who were managed in a stroke unit (Figure 7). The majority of hospitals, where the proportion of patients admitted to a stroke unit was below the 3 SD limit, were hospitals that submitted less than 300 episodes into the AuSCR in 2014. However, some of these hospitals may have introduced new stroke units throughout the year, especially in Queensland where incentive based funding attached to stroke unit development was provided in 2013-2014. Therefore, for these hospitals, the data may not be representative of the number of patients managed in a stroke unit once their stroke unit was actually established.

Five hospitals did not offer a thrombolysis service. These hospitals had less than 100 stroke episodes recorded in the AuSCR for 2014. There were two large hospitals (i.e. those with more than 200 patients recorded in the AuSCR) that had good performance regarding this indicator (Figure 8).

Being discharged on antihypertensive medication was the most consistently adhered to quality indicator. Only five sites were below the 3 SD limit for this indicator (Figure 9).

Adherence to receiving a care plan on discharge, if discharged home or to residential care, showed the greatest variation between hospitals (Figure 10). The majority of hospitals were not within 'normal variation'. There were many hospitals with good performance but a number with poor performance indicating 'special cause





variation' in comparison to the overall average. However, these data need to be interpreted with caution. It was noted that many episodes of care that resulted in a discharge to home or to a residential aged care facility were incorrectly indicated as being *ineligible* (16% of those discharged to the community; range: 0-98%) for a care plan. These episodes were re-categorised during analysis so that they were counted as eligible but did not receive a care plan at discharge. There is continuing work to ensure appropriate and standardised collection of this variable.

OVERALL ADHERENCE TO QUALITY INDICATORS SPECIFIC TO QUEENSLAND HOSPITALS

Adherence to the additional quality indicators collected in the AuSCR for Queensland is outlined in Table 10. The majority (85%) of Queensland patients registered in the AuSCR were mobilised during admission. Among the 2291 patients who were unable to walk independently, the method of mobilisation was either walking (50%), standing (24%) or sitting (27%). More than one-third (45%) were assessed for dysphagia, 72% received aspirin within 48 hours, and approximately 90% with ischaemic stroke or TIA were discharged on anti-platelets or antithrombotic medication.

 TABLE 10:
 STROKE EVALUATION AND THERAPY (INCLUDING MULTIPLE EPISODES): QUEENSLAND SPECIFIC VARIABLES

| HOSPITAL STROKE CARE | ALL EPISODES | ISCHAEMIC | TIA |
|---|-----------------|-----------------|----------------|
| Mobilisation during admission | 3831/4491 (85%) | 2430/2691 (90%) | 965/1055 (91%) |
| Same day or day after admission | 3259/3825 (85%) | 2015/2429 (83%) | 907/961 (94%) |
| If unable to walk independently, patient mobilised | 1929/2291 (84%) | 1428/1641 (87%) | 234/250 (94%) |
| Same day or day after admission | 1524/1928 (79%) | 1119/1428 (78%) | 217/234 (93%) |
| Dysphagia screen tool used within 24 hours | 2013/4491 (45%) | 1327/2691 (49%) | 432/1055 (41%) |
| Screen or swallow assessment undertaken | 3658/4491 (81%) | 2461/2691 (91%) | 760/1055 (72%) |
| Within 24 hours | 2557/3658 (70%) | 1677/2461 (68%) | 573/760 (75%) |
| Aspirin administration within 48 hours (if not intracerebral haemorrhage) | 2831/3860 (73%) | 2003/2596 (77%) | 750/1003 (75%) |
| Discharged on antiplatelets or antithrombotics (if not intracerebral haemorrhage) | 3155/3395 (93%) | 2171/2225 (98%) | 886/950 (93%) |

Includes only patients admitted to hospitals in Queensland

PATIENTS ADMITTED WITH TRANSIENT ISCHAEMIC ATTACK

Among the 1679 episodes of TIA, the mean age was 72 years (SD 14 years) and 47% were female. Five patients with TIA were reported to have died while in hospital. The median length of stay was two days (Q1 to Q3: 1 to 3 days). Among those alive at discharge, 71% were discharged on an antihypertensive agent. Among patients with TIA who were discharged home, or to a residential aged care facility, 45% received a care plan (Table 7). Most patients with TIA (87%, n = 1452) were discharged to a home setting, 3% (n = 47) went to rehabilitation and the remainder went to aged care, transitional care services or other hospitals. It is unclear whether these patients had already been in aged care prior to this event or had other co-morbidities, or complications while in hospital, which may have influenced their discharge destination. However, of the 45 registrants with TIA who were discharged to residential aged care, 17/43 (40%) had a documented history of a previous stroke.

DISCHARGE CODING OF STROKE TYPE

The AuSCR provides an important opportunity to review the clinical classification of stroke or TIA against the international classification of diseases (ICD) discharge coding which is usually undertaken by health information managers in hospitals. Using the primary diagnosis discharge code (version ICD10) compared with the stroke sub-type provided by hospital clinicians, 82% of TIA episodes were coded as TIA and 4% of TIA episodes were coded with stroke codes (Table 11). Two percent were coded with non-stroke diagnostic codes. Seventyfour percent of ischaemic stroke episodes were coded within the I63 range (cerebral infarction: I63.0-I63.9), 9% of ischaemic stroke episodes were coded as I64 codes (stroke, not specified), and 4% were coded with non-stroke diagnostic codes. In-hospital stroke events did not account for the assignment of non-stroke discharge codes or 'undetermined' diagnoses by the clinicians for stroke subtype. These data may provide evidence of where improvements to administrative discharge coding is needed to ensure more reliable data.

| | STROKE SUB-TYPE ASSIGNED BY CLINICIANS | | | ICIANS |
|--|--|-----------------|----------------|-------------------------|
| | IS (N=5465) | TIA (N=1679) | ICH (N=972) | UNDETERMINED (N=508) |
| ICD10 DIAGNOSIS CODE | n (%) | n (%) | n (%) | n (%) |
| l63: Cerebral infarction | 4071 (74) | 32 (2) | 38 (4) | 114 (22) |
| G45: Transient cerebral ischaemic attacks and related syndromes | 68 (1) | 1377 (82) | 3 (0) | 44 (9) |
| l61 and l62: Nontraumatic ICH and Other and unspecified nontraumatic ICH | 56 (1) | 3 (0) | 756 (78) | 32 (6) |
| I64: Stroke, not specified ischaemic or haemorrhagic | 519 (9) | 30 (2) | 9 (1) | 197 (39) |
| I60: Non-traumatic SAH from carotid siphon and bifurcation | 3 (0) | 0 (0) | 27 (3) | 17 (3) |
| 165-169: Other cerebrovascular diseases | 72 (1) | 13 (1) | 3 (0) | 2 (0) |
| Goo-G44 and G46-G99: Other diseases of the nervous system | 6 (0) | 20 (1) | 8 (1) | 4 (1) |
| Other ICD10 diagnosis code | 96 (2) | 6 (0) | 19 (2) | 73 (14) |
| Missing ICD10 diagnosis code | 574 (11) | 198 (12) | 109 (11) | 25 (5) |

TABLE 11: COMPARISON OF CLINICAL DIAGNOSIS AND ICD10 PRIMARY DIAGNOSIS CODES

Dark shaded cells indicate a matching clinical and primary ICD10 diagnosis code IS: ischaemic stroke, TIA: transient ischaemic attack, ICH: intracerebral haemorrhage, SAH: subarachnoid haemorrhage

SUMMARY OF THE MOST COMMON PROCEDURE CODES ASSIGNED TO REGISTRANTS WHILE IN HOSPITAL

Multiple procedure codes can be assigned to patients while they are in hospital as part of the discharge coding process and this information may provide information on additional aspects of clinical care. As reported in Table 4, from the data that were available only 43% of these procedure codes were submitted. The ten most common procedure codes assigned to the AuSCR registrants while in hospital, and their primary procedure codes related to receipt of allied health interventions are outlined in Tables 12 and 13.

TABLE 12: TEN MOST COMMON PROCEDURE CODES FOR ALL PATIENTS IN THE AUSCR

| CODES | DESCRIPTION | TOTAL | % |
|---------|--|-------|------|
| 9555003 | Allied health intervention: physiotherapy | 2955 | 21% |
| 9555002 | Allied health intervention: occupational therapy | 2831 | 20% |
| 9555005 | Allied health intervention: speech pathology | 2746 | 19% |
| 9555001 | Allied health intervention: social work | 1415 | 10% |
| 9555000 | Allied health intervention: dietetics | 1226 | 9% |
| 9555009 | Allied health intervention: pharmacy | 1174 | 8% |
| 9602700 | Prescribed/self-selected medication assessment | 180 | 1% |
| 9555014 | Allied health intervention: diabetes education | 104 | 1% |
| 9251599 | Sedation, ASA 99* | 99 | 1% |
| 1370602 | Administration of packed cells | 62 | 0.4% |

 $[\]hbox{``American Society of Anaesthesiologists classification'}\\$

TABLE 13: TEN MOST COMMON PRIMARY PROCEDURE CODES FOR ALL PATIENTS IN THE AUSCR

| CODES | DESCRIPTION | COUNT | % |
|---------|--|-------|------|
| 9555003 | Allied health intervention: physiotherapy | 1371 | 37% |
| 9555002 | Allied health intervention: occupational therapy | 1244 | 34% |
| 9555009 | Allied health intervention: pharmacy | 254 | 7% |
| 9555005 | Allied health intervention: speech pathology | 206 | 6% |
| 9555001 | Allied health intervention: social work | 175 | 5% |
| 9602700 | Prescribed/self-selected medication assessment | 142 | 4% |
| 9251599 | Sedation, ASA 99* | 29 | 1% |
| 9555012 | Allied health intervention: pastoral care | 20 | 1% |
| 1310000 | Haemodialysis | 18 | 0.5% |
| 3900000 | Lumbar puncture | 13 | 0.4% |

 $[\]hbox{``American Society of Anaesthesiologists classification'}\\$

DISCHARGE INFORMATION

Hospital outcome measures include length of stay, discharge destination and discharge status. In the case where data for an individual person is segregated across two hospitals for the same stroke episode, the discharge information is reported from the first hospital providing care. Unless otherwise stated, the data presented in this section relate to the hospital that provided the initial care.

LENGTH OF STAY

The median length of stay was four days (Q1 to Q3: 2 to 7 days). Of the 7817 episodes resulting in discharge from hospital, 7777 had length of stay data. Of these episodes, 399 (5%) stayed 21 days or more. Similar to our findings in 2013, there was a statistically significant difference between the length of stay for episodes treated in stroke units (median 4 days, Q1 to Q3: 2 to 8 days) and those not managed in stroke units (median 3 days, Q1 to Q3: 1 to 6 days) (p < 0.001). This finding may be due to more severe cases being treated in the stroke unit and requires further exploration. Patients with TIA were more likely to have a short length of stay (less than four days) compared to patients with stroke (75% TIA, 35% stroke, p < 0.001).

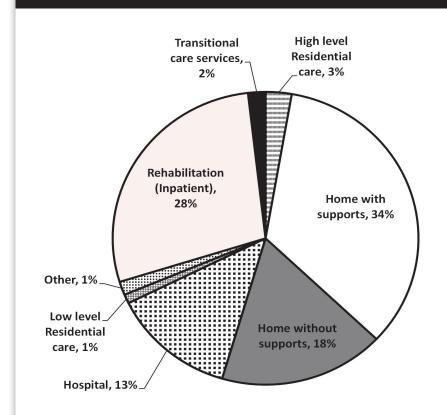
DISCHARGE STATUS

In 2014, approximately half of the episodes of care resulted in discharge home (n = 4038; 52%), (Figure 11). Patients managed in a stroke unit had a 2.5 fold increased odds of being discharged to a rehabilitation facility compared to those patients not managed in a stroke unit (95% confidence interval [CI] 2.0 to 3.1) when adjusted for age, gender, type of stroke, ability to walk on admission, inpatient or community-onset stroke, and whether or not the patient was transferred from another hospital. Patients treated in a stroke unit are more often discharged to rehabilitation regardless of whether or not they are able to walk on admission.

IN-HOSPITAL DEATHS

Among the 8604 registered adult episodes of care (i.e. excludes cases from the paediatric hospital), 661 (8%) patients died whilst in hospital. Although case fatality in hospital was slightly greater for women, there were no gender differences in case fatality during hospitalisation after adjustment for age (p = 0.07). There were no paediatric in-hospital deaths reported.

FIGURE 11: DISCHARGE STATUS INCLUDING MULTIPLE EPISODES, n=7788



Excludes paediatric cases and episodes of care resulting in death in hospital Queensland registrants coded as sub or non-acute patients (SNAP) were included in the hospital category

POST-DISCHARGE HEALTH OUTCOME INFORMATION

The following section provides the findings from the registrants who were eligible for follow-up in 2014.

Excluding cases admitted to the children's hospital, there were 8265 patients registered in 2014 (Figure 12). Of these 8265 registrants, 1213 (15%) registrants died within 90 days of their admission. No attempt at follow-up was made for 1252 registrants (15%) who had their primary data entered into the AuSCR system after the 180 day follow-up limit, 260 registrants (3%) who had a previous stroke registered in the AuSCR prior to 2014, and 55 registrants (1%) who refused a follow-up survey at the time of their stroke/TIA. Of the remaining 5485 registrants, a further 250 (5%) refused follow-up when contacted, 83 (2%) were reported as deceased when follow-up was attempted, and 1263 (23%) registrants were unable to be followed up via survey methods because their details were not accurate or had changed, and they were considered 'lost'.

A follow-up survey was completed, or death status determined, for 4014 registrants (73%) eligible for follow-up in 2014. Median time from the stroke onset to the completion of follow-up for these 3889 patients was 101 days (IQR 96 to 109 days). As we are able to link the registrant data to the National Death Index, survival status in the community was known for all patients registered in 2014.

Characteristics of the 4014 registrants with any post-discharge information collected via survey are summarised in Table 14. The mean age was 75 years and 45% were female; 67% of them had an ischaemic stroke. Responders were older, more often male, less often of Aboriginal and/or Torres Strait Islander descent, were more often treated in a stroke unit, and more often had an ischaemic stroke when they presented to hospital.

| | the AuSCR in 2014 3265)* | | | | |
|--|---|--|---------------------------------------|--|--|
| Registrants with a first-ever episode in 2014 (n=8005) | | Registrants with first-ever episode prior to 2014 Not eligible for follow-up in 2014 (n=260) | | ow-up in 2014 | |
| | | | | | |
| | ollowing admission 6792) | Died in hospital (n=661)† Died after discharge and within 90 days of admission (n=552)† | | n 90 days of admission | |
| | | | | | |
| | Follow-up survey generated (eligible for follow-up) (n=5485) ^c | | Ineligible for follow-up (n=1307)‡ | | |
| | | | | | |
| Alive and followed up (n=3869) | Followed-up prior to death between 90 and 180 days (n=20) | Lost to follow-t (unable to be conta (n=1263)§# | - | Refused follow-up (n=250)§B or deceased (n=83)# | |
| | | <u></u> | | = | |
| | | | dex, without (n=125) | rding to the National out follow-up | |
| | | | <u></u> | | |
| Followed up | | Patients followed | up and/o [A+B] | r died within 180 days | |
| | 889) ^A | Respon | (n=4014 use rate: 73 | 4) 3% [A+B/C] | |
| | | | | | |

^{*} Excludes cases admitted to the participating paediatric hospital

[†] There were 43 patients with a missing date of discharge who died within 90 days of their admission ‡ There were 1252 registrants who had their data entered into the AuSCR database after 180 days of their admission and 55 who opted out of follow-up

[§] There were 40 patients lost to follow-up and two patients who refused follow-up who died within 180 days of their admission

[#] There were 18 patients who were classified as deceased at follow-up who did not die within 180 days according to the NDI. These patients were reclassified as lost to follow-up

| TABLE 14: BASELINE CHARACTERISTICS FOR REGISTRANTS WITH AND WITHOUT ANY POST-DISCHARGE INFORMATION | | PATIENTS WITH ANY POST-DISCHARGE IN- FORMATION (COMPLETE FOLLOW-UP OR DEATH) (N=4022) | PATIENTS WITHOUT POST-DISCHARGE INFORMATION (REFUSED OR LOST, AFTER 180 DAYS) (N=1471) | p VALUE |
|--|---|---|--|---------|
| Age (years), mean (SD) | | 72 (14) | 69 (15) | <0.001 |
| Female, n (%) | | 1815/4008 (45%) | 618/1471 (42%) | 0.041 |
| Aboriginal and/or Torres | Aboriginal and/or Torres Strait Islander, n (%) | | 51/1459 (4%) | <0.001 |
| Type of stroke, n (%) | Ischaemic | 2689/4022 (67%) | 933/1471 (63%) | |
| | Haemorrhagic | 328/4022 (8%) | 150/1471 (10%) | 0.046 |
| | Transient ischaemic attack | 838/4022 (21%) | 321/1471 (22%) | |
| | Undetermined | 167/4022 (4%) | 67/1471 (5%) | |
| Able to walk on admission, n (%) | | 1698/3670 (46%) | 625/1351 (46%) | 0.997 |
| Length of hospital admission (days), median (IQR) | | 4 (2 to 7) | 4 (2 to 7) | 0.851 |
| Treated in a stroke unit, r | 1 (%) | 3437/4022 (85%) | 1207/1471 (82%) | 0.002 |

Excludes cases admitted to the participating paediatric hospital SD: standard deviation IQR: inter quartile range

SURVIVAL AND THE INFLUENCE OF STROKE UNIT CARE

Of 8265 registrants, 1213 (15%) had died within 90 days of admission (inclusive of the 631 inpatient deaths). After adjustment for age, case fatality within 90 days of stroke admission was significantly different between males and females (odds ratio 1.17, 95% CI 1.05 - 1.33, p = 0.007). At the time of the follow-up assessment (between 90 and 180 days after admission), a further 185 registrants were reported to have died.

We also found that those who were admitted to a stroke unit were much more likely to still be alive at 180 days following stroke (Figure 13). After adjusting for age, gender, stroke sub-type, ability to walk on admission, inpatient stroke and transfer from another hospital, stroke unit care was associated with 59% reduced risk of death at 180 days compared to non-stroke unit care (adjusted mortality hazard ratio 0.41, 95% confidence interval: 0.36 – 0.47, p < 0.001).

FOLLOW-UP DATA

Of the 3889 registrants who completed follow-up surveys, there were 3745 registrants who were able to answer all questions and 144 who answered some of the questions. The main follow-up results are summarised in Table 15.

READMISSIONS

There were 779 registrants (20%) who reported that they were readmitted to hospital and 181/779 (23%) of these were reported to be for a readmission related to a stroke or cardiovascular cause (Table 15).

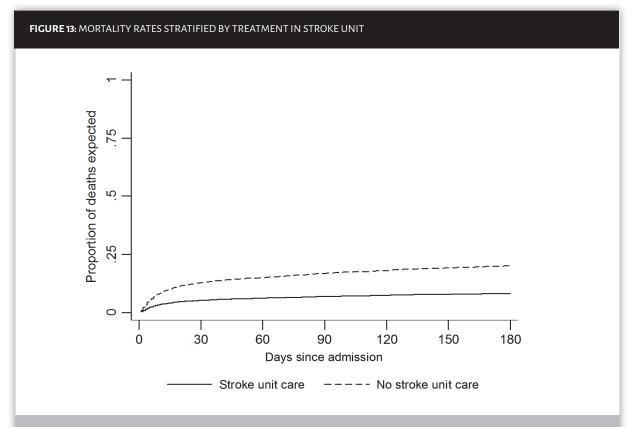


TABLE 15: POST-DISCHARGE INFORMATION AND SURVIVAL STATUS

| | | | n/N (%) |
|--|---|---------------------------------------|-----------------|
| | Registrants who died within 180 days of admission | | 1398/8265 (17%) |
| F .II | Died during hospit | alisation | 631/8265 (8%) |
| Follow-up status | Died after discharg | ge and within 90 days of admission | 582/8265 (7%) |
| | Deaths registered b | oetween 90 and 180 days | 188/8265 (2%) |
| Registrants who completed follow-up | Registrants who an | swered all questions | 3745/3889 (96%) |
| Registrants who completed follow-up | Registrants who an | swered some questions | 144/3889 (4%) |
| Registrants who had another stroke | | | 211/3889 (5%) |
| Registrants who were readmitted to hospital | | | 779/3889 (20%) |
| | Reason for readmis | ssion was stroke/cardiovascular cause | 181/779 (23%) |
| Location of stroke survivor at time of follow-up interview | | | |
| | Living alone | | 785/3311 (24%) |
| Home | Living at home | | 3311/3847 (86%) |
| nome | | Home with support | 1420/3311 (43%) |
| | | Home without support | 1883/3311 (57%) |
| | In hospital | | 42/3847 (1%) |
| | Transitional care se | ervice | 41/3847 (1%) |
| Institutional care or other setting | Low level care (hos | tel care) | 44/3847 (1%) |
| misultunollal care of other selling | High level care (nu | rsing home) | 322/3847 (8%) |
| | Inpatient rehabilita | ation | 34/3847 (1%) |
| | Other | | 53/3847 (1%) |

Excludes cases admitted to a paediatric hospital

HEALTH-RELATED QUALITY OF LIFE

In the AuSCR, we measure health-related quality of life (HRQoL) using the EQ-5D™ instrument. The EQ-5D is a standardised instrument for use as a measure of health outcome (see http://www.euroqol.org/). It provides a simple descriptive profile across five dimensions: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Each of these profiles is divided into three levels: no problems (1), some or moderate problems (2) and extreme problems (3). In addition, the EQ-5D provides a single index value for health status using a visual analogue scale (VAS) (Figure 14).

Possible scores for the VAS span a scale from 0 to 100. An EQ-5D index score of zero corresponds to a HRQoL state that is all but death, while a score of 100 would represent perfect quality of life.

Based on the various dimensions of the EQ-5D questionnaire, nearly half of the respondents reported problems in mobility (47%) and more than half reported problems in usual activities (56%) (Table 16). The summary score for the VAS was well below the normal population measure for people aged 70 to 79 years (Figure 14).

TABLE 16: QUALITY OF LIFE ASSESSMENT AMONG SURVEY RESPONDENTS

| EQ-5D DIMENSIONS | | n/N (%) |
|---------------------------------------|-------------------------|-----------------|
| AA-L:II | No problems (Level 1) | 2047/3865 (53%) |
| Mobility | Problems (Levels 2 & 3) | 1818/3865 (47%) |
| Self-care | No problems (Level 1) | 2728/3876 (70%) |
| Sen-care | Problems (Levels 2 & 3) | 1148/3876 (30%) |
| Usual Activities | No problems (Level 1) | 1692/3864 (44%) |
| Usual Activities | Problems (Levels 2 & 3) | 2172/3864 (56%) |
| Pain/Discomfort | No problems (Level 1) | 2009/3850 (52%) |
| Paili/Discomfort | Problems (Levels 2 & 3) | 1841/3850 (48%) |
| Anvioty/Depression | No problems (Level 1) | 2149/3844 (56%) |
| Anxiety/Depression | Problems (Levels 2 & 3) | 1695/3844 (44%) |
| VISUAL ANALOGUE SCALE (0 - 100) REPOR | n/N (%) | |
| Mean (SD) | | 68.9 (20.9) |
| Median (Q1, Q3) | | 71 (55 to 85) |

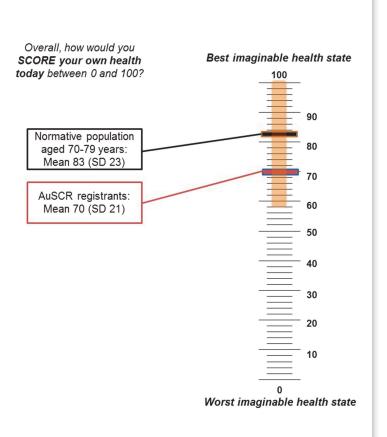
 $Excludes\ cases\ admitted\ to\ a\ paediatric\ hospital\ SD:\ standard\ deviation\ Q1:\ 25th\ percentile;\ Q3:\ 75th\ percentile$

Index-based values ('utilities') for the EQ-5D can also be reported using health values derived using Discrete Choice Experiment (DCE) methods. ¹² The advantage of reporting the utility scores is that it enables death data to be incorporated into the values and allows for scores less than zero to be counted as these scores indicate a health state considered worse than death. A total of 237 registrants (6%) had a utility score of less than zero, based on their 90-180 day follow-up interview using the DCE method.

PAEDIATRIC OUTCOMES

There were 21 registrants under the age of 18 years and eight were followed up at 90 to 180 days following stroke. Four of these were admitted to a children's hospital and four were admitted to adult hospitals. Three were aged between one and 13 years, and five were aged between 14 and 18 years. Two of these eight paediatric registrants with follow-up data provided answers to all the questions.





Normative population Visual Analogue Scale responses obtained from Kind et al¹¹

PARTICIPATION IN FUTURE RESEARCH

Among the 3889 registrants who answered the question about whether they would be willing to be contacted to participate in future research, 2333 registrants (60%) replied affirmatively. Compared to those who did not reply in the affirmative, these patients were younger (72 vs 78 years, p < 0.001) and more often male (59% vs 47%, p < 0.001).

UNMET INFORMATION NEEDS

Stroke can be a devastating and life changing event for people and there is a possibility that stroke survivors and their care providers have unmet care and information needs. Given that the AuSCR protocol includes a follow-up survey with survivors at 90 to 180 days post stroke or TIA, it presents an opportunity to ask registered patients whether they would like to receive further information about stroke from the National Stroke Foundation. In 2014, 39% (n = 1510) of the 3899 registrants who completed a follow-up survey, indicated that they would like to receive information about stroke from the National Stroke Foundation.

DISCUSSION

This is the sixth annual report of the AuSCR. Since the release of the first annual report in 2009, use of the AuSCR has continued to grow. In this 2014 report, we provide information contributed from 40 hospitals in Australia on 8625 episodes of stroke or TIA. These 40 hospitals represent 21 % of 195 hospitals known to admit people with acute stroke and TIA in Australia. 13

Since the registry has not yet obtained complete coverage in any state or region these data may have limited representativeness for some aspects of care and outcomes. However, the majority of hospitals that treat patients with stroke in Queensland (n = 23) are now approved to contribute data to the AuSCR. The high level of coverage in Queensland has meant that the AuSCR data have been able to be used to facilitate statewide quality improvement activities, including providing the evidence for peer-review discussions at the Queensland Statewide Stroke Clinical Network Fora.

There continues to be wide variability in adherence to the nationally endorsed quality indicators among the different participating hospitals, and important care gaps ranging from 9% (access to intravenous thrombolysis) to 33% (care plans on discharge) existed between the benchmark hospital results and average performance. We found that, on average only 79% of the AuSCR patients (with stroke or TIA) were managed in a stroke unit during 2014. However the best performing hospitals achieved 96%. The reason for poor access should be investigated including bed capacity issues. Further, we found that patients who were treated in a stroke unit had a 59% reduced risk of death at 180 days when compared to patients not treated in stroke units when we adjusted for differences in the casemix of patients. If all hospitals were able to achieve the achievable benchmark target then potentially a further 1450 patients would have benefited from stroke unit care in 2014 and subsequently survival outcomes improved for 3 in 5 of these cases.

We acknowledge that in our sample of participating hospitals there is a bias towards hospitals with stroke units, as all hospitals represented in this report, except one, had a stroke unit. Overall adherence to this quality indicator is greater than data reported in the cross-sectional national audits (67% from 108 hospitals14 versus 83% AuSCR 2014 stroke only [non TIA] events). Therefore, the benefits of stroke unit care and overall care gaps are likely to be underestimated from these data. Nonetheless, these findings reinforce the need to ensure all Australians who experience an acute stroke have access to stroke unit care; and overall, that further action is needed in supporting organisational systems and clinical practices that are conducive to providing best practice stroke care as illustrated by the care gaps found across all AuSCR quality indicators. The AuSCR Office staff will collaborate with hospitals where performance falls outside accepted levels of variation to explore possible explanations and inform efforts to address the issues (see AuSCR Outlier Special Cause Variation Communication Policy: http://www.auscr.com.au/ auscr/policy-documents/).

The AuSCR data highlight important areas of focus for quality improvement based on having a large representative sample of patients managed at each of the participating hospitals. It is therefore important that hospitals use the AuSCR to its full potential and regularly review their summary data that are available in 'on-demand' live reports. The AuSCR Office staff are available for training new staff in generating these reports, as well as obtaining data

extracts of individual hospital data sets. The AuSCR Office provides a regular newsletter to highlight: ways in which the quality of the data could be improved at the participating hospitals; communicate progress being made; and share successes and lessons learnt.

In relation to data completeness in the AuSCR, generally speaking most demographic data were near complete, although about a quarter of registrants did not have a telephone number provided. Comprehensive contact details for registrants and their emergency/alternate contacts are important to facilitate collection of the follow-up data. Whilst registry participation is voluntary, it is important that the data are not biased by missed cases and that process of care reporting is reflective of the patient base. Provision of case ascertainment data was only provided by just over half of the hospitals and there was poor access to ICD10 codes being provided for medical conditions, complications and procedures. Stroke service staff are reliant on other departments to provide this information and it is usually not available until well after the patient has been discharged. In the future, centralised collection via state health departments might reduce workloads for hospitals as well as improving case ascertainment evaluations for the AuSCR. In relation to data quality that was assessed using random external audits conducted by the AuSCR Office staff, most variables were consistently collected. However, variables reliant on more subjective judgements or that tended to be poorly recorded in medical records such as stroke onset date and time, ability to walk on admission, and evidence of a care plan on discharge require further education and training to improve their reliability.

The follow-up of patients at 90-180 days, for those who are discharged from hospital, is a unique attribute of the AuSCR in providing national longer term outcome data on stroke. At the time of follow-up, 12% (compared with 14% in 2013) of patients were living in institutionalised care or were in a hospital setting, and more than 86% (82% in 2013) were living at home. The 90-180 day outcomes data provide critical information about the

impact of stroke or TIA in Australia; in-depth analyses are currently underway to enhance our understanding of the burden of stroke post-discharge.

As in 2013, these data from 2014 show that one in five registrants were readmitted to hospital. In 23% of these cases (a decrease compared with 29% in 2013), readmission was due to a stroke or cardiovascular cause. Understanding the factors that influence readmissions to hospital is important. 15 Once again these data also highlight that registrants who were still alive at follow-up were experiencing lower quality of life compared to age matched population normative data (13 points lower on the EQ-5D VAS). The AuSCR data provide information, not available in current government data, on hospital readmissions and quality of life and can be explored to better understand factors that contribute to readmissions and quality of life within 180 days of stroke. We are currently exploring the complete AuSCR data set in more detail to determine the factors related to the likelihood of readmission.

Following our second year of linking AuSCR data to the National Death Index, analyses of the casemix adjusted data once again demonstrate the survival advantage of stroke unit care i.e. 59% reduced risk of death at 180 days compared to non-stroke unit care. This finding reinforces the need to ensure all Australians have access to stroke unit care. Incentive funding programs in Queensland provide a useful model for increasing stroke unit availability and access. As the number of episodes in the AuSCR increases, we will have further opportunities to explore other factors contributing to survival after stroke.

The commitment of 60% of registrants completing a follow-up survey to be contacted about further stroke-related research is gratifying and allows the AuSCR Office to support third party research on specific research questions or for recruitment for clinical trials or surveys. A small, but steady, number of requests to access AuSCR data and registrants is indicative of the value of the registry to external parties.

FUTURE DIRECTIONS

At a national level, clinical registry development should be prioritised to target conditions or procedures that are suspected of being associated with large variations in processes or outcomes of care and that impact significantly on health care costs and patient morbidity.⁵ As stroke is a leading cause of death and disability, there should be no doubt that a national, clinical quality stroke registry has a critical role in monitoring stroke care. Future goals and directions for the registry are outlined below.

ENSURING COMPLETE CASE ASCERTAINMENT FROM PARTICIPATING HOSPITALS

Case ascertainment should be assessed yearly in a clinical quality registry. The modest response rate described in this report suggests that it is quite an onerous task for hospitals to verify potentially missed cases. As part of the Stroke123 partnership project we planned to establish use of routine data linkage with hospital data at a state level to ensure that this task could sit outside the role of individual hospitals in order to reduce the associated workload. These state level data linkage processes have continued to be challenging and protracted and it is only in late 2015 and early 2016 (for the final state) that the linked data will have all been received. (See below: 'Maximising the use of data through data linkage'.)

TECHNOLOGY SOLUTIONS FOR SIMPLIFYING DATA COLLECTION FOR CLINICIANS

Data importing into the AuSCR provides the opportunity to reduce the burden of manual data collection, enhance data accuracy and improve case ascertainment. Whilst there has been some uptake of such approaches it is far from universal. One creative solution could include centralised data extracts from state health departments which may be possible in Queensland where common systems are in use across hospitals. In Victoria an infrastructure development opportunity became available

through state government funding and an application, auspiced by the Victorian Stroke Clinical Network, was successful, thus paving the way for hospitals to apply for funding in 2015 to develop innovative information technology solutions for their AuSCR data uploads.

HARMONISATION OF NATIONAL STROKE DATA COLLECTION PROGRAMS: Ausdat

The success of harmonising the NSF acute audit and the AuSCR data collection processes in 2013, provided a proof of concept for processes to be used in the development of the Australian Stroke Data Tool (AuSDaT, see page 12 under Partnerships and Collaborations). There was significant cross-program teamwork involved in: establishing a National Stroke Data Dictionary (with standardised variable definitions see http://australianstrokecoalition.com.au/aus-tions dat/); the associated Master Data List; and the design of the AuSDaT. Project requirements and tender specifications were developed and a tender process was conducted. The successful vendor commenced the build in October 2014 with the project funded by the NSF. The AuSCR committee members and staff have been heavily involved in all aspects of the build which needed to complete its first phase in time for the NSF acute audit in April 2015, after which AuSCR specific functionality (opt-out, follow-up, live reporting) would be created. From mid-2016, the AuSCR will obtain its data using this new data management system software.

CLOSING THE QUALITY FEEDBACK LOOP

As part of the Stroke123 project, the Queensland Quality Improvement sub-study has made extensive use of the AuSCR acute and follow-up data, as well as the traditionally employed NSF audit data, for informing hospital staff participating in the NSF StrokeLink workshops. These workshops provide data feedback to inform quality improvement activities based on identified gaps in care. Assisting clinicians to engage with their data is one way of enhancing quality of care and patient outcomes. As in past years, the AuSCR data have also been presented at the Queensland Statewide Stroke Clinical Network (QSSCN) fora, both at an aggregated level but also by hospitals presenting aspects of their own use of their AuSCR data e.g. gap analysis. The AuSCR data are also used by the QSSCN to prepare stroke indicator reports to Queensland CEOs.

Following on from the NSF's StrokeLink (quality improvement) program funded by Queensland Health, a new agreement in 2015 has been established which includes support for the AuSCR operations in Queensland and ongoing externally facilitated quality improvement that is informed by the AuSCR and National Audit data. This Queensland Stroke Quality Improvement (QSQIP) program will build on the StrokeLink-AuSCR collaboration from Stroke123 and sustain these important activities for the next three years.

REDUCING THE DATA COLLECTION BURDEN ASSOCIATED WITH HEALTH SERVICES RESEARCH

In 2014, we have continued to use the AuSCR as important infrastructure to support further health services programs focused on improving the quality of care in regional and rural hospitals in Victoria. The Victorian Stroke Telemedicine (VST) program is an acute telestroke service designed to support 16 hospitals in rural and regional Victoria with around the clock neurologist consultations to improve access to thrombolysis and other evidence-based acute stroke treatments (www.vst.org.au). Over the duration of the VST Program, data are collected from the hospitals that are participating in the VST program. Use of the AuSCR permits standardised data on the number of patients receiving intravenous thrombolysis to be captured as part of routine practice and also 90 day health outcomes. The VST program requires measurement of these indicators during, and up to five years after, the program has been implemented. To ensure responder burden is minimised and to avoid duplication of effort whilst maximising the available funds for both programs of work, it was agreed to: a) share data between the VST and the AuSCR program; b) include the AuSCR follow-up variables in the VST 90 day questionnaire and establish a process for the applicable data to be securely submitted to the AuSCR at regular intervals so that patients would not be contacted twice for similar information; and c) create a telemedicine specific minimum data-spine that could provide additional needed data for VST, including whether a telemedicine consult was received and if a patient was treated with thrombolysis. Ethical approval was obtained for this process in 2014. Achieving these solutions shows the importance of how collaboration can be achieved to ensure maximal use of limited resources, whilst placing the patient at the centre of our efforts to better understand and improve stroke care.

MAXIMISING THE USE OF DATA THROUGH DATA LINKAGE

Data on patients in Australia are collected in various forms, but are limited in their use because there is no relationship between the different pieces of information held in different databases. In order to ensure that the AuSCR data are maximised to their full potential, and can be used to provide a greater understanding of the factors that influence patient outcome, a data linkage sub-study has been facilitated through the Stroke123 grant. 16 As part of the opt-out model, patients who have their data registered in the AuSCR are made aware that their data may be linked to other sources of data to enable the collection of further information regarding their health care needs and how they have recovered. In 2014 some progress was made with regards to achieving cross-jurisdictional data linkage between the AuSCR and government held routinely collected health data. Once again data were successfully linked between the AuSCR and the National Death Index, the results of which have been utilised in this annual report thus ensuring reliable data on date and cause of death for all registrants. Approvals from Queensland, New South Wales, Victoria and Western Australia to link the AuSCR with hospital admission and emergency department data have been received and data received from all but one state. Analysis is to be conducted in 2016.

REPERFUSION AND TELE-MEDICINE DATA MONITORING TO BE ESTABLISHED IN 2016

We are very conscious of the AuSCR data capturing advances in stroke treatment of national importance. Since its inception, the minimum data set has expanded incrementally to accommodate data monitoring needs for different state jurisdictions including having routine and standardised information on telemedicine and thrombolysis intervention. With the strength of evidence now supporting use of endovascular clot retrieval (ECR), and new national standards of care related to reperfusion treatment being offered to eligible patients, the ability to reliably monitor benefits and harm from a quality perspective was required. State health departments are increasingly interested in this intervention. In Victoria and Queensland, where there is a statewide commitment to use the AuSCR, it was determined that a minimum data set for reperfusion therapies be established and made available for all participating hospitals to collect commencing in 2016. The variables for this new aspect of the AuSCR were established by a small interest group of experts who selected these from those listed in the comprehensive National Stroke Data Dictionary endorsed by the Australian Stroke Coalition in 2015 (see http:// australianstrokecoalition.com.au/ausdat/). Given that ECR is mainly used in a few hospitals, oversight of the data and its use is important. To this end we will be establishing an AuSCR Reperfusion and Telemedicine Sub-Committee (refer Appendix D for variables list.)

CONCLUDING COMMENTS

The purpose of the AuSCR is to provide high quality independent data on the quality of care and its relationship to health outcomes for acute stroke in Australia. With the increasing volume of registrants, we now have enhanced capacity to conduct robust analyses of the factors that impact on the quality of care for stroke and TIA, and how that care can influence morbidity and mortality. We hope that the data in this 2014 AuSCR Annual Report are useful to clinicians, patients and policy makers.

In particular, we hope that the provision of achievable benchmarks from the top performing hospitals using methods that took into account participation factors such as number of registrants, will create impetus for facilitating strong efforts to address areas of underperformance; and also provide an example for other groups that rely on reporting national average performance in efforts to guide quality improvement activity.

The AuSCR is in a unique position to inform the field and we hope that the quality, and indeed the viability, of the registry will not be compromised by the lack of sustainable funding. We continue to explore all avenues of financial support through government and industry in order to secure the future of the registry. We are grateful to the Victorian and Queensland governments and to our industry and academic partners, who continue to support and provide short-term security for this registry.

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STEERING COMMITTEE MEMBERSHIP

| | STEERING COMMITTEE MEM | STEERING COMMITTEE MEMBERSHIP 2014 | | | | |
|---------------------------------|---|--|-------|--|--|--|
| NAME | POSITION | ORGANISATION | STATE | | | |
| Prof Sandy Middleton (Chair) | Director, Nursing Research Institute | St Vincent's Health Australia (Sydney) and Australian Catholic University | NSW | | | |
| Prof Craig Anderson | Senior Director, Neurological & Mental Health Division Professor of Stroke Medicine and Clinical Neuroscience Head, Neurology Department, Royal Prince Alfred Hospital NHMRC Senior Principal Research Fellow | The George Institute for Global Health, affiliated with the Royal Prince Alfred Hospital and University of Sydney | NSW | | | |
| Dr Michael Pollack | Director, Rehabilitation Medicine Chairman, Hunter Stroke Service Chairman, GMCT NSW | John Hunter Hospital | NSW | | | |
| Ms Frances Simmonds | Director, Australasian Rehabilitation Outcomes Centre (AROC) | Australian Health Services Research Institute, University of Wollongong | NSW | | | |
| Prof Julie Bernhardt | Head, Stroke Division | The Florey Institute of Neuroscience and Mental Health | VIC | | | |
| Prof Christopher Bladin | Director, Victorian Stroke Telemedicine Program Neurologist, Eastern Health | The Florey Institute of Neuroscience and Mental Health Eastern Health (Monash University) | VIC | | | |
| Prof Geoffrey Donnan | Director Professor of Neurology | The Florey Institute of Neuroscience and Mental Health University of Melbourne | VIC | | | |
| Dr Mark Mackay | Paediatric Neurologist | Royal Children's Hospital, Melbourne | VIC | | | |
| Dr Erin Lalor | Chief Executive Officer | National Stroke Foundation | VIC | | | |
| Prof John McNeil | Head, Department of Epidemiology and Preventive Medicine | Monash University | VIC | | | |
| Mr Mark Simcocks | Consumer Representative | Self employed | VIC | | | |
| Prof Amanda Thrift | Head, Epidemiology and Prevention Unit NHMRC Senior Research Fellow | Monash University | VIC | | | |
| Dr Andrew Lee | Neurologist & Stroke Physician NHMRC - NICS Fellow | Flinders Comprehensive Stroke Centre, Flinders Medical Centre | SA | | | |
| Dr Helen Castley | Neurologist Co-chair | Royal Hobart Hospital Clinical Advisory Group (Neurology and Stroke) | TAS | | | |
| Mr Greg Cadigan | Principal Project Officer | Queensland Statewide Stroke Clinical Network | QLD | | | |

| NAME | POSITION | ORGANISATION | STATE |
|------------------------------|--|--|-------|
| Dr Rohan Grimley | Conjoint Senior Lecturer Clinical Chair | Sunshine Coast Clinical School Queensland Statewide Stroke Clinical Network | QLD |
| Prof Richard Lindley | Professorial Fellow Professor of Geriatric Medicine | The George Institute for Global Health Sydney Medical School, University of Sydney. | NSW |
| A/Prof Dominique Cadilhac | Head, Public Health, Stroke Division NHMRC/NSF Fellow Head, Translational Public Health Division Stroke and Ageing Research | The Florey Institute of Neuroscience and Mental Health Monash University | VIC |



DESCRIPTION OF RESULTS CALCULATIONS FOR PARTICULAR VARIABLES

| INDICATOR | NUMERATOR | DENOMINATOR | COMMENTS |
|--|-----------|--|---|
| INDICATOR | NUMERATOR | DENOMINATOR | COMMENTS |
| Sex - Male | Yes | Yes + No + Intersex/ indeterminate | Excludes Not stated / Inadequately described |
| Transferred from another hospital | Yes | Yes + No | Excludes Unknown |
| In-hospital stroke | Yes | Yes + No | Excludes Unknown |
| Able to walk independently on admission | Yes | Yes + No | Excludes Not documented |
| Received care in stroke unit | Yes | Yes + No + Unknown + Missing | |
| Type of stroke | Yes | Haemorrhagic + Ischaemic + TIA + Undetermined | Excludes missing |
| Received intravenous throm- bolysis if ischaemic stroke | Yes | Yes + No + Unknown + Missing | Includes ischaemic strokes only |
| Mobilisation during admission | Yes | Yes + No + Unknown + Missing | Includes Queensland patients only |
| If patient unable to walk, patient mobilised | Yes | Yes + No + Unknown + Missing | Includes Queensland patients only Includes only patients who were not able to walk independently on admission |
| Dysphagia screen tool used | Yes | Yes + No + Unknown + Missing | Includes Queensland patients only |
| Screen or swallow assessment undertaken | Yes | Yes + No + Unknown + Missing | Includes Queensland patients only |
| Aspirin administration within 48 hours | Yes | Yes + No + Unknown + Missing | Includes Queensland patients only Excludes patients with haemorrhagic stroke or if contraindicated |
| Died | Yes | Yes + No | Excludes missing |
| Discharged home | Yes | Yes + No | Excludes deaths Excludes missing |
| Care plan, outlining post-discharge care in the community, developed with the team and the patient and/or family | Yes | Yes + No + Unknown + Missing | Includes patients discharged home or to a residential aged care facility There were episodes of care that resulted in discharge home or to a residential aged care facility that were incorrectly categorised as being ineligible for a care plan. These episodes were re-categorised as not receiving this indicator |
| Discharged on antihypertensive | Yes | Yes + No + Unknown + Missing | Includes patients discharged only |
| Discharged on antiplatelets or antithrombotics | Yes | Yes + No + Unknown + Missing | Includes Queensland patients only Includes patients discharged only Excludes patients with haemorrhagic stroke |



ADHERENCE DATA BY PARTICIPATING HOSPITAL

TREATED IN A STROKE UNIT (ACHIEVABLE PERFORMANCE BENCHMARK 96%)

| 10 | HOSPITAL (CODED) | ALL EPISODES, n/N (%) | ISCHAEMIC, n/N (%) | TIA, n/N (%) | HOSPITAL (CODED) | ALL EPISODES, n/N (%) | ISCHAEMIC, n/N (%) | TIA, n/N (%) |
|--|---------------------|--------------------------|-----------------------|-----------------|---------------------|--------------------------|-----------------------|-----------------|
| 11 | 9 | 185/194 (95) | 122/128 (95) | 41/44 (93) | 36 | 168/213 (79) | 113/132 (86) | 31/44 (70) |
| 12 594/623 (95) 380/395 (96) 141/149 (95) 40 198/250 (79) 112/121 (93) 63/105 (60) 15 3/17 (18) 6/29 (21) 0/4 (0) 41 260/325 (80) 207/251 (82) 24/33 (73) 16 53/59 (90) 22/23 (96) 14/17 (82) 43 84/193 (44) 54/75 (72) 12/86 (14) 19 0/6 (0) 0/6 (0) 0/0 (0) 44 172/203 (85) 92/107 (86) 30/40 (75) 20 155/188 (82) 96/109 (88) 37/46 (80) 45 172/251 (69) 139/164 (85) 19/65 (29) 21 108/127 (85) 68/81 (84) 33/38 (87) 46 164/194 (85) 155/179 (87) 0/0 (0) 22 380/475 (80) 251/287 (87) 7/7 (100) 47 236/248 (95) 175/180 (97) 35/36 (97) 23 463/563 (82) 362/425 (85) 50/72 (69) 48 117/120 (98) 61/62 (98) 47/49 (96) 25 19/19 (100) 13/13 (100) 6/6 (100) 49 225/303 (74) 133/158 (84) 57/99 (58) 26 12/13 (92) 7/8 (88) 5/5 (100) 50 305/355 (86) 219/256 (86) 52/57 (91) 28 255/352 (72) 192/243 (79) 27/58 (47) 51 52/75 (69) 40/46 (87) 2/12 (17) 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (100) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (70) 37/50 (74) 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (100) | 10 | 253/257 (98) | 186/189 (98) | 28/28 (100) | 37 | 23/25 (92) | 10/10 (100) | 9/10 (90) |
| 15 3/17 (18) 6/29 (21) O/4 (O) 41 260/325 (8O) 207/251 (82) 24/33 (73) 16 53/59 (9O) 22/23 (96) 14/17 (82) 43 84/193 (44) 54/75 (72) 12/86 (14) 19 O/6 (O) O/6 (O) O/0 (O) 44 172/203 (85) 92/107 (86) 30/40 (75) 20 155/188 (82) 96/109 (88) 37/46 (8O) 45 172/251 (69) 139/164 (85) 19/65 (29) 21 108/127 (85) 68/81 (84) 33/38 (87) 46 164/194 (85) 155/179 (87) O/0 (O) 22 380/475 (8O) 251/287 (87) 7/7 (10O) 47 23/6/248 (95) 175/180 (97) 35/36 (97) 23 463/563 (82) 362/425 (85) 50/72 (69) 48 117/120 (98) 61/62 (98) 47/49 (96) 25 19/19 (10O) 13/13 (10O) 6/6 (10O) 49 225/303 (74) 133/158 (84) 57/99 (58) 26 12/13 (92) 7/8 (88) 5/5 (10O) 50 305/355 (86) 219/256 (86) 52/57 (91) 28 255/352 (72) 192/243 (79) 27/58 (47) 51 52/75 (69) 40/46 (87) 2/12 (17) 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (10O) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (7O) 37/50 (74) 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (10O) | 11 | 249/268 (93) | 181/194 (93) | 10/11 (91) | 39 | 55/69 (80) | 46/56 (82) | 4/8 (50) |
| 16 53/59 (90) 22/23 (96) 14/17 (82) 43 84/193 (44) 54/75 (72) 12/86 (14) 19 0/6 (0) 0/6 (0) 0/0 (0) 44 172/203 (85) 92/107 (86) 30/40 (75 20 155/188 (82) 96/109 (88) 37/46 (80) 45 172/251 (69) 139/164 (85) 19/65 (29) 21 108/127 (85) 68/81 (84) 33/38 (87) 46 164/194 (85) 155/179 (87) 0/0 (0) 22 380/475 (80) 251/287 (87) 7/7 (100) 47 236/248 (95) 175/180 (97) 35/36 (97) 23 463/563 (82) 362/425 (85) 50/72 (69) 48 117/120 (98) 61/62 (98) 47/49 (96) 25 19/19 (100) 13/13 (100) 6/6 (100) 49 225/303 (74) 133/158 (84) 57/99 (58) 26 12/13 (92) 7/8 (88) 5/5 (100) 50 305/355 (86) 219/256 (86) 52/57 (91) 28 255/352 (72) 192/243 (79) 27/58 (47) 51 52/75 (69) 40/46 (87) 2/12 (17) 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (100) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (70) 37/50 (74) | 12 | 594/623 (95) | 380/395 (96) | 141/149 (95) | 40 | 198/250 (79) | 112/121 (93) | 63/105 (60) |
| 19 | 15 | 3/17 (18) | 6/29 (21) | 0/4 (0) | 41 | 260/325 (80) | 207/251 (82) | 24/33 (73) |
| 20 155/188 (82) 96/109 (88) 37/46 (80) 45 172/251 (69) 139/164 (85) 19/65 (29) 21 108/127 (85) 68/81 (84) 33/38 (87) 46 164/194 (85) 155/179 (87) 0/0 (0) 22 380/475 (80) 251/287 (87) 7/7 (100) 47 236/248 (95) 175/180 (97) 35/36 (97) 23 463/563 (82) 362/425 (85) 50/72 (69) 48 117/120 (98) 61/62 (98) 47/49 (96) 25 19/19 (100) 13/13 (100) 6/6 (100) 49 225/303 (74) 133/158 (84) 57/99 (58) 26 12/13 (92) 7/8 (88) 5/5 (100) 50 305/355 (86) 219/256 (86) 52/57 (91) 28 255/352 (72) 192/243 (79) 27/58 (47) 51 52/75 (69) 40/46 (87) 2/12 (17) 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (100) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (70) 37/50 (74) 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (100) | 16 | 53/59 (90) | 22/23 (96) | 14/17 (82) | 43 | 84/193 (44) | 54/75 (72) | 12/86 (14) |
| 21 108/127 (85) 68/81 (84) 33/38 (87) 46 164/194 (85) 155/179 (87) 0/0 (0) 22 380/475 (80) 251/287 (87) 7/7 (100) 47 236/248 (95) 175/180 (97) 35/36 (97) 23 463/563 (82) 362/425 (85) 50/72 (69) 48 117/120 (98) 61/62 (98) 47/49 (96) 25 19/19 (100) 13/13 (100) 6/6 (100) 49 225/303 (74) 133/158 (84) 57/99 (58) 26 12/13 (92) 7/8 (88) 5/5 (100) 50 305/355 (86) 219/256 (86) 52/57 (91) 28 255/352 (72) 192/243 (79) 27/58 (47) 51 52/75 (69) 40/46 (87) 2/12 (17) 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (100) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (70) 37/50 (74) 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (100) | 19 | 0/6 (0) | 0/6 (0) | 0/0 (0) | 44 | 172/203 (85) | 92/107 (86) | 30/40 (75) |
| 22 380/475 (80) 251/287 (87) 7/7 (100) 47 236/248 (95) 175/180 (97) 35/36 (97) 23 463/563 (82) 362/425 (85) 50/72 (69) 48 117/120 (98) 61/62 (98) 47/49 (96) 25 19/19 (100) 13/13 (100) 6/6 (100) 49 225/303 (74) 133/158 (84) 57/99 (58) 26 12/13 (92) 7/8 (88) 5/5 (100) 50 305/355 (86) 219/256 (86) 52/57 (91) 28 255/352 (72) 192/243 (79) 27/58 (47) 51 52/75 (69) 40/46 (87) 2/12 (17) 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (100) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (70) 37/50 (74) 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (100) | 20 | 155/188 (82) | 96/109 (88) | 37/46 (80) | 45 | 172/251 (69) | 139/164 (85) | 19/65 (29) |
| 23 463/563 (82) 362/425 (85) 50/72 (69) 48 117/120 (98) 61/62 (98) 47/49 (96) 25 19/19 (100) 13/13 (100) 6/6 (100) 49 225/303 (74) 133/158 (84) 57/99 (58) 26 12/13 (92) 7/8 (88) 5/5 (100) 50 305/355 (86) 219/256 (86) 52/57 (91) 28 255/352 (72) 192/243 (79) 27/58 (47) 51 52/75 (69) 40/46 (87) 2/12 (17) 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (100) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (70) 37/50 (74) 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (100) | 21 | 108/127 (85) | 68/81 (84) | 33/38 (87) | 46 | 164/194 (85) | 155/179 (87) | 0/0 (0) |
| 25 19/19 (100) 13/13 (100) 6/6 (100) 49 225/303 (74) 133/158 (84) 57/99 (58) 26 12/13 (92) 7/8 (88) 5/5 (100) 50 305/355 (86) 219/256 (86) 52/57 (91) 28 255/352 (72) 192/243 (79) 27/58 (47) 51 52/75 (69) 40/46 (87) 2/12 (17) 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (100) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (70) 37/50 (74) 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (100) | 22 | 380/475 (80) | 251/287 (87) | 7/7 (100) | 47 | 236/248 (95) | 175/180 (97) | 35/36 (97) |
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| 29 414/508 (81) 320/350 (91) 55/90 (61) 53 30/144 (21) 17/73 (23) 4/44 (9) 30 72/79 (91) 57/63 (90) 1/1 (100) 54 51/88 (58) 28/39 (72) 9/27 (33) 31 100/205 (49) 62/93 (67) 23/82 (28) 55 82/121 (68) 31/44 (70) 37/50 (74) 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (100) | 26 | 12/13 (92) | 7/8 (88) | 5/5 (100) | 50 | 305/355 (86) | 219/256 (86) | 52/57 (91) |
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| 32 345/487 (71) 246/266 (92) 73/102 (72) 56 523/564 (93) 395/421 (94) 41/41 (100 | 30 | 72/79 (91) | 57/63 (90) | 1/1 (100) | 54 | 51/88 (58) | 28/39 (72) | 9/27 (33) |
| | 31 | 100/205 (49) | 62/93 (67) | 23/82 (28) | 55 | 82/121 (68) | 31/44 (70) | 37/50 (74) |
| 34 72/158 (46) 57/65 (88) 14/29 (48) 57 55/86 (64) 34/44 (77) 5/21 (24) | 32 | 345/487 (71) | 246/266 (92) | 73/102 (72) | 56 | 523/564 (93) | 395/421 (94) | 41/41 (100) |
| | 34 | 72/158 (46) | 57/65 (88) | 14/29 (48) | 57 | 55/86 (64) | 34/44 (77) | 5/21 (24) |
| 35 92/180 (51) 55/80 (69) 11/41 (27) 62 3/3 (100) 0/0 (0) | 35 | 92/180 (51) | 55/80 (69) | 11/41 (27) | 62 | 3/3 (100) | 0/0 (0) | 0/0 (0) |

APPENDIX C (CONT'D)

TREATED WITH INTRAVENOUS THROMBOLYSIS (i.e. tpA), IF AN ISCHAEMIC STROKE (ACHIEVABLE PERFORMANCE BENCHMARK 20%)

| HOSPITAL (CODED) | ALL EPISODES, n/N (%) | ISCHAEMIC, n/N (%) | TIA, n/N (%) |
|------------------|-----------------------|--------------------|--------------|
| 9 | | 10/128 (8) | |
| 10 | | 34/189 (18) | |
| 11 | | 41/194 (21) | |
| 12 | | 75/395 (19) | |
| 15 | | 0/29 (0) | |
| 16 | | 0/23 (0) | |
| 19 | | 1/6 (17) | |
| 20 | | 8/109 (7) | |
| 21 | | 7/81 (9) | |
| 22 | | 43/287 (15) | |
| 23 | | 67/425 (16) | |
| 25 | | 0/13 (0) | |
| 26 | | 1/8 (13) | |
| 28 | | 14/243 (6) | |
| 29 | | 35/350 (10) | |
| 30 | | 4/63 (6) | |
| 31 | | 5/93 (5) | |
| 32 | | 46/266 (17) | |
| 34 | | 1/65 (2) | |
| 35 | | 0/80 (0) | |
| 36 | | 10/132 (8) | |
| 37 | | 0/10 (0) | |
| 39 | | 2/56 (4) | |
| 40 | | 9/121 (7) | |
| 41 | | 19/251 (8) | |
| 43 | | 0/75 (0) | |
| 44 | | 5/107 (5) | |
| 45 | | 2/164 (1) | |
| 46 | | 14/179 (8) | |
| 47 | | 6/180 (3) | |
| 48 | | 2/62 (3) | |
| 49 | | 12/158 (8) | |
| 50 | | 19/256 (7) | |
| 51 | | 5/46 (11) | |
| 53 | | 8/73 (11) | |
| 54 | | 2/39 (5) | |
| 55 | | 6/44 (14) | |
| 56 | | 82/421 (19) | |
| 57 | | 8/44 (18) | |
| 62 | | 0/0 (0) | |

APPENDIX C (CONT'D)

DISCHARGED ON AN ANTIHYPERTENSIVE AGENT (ACHIEVABLE PERFORMANCE BENCHMARK 88%)

| HOSPITAL (CODED) | ALL EPISODES, n/N (%) | ISCHAEMIC, n/N (%) | TIA, n/N (%) |
|------------------|-----------------------|--------------------|--------------|
| 9 | 133/189 (71) | 89/126 (71) | 29/43 (67) |
| 10 | 179/238 (75) | 131/175 (75) | 20/28 (71) |
| 11 | 181/240 (75) | 131/175 (75) | 25/33 (76) |
| 12 | 410/559 (73) | 260/358 (73) | 108/147 (73) |
| 15 | 16/23 (65) | 11/18 (61) | 4/4 (100) |
| 16 | 39/58 (67) | 18/22 (82) | 11/17 (65) |
| 19 | 0/6 (0) | 0/6 (0) | 0/0 (0) |
| 20 | 118/171 (69) | 72/99 (73) | 28/46 (61) |
| 21 | 89/118 (75) | 52/75 (69) | 33/38 (87) |
| 22 | 324/390 (83) | 218/257 (85) | 3/4 (75) |
| 23 | 468/503 (93) | 361/385 (94) | 69/72 (96) |
| 25 | 17/19 (89) | 13/13 (100) | 4/6 (67) |
| 26 | 8/13 (62) | 4/8 (50) | 4/5 (80) |
| 28 | 235/309 (76) | 165/215 (77) | 44/58 (76) |
| 29 | 321/466 (69) | 226/326 (69) | 64/90 (71) |
| 30 | 59/67 (88) | 50/55 (91) | 1/1 (100) |
| 31 | 131/186 (70) | 68/84 (81) | 52/82 (63) |
| 32 | 276/456 (61) | 186/248 (75) | 67/102 (66) |
| 34 | 64/145 (44) | 42/58 (72) | 22/29 (76) |
| 35 | 104/155 (67) | 46/72 (64) | 34/40 (85) |
| 36 | 139/189 (74) | 89/115 (77) | 31/41 (83) |
| 37 | 17/24 (71) | 6/9 (67) | 7/10 (70) |
| 39 | 44/60 (73) | 35/49 (71) | 6/8 (75) |
| 40 | 212/241 (88) | 102/115 (89) | 90/104 (87) |
| 41 | 243/294 (83) | 193/231 (84) | 27/33 (82) |
| 43 | 103/178 (58) | 41/65 (63) | 45/85 (53) |
| 44 | 138/193 (72) | 72/104 (69) | 35/40 (88) |
| 45 | 174/238 (73) | 118/158 (75) | 43/64 (67) |
| 46 | 119/170 (70) | 111/160 (69) | 0/0 (0) |
| 47 | 176/229 (77) | 138/170 (81) | 24/36 (67) |
| 48 | 101/112 (90) | 52/58 (90) | 44/48 (92) |
| 49 | 194/289 (67) | 108/149 (72) | 60/98 (61) |
| 50 | 212/321 (66) | 156/232 (67) | 33/56 (59) |
| 51 | 45/65 (69) | 33/43 (77) | 5/12 (42) |
| 53 | 62/123 (50) | 33/62 (53) | 19/44 (43) |
| 54 | 70/80 (88) | 28/35 (80) | 26/27 (96) |
| 55 | 71/103 (69) | 30/38 (79) | 29/49 (59) |
| 56 | 218/511 (43) | 161/390 (41) | 11/41 (27) |
| 57 | 51/73 (70) | 27/38 (71) | 15/20 (75) |
| 62 | 0/0 (0) | 0/0 (0) | 0/0 (0) |

APPENDIX C (CONT'D)

CARE PLAN OUTLINING POST DISCHARGE CARE IN THE COMMUNITY DEVELOPED WITH THE TEAM AND THE PATIENT AND/OR FAMILY (ACHIEVABLE PERFORMANCE BENCHMARK 86%)

| HOSPITAL (CODED) | ALL EPISODES, n/N (%) | ISCHAEMIC, n/N (%) | TIA, n/N (%) |
|------------------|-----------------------|--------------------|--------------|
| 9 | 86/118 (73) | 50/68 (74) | 31/42 (74) |
| 10 | 50/91 (55) | 31/60 (52) | 15/25 (60) |
| 11 | 1/134 (1) | 1/89 (1) | 0/32 (0) |
| 12 | 108/238 (45) | 46/101 (46) | 59/129 (46) |
| 15 | 8/12 (67) | 6/8 (75) | 2/4 (50) |
| 16 | 4/52 (8) | 2/19 (11) | 1/16 (6) |
| 19 | 0/5 (0) | 0/5 (0) | 0/0 (0) |
| 20 | 82/126 (65) | 54/69 (78) | 18/41 (44) |
| 21 | 60/74 (81) | 30/36 (83) | 27/35 (77) |
| 22 | 181/201 (90) | 123/134 (92) | 3/5 (60) |
| 23 | 242/289 (84) | 166/198 (84) | 59/66 (89) |
| 25 | 5/7 (71) | 2/2 (100) | 3/5 (60) |
| 26 | 7/10 (70) | 3/5 (60) | 4/5 (80) |
| 28 | 85/203 (42) | 68/130 (52) | 6/56 (11) |
| 29 | 170/240 (71) | 106/145 (73) | 57/84 (68) |
| 30 | 18/26 (69) | 16/24 (67) | 1/1 (100) |
| 31 | 71/129 (55) | 25/43 (58) | 40/75 (53) |
| 32 | 171/270 (63) | 82/117 (70) | 81/96 (84) |
| 34 | 28/105 (27) | 18/37 (50) | 10/29 (34) |
| 35 | 10/79 (13) | 6/29 (21) | 3/33 (9) |
| 36 | 46/121 (38) | 28/65 (43) | 13/42 (31) |
| 37 | 9/22 (41) | 5/8 (63) | 3/10 (30) |
| 39 | 18/29 (62) | 15/20 (75) | 2/7 (29) |
| 40 | 80/142 (56) | 34/49 (69) | 43/84 (51) |
| 41 | 106/149 (71) | 77/106 (73) | 19/30 (63) |
| 43 | 17/122 (14) | 7/44 (16) | 8/64 (13) |
| 44 | 48/98 (49) | 23/42 (55) | 14/32 (44) |
| 45 | 57/120 (48) | 32/58 (55) | 21/58 (36) |
| 46 | 6/59 (10) | 6/56 (11) | 0/0 (0) |
| 47 | 10/141 (7) | 8/97 (8) | 1/33 (3) |
| 48 | 10/75 (13) | 4/27 (15) | 4/44 (9) |
| 49 | 53/192 (28) | 30/78 (38) | 15/93 (16) |
| 50 | 151/175 (86) | 95/110 (86) | 49/54 (91) |
| 51 | 24/30 (80) | 14/17 (82) | 8/11 (73) |
| 53 | 20/60 (33) | 7/19 (37) | 11/37 (30) |
| 54 | 15/56 (27) | 8/19 (42) | 3/24 (13) |
| 55 | 54/78 (69) | 17/21 (89) | 28/46 (61) |
| 56 | 201/235 (86) | 169/175 (97) | 10/36 (28) |
| 57 | 9/30 (30) | 6/12 (50) | 0/13 (0) |
| 62 | 0/0 (0) | 0/0 (0) | 0/0 (0) |
| | | | |



PROPOSED MINIMUM DATA SET FOR REPERFUSION THERAPIES

| CURRENT AuSCR STATUS | VARIABLE | RESPONSE SET | | | |
|---|--|--|--|--|--|
| AT REFERRING HOSPITAL | | | | | |
| TO BE ADDED | Did the patient have a brain scan after this stroke? | Yes/No | | | |
| ~Telemedicine | Date of first brain scan after the stroke | DDMMYYYY | | | |
| ~Telemedicine | Time of first brain scan after the stroke | hh:mm | | | |
| Telemedicine | Was a stroke telemedicine consultation conducted? | Yes/No/Unknown | | | |
| AuSCR | Did the patient receive intravenous thrombolysis? | Yes/No/Unknown | | | |
| Telemedicine | Date of delivery | DDMMYYYY | | | |
| Telemedicine | Time of delivery | hh:mm | | | |
| Telemedicine | Was there a serious adverse event related to thrombolysis? | Yes/No | | | |
| Telemedicine | Type of adverse event. [Tick all that apply.] | Intracranial haemorrhage/ Extracranial haemorrhage/ Angioedema/Other | | | |
| ACUTE | PHASE AT RECEIVING HOSPITAL/ENDOVASCULAR CLOT RETRIEVAL | CENTRE (ECR) CENTRE | | | |
| TO BE ADDED | Direct admission to hospital (bypass Emergency Department) | Yes/No | | | |
| AuSCR | Was the patient transferred from another hospital? | Yes/No/Unknown | | | |
| TO BE ADDED | What was the reason for transfer? Need for intravenous tPA: Need for stroke unit care; Need for rehabilitation; Need for brain imaging only; Need for intensive care unit; Need for specialist medical assessments; Need for specialist surgical interventions; Need for diagnostic tests; Need for coordinated care by a stroke service; Need for endovascular therapy; Unknown; Other (specify); | Yes/No to all reasons | | | |
| TO BE ADDED | Date of subsequent brain scan after the stroke | DDMMYYYY Not applicable (no further scans) | | | |
| TO BE ADDED | Time of subsequent brain scan after the stroke | hh:mm not documented | | | |
| TO BE ADDED | Was other reperfusion (endovascular) treatment provided? | Yes/No | | | |
| TO BE ADDED | Treatment date for other reperfusion | DDMMYYYY | | | |
| TO BE ADDED | National Institutes of Health Stroke Scale (NIHSS) before endovascular treatment | Number: 0-42, 99 | | | |
| TO BE ADDED | Time groin puncture | hh:mm | | | |
| TO BE ADDED | Time of completing recanalisation/ procedure | hh:mm | | | |
| TO BE ADDED | Final TICI (Thrombolysis in cerebral infarction score) | 0, 1, 2a, 2b, 3 | | | |
| 24 HOUR DATA AT RECEIVING HOSPITAL/ECR CENTRE | | | | | |
| TO BE ADDED | 24 hour NIHSS | Number: 0-42, 99 | | | |
| TO BE ADDED | Was there haemorrhage within the infarct on follow-up imaging? | Yes/No/Unknown | | | |
| TO BE ADDED | Details of haemorrhage | HI1: small petechiae/ HI2: more confluent petechiae/ PH1: 30% of the infarcted area with mild space-occupying effect/ PH2: 30% of the infarcted area with significant space-occupying effect | | | |

