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ONLINE SUPPLEMENT

Establishment of an internationally agreed minimum data set for acute telestroke

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FILE #1: DETAILED METHODS

Phase 1: Identification of potential variables

The potential pool of variables was identified by searching the academic literature, grey literature, and contacting our colleagues involved in telestroke programs. This aspect was commenced in 2015. A review of the academic and grey literature included keyword combinations of 'telemedicine', 'telestroke', 'telecommunications', 'technology' and 'acute stroke', and 'care', 'processes', 'monitoring', 'evaluation'. Searches were limited to: 1) the English language, and 2) full text available. Websites of telemedicine networks identified through literature or colleagues were also examined. Data collection tools and data dictionaries were sourced directly from established telemedicine networks in Australia (Victorian Stroke Telemedicine program),[1, 2] Germany (TEMPIS),[3] United States of America (REACH and STROKE DOC)[4, 5] and the United Kingdom (ASTUTE).[6]

Processes of acute stroke care and patient outcomes relevant to telestroke were reviewed from the identified publications (and their reference lists). Reported summary variables such as quality indicators that might be derived from two or more variables (e.g., door-to-needle time) and associated, specific variables (e.g., patient arrival time, needle time) were extracted. Seeking additional sources ceased when no new variables were identified. The variable options were then summarised into three major themes: Service configuration, Consultations, and Patient information.

Same or similar variables were harmonised i.e. merged and translated into a common language from within and between different data sources[7]. Where applicable, authors KB, NP and DAC reviewed and made a decision to use the simpler English representation of the variable to be described.

Phase 2: Review of variable options via modified Delphi technique

The review process of the potential variable options was undertaken using a modified Delphi technique.[8, 9] This well-established group communication process provides a method for consensus-building from a group of experts.[8, 9] Our modified Delphi technique involved an expert panel undertaking two rounds of on-line surveys, with iterative teleconferences and document circulation via email to review and discuss interim and final results. Not all members participated in each phase and some joined later as part of an iterative feedback process. The basic principles for choosing the TS-MDS variables was to select those that would be critical to evaluating a telestroke program and be meaningful as a collective set.

Expert Panel

Consistent with establishing Delphi panels,[10] we set no limit to the panel size. Participation required experience and expertise with acute stroke care within a telemedicine context, including clinical, research and/or management perspective. Using our networks and through our review of the literature, we identified and invited an international panel of 23 experts actively involved in telestroke programs or research from Australia (n=4), New Zealand (n=1), United States of America (n=8), England (n=4), France (n=1), Germany (n=2), and India (n=3). Panel members represented clinicians, researchers or telestroke managers to ensure broad representation. In some instances, Directors of telestroke programs delegated participation to another team member with a relevant interest in this project (e.g., data manager). Each program could have more than one participant, if desired.

Written surveys

Two surveys were administered online (Survey Monkey®, online survey software) focusing on reviewing each potential variable. At this stage, we did not offer variable response options. We also collected information to describe the characteristics of the experts who responded to these surveys such as role and amount of telestroke experience.

Participants were asked to consider each variable and determine its importance for retention. Response options were on a 5-point Likert scale: 1 'totally irrelevant', 2 'irrelevant', 3 'indifferent', 4 'relevant', and 5 'totally relevant'. Each item also included an open–ended question with a free-text box. Members of the expert panel were also invited to nominate additional variables that were not included, but that they considered would be of value for a TS-MDS.

Subsequently, the first survey results were collated with the percentage agreement calculated for each item. Cut-off points for degree of concordance determined if the item would be included (≥ 80%), excluded (<50%) or if further review would be required (50%-79%) (see also *Data management and analysis* section*)*. The variables were then reorganised into these categories and were distributed to panel members for a second round of review and feedback.

The second survey included variables that required further review or had achieved poor agreement in the first round, plus participant demographics. Panel members were invited to complete the same relevance scale as presented in the first survey and to review the potentially excluded items and nominate any items that should be retained.

Subsequently, these survey results were collated and combined with the first survey results and distributed to panel members for a final review.

Consensus meetings via teleconference
In the next review stage, the expert panel met by teleconference to discuss the survey results and identify opportunities for further harmonisation and refinement. Two separate teleconferences were held to discuss the remaining items from round 2 that had received 50-79% agreement. The separate teleconferences were required due to time zone differences and to encourage more options for participation. The first teleconference was between experts from Australia and America, and the second between participants from Australia, England and Europe.

Phase 3: Finalise variables and propose suggested response options
Once the final TS-MDS variables had been identified from Phase 2, variable wording and potential response options were identified or developed for the patient-level and organisational level questions, as required. For this latter task, we drew on established data dictionaries from the Australian National Stroke Data Dictionary (NSDD, established 2016; https://strokefoundation.org.au/Australian%20Stroke%20Coalition/AusDAT), the Australian Institute of Health and Welfare Metadata Online Registry (METeOR; established 2005), and the American Heart Association's Get With The Guidelines® - Stroke (GWTG; established 2003).[11] METeOR (https://meteor.aihw.gov.au/content/index.phtml/itemId/181162) provides nationally endorsed data definitions and standards, and is used by stroke-specific data collection systems including the Australian Stroke Clinical Registry (AuSCR; established 2009)[12] and the AuSDaT (established 2016).

The finalised variables and proposed response options were distributed via email to panel members for review and feedback. The results have been compiled as part of this publication and are presented in the Supplemental File - Data Dictionary.

Supplemental References Detailed Methods

1. Bladin CF, Moloczij N, Ermel S, Bagot KL, Kilkenny M, Vu M, et al. Victorian Stroke Telemedicine Project: implementation of a new model of translational stroke care for Australia. *Intern Med J*. 2015;45:951-956

2. Bagot KL, Cadilhac DA, Kim J, Vu M, Savage M, Bolitho L, et al. Transitioning from a single-site pilot project to a state-wide regional telehealth service: the experience from the Victorian Stroke Telemedicine programme. *J Telemed Telecare*. 2017;23:850-855

3. Audebert HJ, Schultes K, Tietz V, Heuschmann PU, Bogdahn U, Haberl RL, et al. Long-term effects of specialized stroke care with telemedicine support in community hospitals on behalf of the Telemedical Project for Integrative Stroke Care (TEMPiS). *Stroke; a journal of cerebral circulation*. 2009;40:902-908

4. Meyer BC, Raman R, Hemmen T, Obler R, Zivin JA, Rao R, et al. Efficacy of site-independent telemedicine in the STRokE DOC trial: a randomised, blinded, prospective study. *Lancet Neurol*. 2008;7:787-795

5. Hess DC, Wang S, Hamilton W, Lee S, Pardue C, Waller JL, et al. REACH: clinical feasibility of a rural telestroke network. *Stroke; a journal of cerebral circulation*. 2005;36:2018-2020

6. Gibson J, Fitzgerald J, Gibson A, McAdam J, Lightbody L, McLoughlin A, et al. Using telemedicine for acute stroke assessment. *Nursing times*. 2013;109:14-16

7. Svensson-Ranallo PA, Adam TJ, Sainfort F. A framework and standardized methodology for developing minimum clinical datasets. *AMIA Joint Summits on Translational Science proceedings AMIA Summit on Translational Science*. 2011;2011:54-58

8. Ozier W. The Delphi/Modified Delphi technique: a consensus approach to information valuation. . 1998;2016

9. Hsu C-C, Sandford BA. The Delphi technique: making sense of consensus. *Prac Assess Eval*. 2007;12:1-8

10. Akins RB, Tolson H, Cole BR. Stability of response characteristics of a Delphi panel: application of bootstrap data expansion. *BMC medical research methodology*. 2005;5:37-49

11. Schwamm LH, Fonarow GC, Reeves MJ, Pan W, Frankel MR, Smith EE, et al. Get With the Guidelines - stroke is associated with sustained improvement in care for patients hospitalized with acute stroke or transient ischemic attack. *Circulation*. 2009;119:107-115

12. Cadilhac D, Lannin N, Anderson C, Levi C, Faux S, Price C, et al. Protocol and pilot data for establishing the Australian Stroke Clinical Registry (AuSCR). *International journal of stroke : official journal of the International Stroke Society*. 2010:217-226

FILE #2: DATA DICTIONARY

The following Tables outline each of the variables and recommended variable coding for setting up a database for acute telestroke services. Following these formats will permit the ability to reliably pool data or make comparisons between projects/programs.

Contents

Section 1: Service Configuration

Details about Telestroke Program/Network

Variable	Recommended response options and variable coding
1. What year did the telestroke network commence?	- Year commenced first pilot site / program - YYYY e.g., 2018 (only numeric text) - N/A (no pilot site / program used) - Year commenced established network - YYYY e.g., 2018 (only numeric text) - N/A (only currently have a pilot program underway) - Any comments about the year your telestroke network commenced (free text box)
2. What type of telestroke network model is being used?	(select one option) - Hub-and-spoke (Centralised model where specialists are at a single site, e.g., hospital, organisation i.e., 'hub' providing consultations to clinicians at multiple other sites i.e., 'spokes') - Distributed (Decentralised model where specialists are at multiple sites, e.g., hospitals providing consultations to clinicians dispersed across other hospitals) - Horizontal (Decentralised model where specialists provide consultations to clinicians within the same hospital network) - Other _____ (specify other model) (free text)
3. Is the telestroke service available within the Mobile Stroke Unit/Ambulance (MSU)?	(Select one option) 1. Yes, telestroke is available within the MSU 2. No, telestroke is not available within the MSU 9. N/A, we do not have an MSU
4. Does the telestroke service provider network profit from providing service?	(select those that apply. If selected, code = 1) - Our service provider is a for-profit service - Our service provider is not-for-profit - Our service provider is public - Our service provider is private
5. Any comments about your telestroke network model?	Free text box
6. What are the discipline/s and number/s of telestroke consultants?	(select those that apply. If selected, code = 1) - Neurologist - NN (write number of neurologists e.g., 05 or 11) - Stroke physician - NN (write number of stroke physicians e.g., 05 or 11) - Stroke geriatrician

	- NN (write number of stroke geriatricians e.g., 05 or 11)
	- Advanced nurse practitioner
	  - NN (write number of adv. nurse pract. e.g., 05 or 11)
	- Other
	  - _____ (specify other discipline(s)) (free text)
	  - NN (write number for each discipline specified.)

7. How many spoke hospitals are there, and how many of these actively utilise telestroke consultations?	- Number of spoke hospitals
	  - NNN (write number of spoke hospitals e.g., 008) (only numeric text)
	- Number of hospitals utilising telestroke consultations
	  - NNN (write number of hospitals utilising telestroke e.g., 005) (only numeric text)

8. What are the days and hours of operation that the telestroke consultations are available?	(select those that apply. If selected, code = 1) - 24/7 - Outside 8 am to 5 pm Monday to Friday (i.e., after hours, weekends) - For backfill purposes only (e.g., vacation, public holiday) - Other - _____ (specify other) (free text)

9. What telestroke consultation employment model is used?	(select one option)
	1. Consultations part of consultants' work plan
	2. Consultations in addition to usual work role
	  - If separate to usual work role, then roster structure
	    (1) 8 hour shift
	    (2) 12 hour shift
	    (3) 24 hour shift
	    (4) 48 hour shift
	    (5) Other
	      - _____ (specify other) (free text)

10. Where are telestroke consultants providing consults from?	(select one option) - Mobile location - Fixed location
11. What is the telestroke consultation remuneration model for consultation providers?	(select one option) 1. Fee per consultation 2. On-call fee + Fee per consultation 3. Fee per session/shift 4. On-call fee + Fee per session/shift 5. Other - _____ (specify other) (free text)
12. Are there written agreements between hospitals/services providing telestroke services and hospitals using telestroke services for exchange of patient data (e.g., arrival time at receiving hospital or patient outcome post discharge to be	(select one option) 1. Yes, there is a written agreement 2. No, there isn't a written agreement

provided to originating hospital or telestroke network)?	

Details about Initiating Hospital

13. What are the operating days / hours that telestroke consultations are utilised?	(select one option) • 24/7 • outside 8am to 5pm Monday to Friday (i.e., after hours, weekends) • for backfill purposes only (e.g., vacation, public holiday) • Other o _____ (specify other) (free text)
14. Does your hospital have a stroke unit?	1. Yes 2. No
15. Does the hospital have stroke specialists on staff? (i.e., excluding those accessed via telestroke).	(select one option only) 1. Yes, hospital has stroke specialist employed business hours only 2. Yes, hospital has stroke specialist employed 24/7 3. No, hospital does not have stroke specialist employed
16. Does hospital drip-and-ship post-thrombolysis?	(select one option) 1. Yes 2. No 9. Not applicable (hospital does not provide thrombolysis)
17. Does hospital have established procedures to transfer eligible patients for ECR?	(select one option) 1. Yes 2. No
18. Does hospital have established procedures to transfer eligible patients for non-ECR neurosurgical procedures?	(select one option) 1. Yes 2. No
19. What is the distance from the tertiary centre / comprehensive stroke centre / treating hospital (e.g., for post-thrombolysis care, for ECR or non-ECR neurosurgical procedure)?	(select one option) 1. 0-10km 2. 10-50km 3. 50-100km 4. 100-200km 5. >200km
20. How many beds are in the stroke unit?	NNN (write number of beds in stroke unit e.g., 020) (only numeric text)
21. Is real time video and audio available between telestroke using hospital and telestroke consultants?	(select one option) 1. Yes 2. No
22. Is CT imaging available remotely to telestroke consultants?	(select one option) 1. Yes 2. No 9. Unknown/not documented

Section 2: Telestroke Consultation

Variable	Suggested/Preferred Response Options (Coding)
23. Was a telestroke consultation conducted?	(select one option) 1. Yes 2. No 9. Unknown/not documented
24. What was the reason a telestroke consultation was requested? (select one answer option)	(select one answer option) 1. Hyperacute (thrombolysis; other) 2. Acute (assessment; case conference; other) 3. Rehabilitation (assessment/review; therapy; case conference; other). 8. Other o _____ (specify reason for consult) (free text box)

25. Date and start time of when the telestroke neurologist was first contacted by telephone	• Date
	   o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	   o hh:mm (e.g., 13:53) (only numeric text)
	   o Unknown/not documented

26. What was the mode of consultation?	1. Both phone and video 2. Phone only 3. Video only 8. Other (e.g., electronic mail) o _____ (specify mode of consult) (free text box)
27. Who was present at receiving hospital during the consultation?	(select those that apply. If selected, code = 1) • Clinical support staff at receiving hospital present • Medical registrar • Stroke specialist nurse • Emergency department nurse • Consultant Physician • Other o _____ (specify who was present) (free text box)
28. What was the duration of the video call / consultation?	• Time (in minutes) o mm (e.g., 72) (only numeric text)
29. What were the technical observations / difficulties experienced (by remote consultant)?	(select those that apply. If selected, code = 1) • Phone - audio quality • VC – unable to login to software • VC – audio • VC – vision lag • VC – vision drop out • Unable to connect to the cart • PACS – image quality not suitable • PACS – unable to log in • Error message • Other o _____ (specify technical problems) (free text box) • No problems experienced

30. Was a review of CT imaging completed by telestroke consultant?	(select one option) 1. Yes 2. No 9. Unknown/not documented

31. If yes, what was the date/time of review?	• Date
	   o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	   o hh:mm (e.g., 13:53) (only numeric text)
	   o Unknown/not documented

32. What was the preliminary diagnosis by the telestroke consultant?	(select one answer option) 1. Ischaemic 2. Intracerebral Haemorrhage 3. Transient ischaemic attack 4. Not Stroke 5. Undetermined
33. Did telestroke consultant decide/recommend to thrombolyse?	(select one option) 1. Yes 2. No 9. Unknown/not documented
34. Was the thrombolysis recommendation followed by the hospital?	(select one option) 1. Yes 2. No 9. Unknown/not documented
35. Did the telestroke consultant decide / recommend (evaluation of) endovascular clot retrieval?	(select one option) 1. Yes 2. No 9. Unknown/not documented
36. Was the endovascular recommendation followed by the receiving hospital?	(select one option) 1. Yes 2. No 9. Unknown/not documented
37. Did telestroke consultant decide/recommend neurosurgical treatment?	(select one option) 1. Yes 2. No 9. Unknown/not documented
38. Was the other neurosurgical treatment followed by the hospital?	(select one option) 1. Yes 2. No 9. Unknown/not documented
39. National Institute of Health Stroke Scale (i.e., measure of stroke severity) score calculated by telestroke consultant or local clinicians at time of presentation	• Score o NN (e.g., 0-42, 99 not documented) (only numeric text)

Section 3: Patient Characteristics

Socioeconomic demographics

Variable	Suggested/Preferred Response Options (Coding)
40. Gender	(select one option) 1. Male 2. Female 3. Intersex or indeterminate 9. Not stated/inadequately described
41. Date of Birth and age (at presentation to hospital)	• Date ○ DDMMYYYY (only numeric text) • Age calculated automatically from DOB and date of admission
42. Did the patient have any history of known risk factors prior to admission? (select those that apply. If selected, code = 1)	(select those that apply. If selected, code = 1) • Diabetes • Atrial Fibrillation • Coronary Artery Disease • Hypertension • Serious illness that influences prognosis or management of stroke • Other ○ State Other: _____ (free text box) • Unknown/not documented
43. Post code/ Zip code	• Post code/ zip code (free text – 10 characters) ○ Homeless ○ Unknown/not documented
44. Living arrangements prior to admission?	(select one option) 1. Home (alone) 2. Home (with others) 3. Supported accommodations e.g., nursing home, hostel 4. Other ○ _____ (specify other) (free text box) 9. Unknown/not documented
45. Pre-notification to ED by EMS, GP or other health care worker	(select one option) 1. Yes 2. No 9. Unknown/not documented
46. Arrival by ambulance/EMS/MSU?	(select one option) 1. Yes 2. No 9. Unknown/not documented If yes, record mode of transport used: • Road Ambulance/Emergency Medical Service ○ Standard ○ Mobile Stroke Unit • Air Ambulance/Emergency Medical Service ○ Plane ○ Helicopter

Presentation to hospital

47. Functional status prior to stroke? (mRS).	(select one option) 0. No symptoms. 1. No significant disability. Able to carry out all usual activities, despite some symptoms. 2. Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities. 3. Moderate disability. Requires some help, but able to walk unassisted. 4. Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted. 5. Severe disability. Requires constant nursing care and attention, bedridden, incontinent. 9. Unknown/not documented.
48. Previous history of stroke.	(select one option) 1. Yes 2. No 9. Unknown/not documented
49. NIHSS at baseline	• Score NN (e.g., 0-42, 99 not documented) (only numeric text)
50. Did the stroke occur while the patient was in hospital?	(select one option) 1. Yes 2. No 9. Unknown/not documented
51. Was the patient transferred from another hospital?	(select one option) 1. Yes 2. No 9. Unknown/not dcoumented If yes, select reason(s) for transfer (if selected, code=1)? Reasons: • Need for intravenous tPA; • Need for stroke unit care; • Need for rehabilitation; • Need for BRAIN IMAGING only; • Need for ICU; • Need for specialist medical assessments; • Need for surgical interventions; • Need for diagnostic tests; • Need for Coordinated Care by a Stroke Service; • Unknown; • Other: o _____ (specify other) (free text box)

General clinical care within first 24 hours

52. Stroke symptom onset date/time	- Date
	  o DDMMYYYY (only numeric text)
	
	- Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	
	- Time accuracy
	  o KWN = Known time of onset
	  o UNC = If uncertain time of onset, then time last seen well
	  o WAK = If wake up stroke, then time last seen well
	  o TU = Time unknown

53. Discovery of patient with stroke symptoms date/time	- Date
	  o DDMMYYYY (only numeric text)
	
	- Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

54. Emergency Department arrival date/time	- Date
	  o DDMMYYYY (only numeric text)
	
	- Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

55. Did the patient have a brain scan after this stroke?	(select one option) 1. Yes 2. No 9. Unknown/not documented
56. What type of brain scan was performed?	(select those that apply. If selected, code = 1) - CT - MRI

57. Date and time of first brain scan after the stroke	- Date
	  o DDMMYYYY (only numeric text)
	
	- Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

58. Neuroexamination date/time	- Date
	  o DDMMYYYY (only numeric text)
	
	- Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

59. Final ED diagnosis (select only one answer)	(select one answer option) 1. Ischaemic 2. Intracerebral Haemorrhage 3. Transient ischaemic attack 4. Not Stroke 5. Undetermined

60. Definite new diagnosis of acute stroke	(select one option) 1. Yes 2. No 9. Unknown/not documented

61. Decision to proceed to neurosurgery date/time	• Date
	  o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

Thrombolysis treatment

62. Date and time of decision to thrombolyse	• Date
	  o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

63. Reason no thrombolysis given despite being recommended for an ischaemic stroke occurring within 4.5 hours of onset.	(Select those that apply. If selected, code = 1) • Rapidly improving symptoms • Symptoms >4.5hrs • Comorbidities • Current use of oral anticoagulants • Advanced age • Pre-stroke mRS >2 • Infarct core >1/3MCA territory qualitatively • Previous stroke within the last 3 months • Uncontrolled hypertension • CT contraindicated • Use of glycoprotein IIb-IIIa Inhibitors within past 72hrs • Exposure to thrombolytic agent within the previous 72hrs • Patient/family refused • Pregnant woman (clinically evident) • Recent history or clinical presentation of ICH, SAH, AV malformation, aneurysm or cerebral neoplasm • Low NIHSS • Use of heparin in the past 48hrs • A condition posing potential hazard to participant if tPA initiated • Clinically significant hypoglycaemia • Hereditary or acquired haemorrhagic diathesis • Gastrointestinal or urinary bleeding with the past 21 days • Major Surgery • Other o _____ (specify other reason) (free text box)
64. How was the decision to thrombolyse made? (select only one answer)	(select one option) 1. Telephone with imaging 2. Videolink

	3. Other o _____ (specify other) (free text box) 9. Unknown/not documented
65. Did patient consent for thrombolysis treatment?	(select one option) 1. Yes 2. No 9. Unknown/not documented

66. Date and time of patient consent for thrombolysis treatment	• Date
	    o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	    o hh:mm (e.g., 13:53) (only numeric text)
	    o Unknown/not documented

67. What was the date and time thrombolysis commenced?	• Date
	    o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	    o hh:mm (e.g., 13:53) (only numeric text)
	    o Unknown/not documented

68. Was there a serious adverse event related to thrombolysis?	(select one option) 1. Yes 2. No 9. Unknown/not documented
69. Types of complications/adverse event of thrombolysis	(Select those that apply. If selected, code = 1) • Symptomatic/asymptomatic brain haemorrhage • Angioedema • Extra cranial bleed • Other: o _____ (specify other adverse event) (free text box)
70. Adverse events not related to thrombolysis	(select one option) 1. Yes 2. No 9. Unknown/not documented
71. Was it serious, if yes, type of serious adverse event	(select one option) 1. Yes 2. No If yes, select types of serious adverse event (if selected, code=1)? Type of serious adverse event: • Aspiration pneumonia • Other chest infection • Symptomatic haemorrhage • Asymptomatic haemorrhage • Decubitus ulcer • UTI • DVT • Fall

	- Coma - Seizure - Acute MI - Shoulder complications - Pulmonary Embolism - Other _____ (specify other) (free text box)

Endovascular treatment

72. Was other reperfusion (endovascular) treatment recommended?	(select one option) 1. Yes 2. No 9. Unknown/not documented
73. Was other reperfusion (endovascular) treatment provided?	(select one option) 1. Yes 2. No 9. Unknown/not documented
74. If other reperfusion (endovascular) treatment recommended but not provided, why was recommendation not followed?	(Select those that apply. If selected, code = 1) - Significant pre-stroke disability (pre-stroke mRS >1) - No evidence of proximal occlusion - NIHSS <6 - Brain imaging not favourable/haemorrhage transformation (ASPECTS score <6) - Groin puncture could not be initiated within 6 hours of symptom onset - Anatomical reason - unfavourable vascular anatomy that limits access to the occluded artery - Patient/Family refusal - MER performed at outside hospital - Equipment-related delay - No endovascular specialist available - Delay in stroke diagnosis - Vascular imaging not performed - Advanced age - Other _____ (specify other reason) (free text box)
75. Was patient transferred for other reperfusion (endovascular) treatment?	(select one option) 1. Yes 2. No 9. Unknown/not documented If yes, record mode of transport used: - Road Ambulance/Emergency Medical Service - Standard - Mobile Stroke Unit - Air Ambulance/Emergency Medical Service - Plane - Helicopter - Private transport/car service

76. Hospital details patient was transferred to for other reperfusion (endovascular) treatment.	• Hospital name (alphanumeric text box) • State (free text box) • Country (use AuSCR country codes)

77. Date and time of patient transfer for reperfusion (endovascular) treatment?	• Date
	  o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

78. Date and time of patient arrival to reperfusion (endovascular) centre?	• Date
	  o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

79. Date for other reperfusion (endovascular) treatment.	• Date
	  o DDMMYYYY (only numeric text)
	  o Unknown/not documented

80. National Institute of Health Stroke Scale prior to other reperfusion (endovascular) treatment	• Score o NN (0-42, 99=unknown)

81. Time of groin puncture	• Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

82. Time of completing recanalisation / procedure	• Time: 24hr time
	  o hh:mm (e.g., 13:53) (only numeric text)
	  o Unknown/not documented

83. Types of complications of endovascular procedure	• Free text
84. Final thrombolysis in cerebral infarction (TICI) score	(select one option) 0. Grade 0 1. Grade 1 2a. Grade 2a 2b. Grade 2b 2c. Grade 2c 3. Grade 3 9. Unknown/not documented

Neurosurgery treatment

85. Was other neurosurgical treatment recommended?	(select one option) 1. Yes 2. No 9. Unknown/not documented
86. If other neurosurgical treatment recommended but not provided, why was recommendation not followed?	(Select those that apply. If selected, code = 1) • Significant pre-stroke disability (pre-stroke mRS >1) • No evidence of proximal occlusion • NIHSS <6 • Brain imaging not favourable/haemorrhage transformation (ASPECTS score <6)

	- Groin puncture could not be initiated within 6 hours of symptom onset - Anatomical reason - unfavourable vascular anatomy that limits access to the occluded artery - Patient/Family refusal - MER performed at outside hospital - Equipment-related delay - No endovascular specialist available - Delay in stroke diagnosis - Vascular imaging not performed - Advanced age - Other o _____ (specify other reason) (free text box)
87. Was patient transferred for other neurosurgical treatment?	(select one option) 1. Yes 2. No 9. Unknown/not documented
88. Type of neurosurgery performed?	(select one option) 0. None 1. Hemicraniectomy 2. Ventricular shunting 3. Haematoma removal 4. Other o _____ (specify other neurosurgery) (free text box)
89. Hospital details patient was transferred to for neurosurgery treatment.	- Hospital name (alphanumeric text box) - State (free text box) - Country (use AuSCR country codes)

90. Date and time of patient transfer for neurosurgery?	- Date
	   o DDMMYYYY (only numeric text)
	
	- Time: 24hr time
	   o hh:mm (e.g., 13:53) (only numeric text)
	   o Unknown/not documented

91. Date and time of patient arrival to centre for neurosurgery?	- Date
	   o DDMMYYYY (only numeric text)
	
	- Time: 24hr time
	   o hh:mm (e.g., 13:53) (only numeric text)
	   o Unknown/not documented

92. Treatment date and time for neurosurgery.	- Date
	   o DDMMYYYY (only numeric text)
	
	- Time: 24hr time
	   o hh:mm (e.g., 13:53) (only numeric text)
	   o Unknown/not documented

Processes of care beyond the first 24 hours

93. Symptomatic intracerebral haemorrhage reported.	(select one option) 1. Yes 2. No 9. Unknown/not documented
94. Asymptomatic intracerebral haemorrhage reported.	(select one option) 1. Yes 2. No 9. Unknown/not documented
95. Followup Computed Tomography scan at 24 hours.	(select one option) 1. Yes 2. No 9. Unknown/not documented
96. Was there haemorrhage within the infarct on follow-up imaging?	(select one option) 1. Yes 2. No 9. Unknown/not documented
97. Details of haemorrhage at 24 hours followup	• Free text
98. Was the patient treated in a stroke unit at any time during their stay?	(select one option) 1. Yes 2. No 9. Unknown/not documented
99. Was the patient referred to a tertiary centre / comprehensive stroke centre / teaching hospital / other?	(select one option) 1. Yes 2. No 9. Unknown/not documented

Discharge information

100. What is the discharge diagnosis ICD10 Classification Code?	(select one option) • I61.0 – I61.6, I61.8, I61.9 • I62.9 • I63.0 – I63.6, I63.8, I63.9 • I64.0 • G45.9 • Other (OTH) o _____ (specify other) (Alpha numeric field, upper case.)
101. Patient deceased during hospital care? If yes, what is the date of death, and cause?	(select one option) 1. Yes 2. No If yes, provide date: • Date o DDMMYYYY (only numeric text) If yes, select cause of death (select one option) 1. Cerebral infarct (CI)

	2. Cerebral haemorrhage (CH)
	3. Cerebral infarct and haemorrhage without specification (CIH)
	4. Myocardial infarction (MI)
	5. Pulmonary embolism (PE)
	6. Pneumonia (PN)
	7. Cardiac failure (CF)
	8. Other vascular cause (OVC)
	9. Other (OTH)
	o _____ (specify other cause) (free text box)

102. Discharge date and time (from hospital)?	• Date
	    o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	    o hh:mm (e.g., 13:53) (only numeric text)
	    o Unknown/not documented

103. If transferred to another hospital, date and time of arrival at receiving hospital?	• Date
	    o DDMMYYYY (only numeric text)
	
	• Time: 24hr time
	    o hh:mm (e.g., 13:53) (only numeric text)
	    o Unknown/not documented

104. What is the discharge destination/mode?	(select one option) 1. Discharge/transfer to (an)other acute hospital 2. Discharge/transfer to a residential aged care service unless this is the usual place of residence 5. Statistical discharge - type change 6. Left against medical advice/discharge at own risk 8. Died 9. Other 10. Usual residence (e.g., home) with supports 11. Usual residence (e.g., home) without supports 12. Inpatient rehabilitation 13. Transitional care services If discharge/transfer to a residential aged care service unless this is the usual place of residence, select level of care (select one option) 1. Low level residential care (LLRC) 2. High level residential care (HLRC)

Post-discharge and follow-up

105. Time points of follow-up	(Select those that apply. If selected, code = 1) • 3 months • 12 months • Other
106. Is patient deceased post hospital discharge, if so what is the date?	(select one option) 1. Yes 2. No 9. Unknown/not documented If yes, provide date:

	• Date o DDMMYYYY (only numeric text)
107. Where are you staying at present?	0. Missing 1. High level Residential care 2. Low level Residential care 3. Home with supports 4. Home without supports 5. Hospital 6. Rehabilitation (inpatient) 7. Transitional care services 8. Other o _____ (specify other) (free text box)
108. Do you live on your own?	(select one option) 1. Yes 2. No 9. Unknown/not documented
109. Since you were in hospital for stroke, have you had another stroke? Date of readmission.	(select one option) 1. Yes 2. No 9. Unknown/not documented If yes, provide date: • Date o DDMMYYYY (only numeric text)
110. Post stroke modified Rankin score (assessed by self-report, telestroke network)	Collected at day 7-10 or discharge if earlier than day 7 and at 90 days (if resources available) (select one option) 0. No symptoms. 1. No significant disability. Able to carry out all usual activities, despite some symptoms. 2. Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities. 3. Moderate disability. Requires some help, but able to walk unassisted. 4. Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted. 5. Severe disability. Requires constant nursing care and attention, bedridden, incontinent. 6. Death

Other information for database setup

Recommended for data coding:

Yes= 1, No=2, Unknown/Not documented = 9

Dates = DDMMYYYY

Times = hh:mm or mm only

DATA DICTIONARY Supplemental References

Acute Stroke Telemedicine: Utility, Training and Evaluation, http://www.astute-telestroke.org.uk/

Australian National Stroke Data Dictionary, July 2018

Get with The Guidelines, Case Record Form, August 2018

METeOR, National Health Data Dictionary http://meteor.aihw.gov.au AuSDAT

VST Victorian Stroke Telemedicine (VST) Program: Data Dictionary, November 2014, Version 1.3

VST Neurologist Consultation Form, Data Dictionary Code Book, April 2019