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Establishment of an internationally agreed minimum data set for acute telestroke

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Abstract

Introduction: Globally, the use of telestroke programs for acute care are expanding. Currently, a standardised set of variables for enabling reliable international comparisons of telestroke programs does not exist. This study aimed to establish a consensus-based, minimum data set for acute telestroke to enable the reliable comparison of programs, clinical management and patient outcomes.

Methods: An initial scoping review of variables was conducted, supplemented by reaching out to colleagues leading some of these programs in different countries. An international expert panel of clinicians, researchers, and managers (n=20) from the Australasia Pacific region, United States of America, United Kingdom and Europe was convened. A modified-Delphi technique was used to achieve consensus via on-line questionnaires, teleconferences and via email.

Results: Overall, 533 variables were initially identified and harmonised into 159 variables for the expert panel to review. The final dataset included 110 variables covering three themes (service configuration, consultations, patient information) and 12 categories: 1) Details about telestroke network/program (n=12), 2) Details about initiating hospital (n=10), 3) Telestroke consultation (n=17), 4) Patient characteristics (n=7), 5) Presentation to hospital (n=5), 6) General clinical care within first 24 hours (n=10), 7) Thrombolysis treatment (n=10), 8) Endovascular treatment (n=13), 9) Neurosurgery treatment (n=8), 10) Processes of care beyond 24 hours (n=7), 11) Discharge information (n=5), 12) Post-discharge and Follow-up data (n=6).

Discussion: The acute telestroke minimum dataset provides a recommended set of variables to systematically evaluate acute telestroke programs in different countries. Adoption is recommended for new and existing services.

Introduction

Around the world, ensuring there is equitable access to best practice acute stroke care is a major challenge.[1, 2] Innovative models of care are being designed that exploit technology to maximise the opportunities to treat patients.[3] Telemedicine is an example of how clinical care can be facilitated and improved using technology by distributing stroke expertise more effectively, through using video consultation to support the examination of patients in locations removed from specialist care.[4, 5] With telestroke, patients experiencing symptoms have access to a stroke medical expert for clinical assessment, confirmation of diagnosis, and establishment of a management plan.[6]

Various models of telestroke are used in different regions and countries. Telestroke programs most commonly exist as either a distributed or a hub-and-spoke model.[6] However, currently there is no systematic way to compare the effectiveness of these different models. Establishing performance measures for telestroke provides the evidence necessary to refine or potentially expand such programs, and supports continuous quality improvement activities.[6] Further, it has been recommended by the American Heart Association/Stroke Association that every telestroke network hospital should participate in the collection of data for monitoring the quality of stroke care.[6] Much duplication can occur in establishing performance measures for new programs such as telestroke, and variation in measurement may consequently limit the ability to compare services. To enable reliable comparisons of major service features, clinical processes and patient outcomes, standardised data collection for telestroke performance should be undertaken. Our aim was to establish an international expert consensus minimum dataset for acute telestroke (Telestroke Minimum Data Set: TS-MDS).

Methods

The project was led by author Cadilhac and coordinated by the research team based at the Florey Institute of Neuroscience and Mental Health (Australia). Following initial meetings between leaders of telestroke programs in Australia, Germany, the United States, and United Kingdom, it was agreed to progress the initiative of a minimum dataset for acute telestroke. We used an iterative process with multiple project phases to identify (phase 1), review (phase 2) and finalise (phase 3) the variables for the agreed minimum dataset. The methods for each phase are outlined in the following sections, with detailed description available in the Supplemental file Detailed Methodology.

Phase 1: Identification of potential variables

Information about telestroke programs was identified from systematic searches of academic and grey (e.g., Government health department reports) literature. Data collection tools and data dictionaries were sourced directly from established telemedicine networks in Australia (Victorian Stroke Telemedicine program),[7, 8] Germany (TEMPIS),[9] United States of America (REACH and STROKE DOC)[10, 11] and the United Kingdom (ASTUTE).[12] Variables required for the evaluation of telestroke programs were identified and summarised into three major themes: Service configuration, Consultations, and Patient information.

Phase 2: Review of variable options via modified Delphi technique

Our modified Delphi technique involved forming an expert panel, by inviting established telestroke colleagues and published telestroke clinicians, researchers and/or managers. Two rounds of on-line surveys, with iterative teleconferences and document circulation via email to review and discuss interim and final results were undertaken. 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.

Phase 3: Finalise variables and propose suggested response options

Once the final TS-MDS variables had been identified from Phase 2, the investigators established consensus on wording and variable response options for each variable. This process was guided by established data dictionaries for the evaluation of stroke interventions from Australia and the USA. The finalised variables have been compiled as part of this publication.

Data management and analysis

The inclusion criteria or level of concordance was determined by calculating the content validity index (CVI) for each item using the following formula:

$$ \text{CVI} = \frac{\text{Number of responses at 4 or 5 achieved for the item}}{\text{Total number of responses for the item}} \times 100 $$

Items with an agreement level of less than 50% were identified for exclusion, between 50 and 79% required additional review, and 80% or more were accepted.[13, 14]

Results

Phase 1: Compilation of variable options for the minimum data set

There were 533 potential variables identified across all sources. Same or similar variables were harmonised, with a final set of 159 variables initially covering 11 categories across the three major themes. Following the second phase, there were 12 final categories with the inclusion of Neurosurgical treatment (detailed below) in the TS-MDS.

Phase 2: Review of variable options

Delphi Expert Panel

There were 23 (14 male, 9 female) invited experts and 20 actively contributed to the panel, with a median 7 years (IQR=4.75) telemedicine experience. Panel members' primary roles were 11 clinicians, 7 researchers, and 2 management roles, with 9 panel members reporting multiple roles. Panel members were from Australasia (n=6), United States of America (n=7), the United Kingdom and Europe (n=7).

Assessment of concordance

Results from across the three rounds of review and feedback completed in Phase 2 are summarised in Table 1, with final results presented in Table 2. From the first survey, 38% of the reviewed variables (n=61) received over 80% concordance, with 28% (n=45) excluded, and 33% (n=53) requiring further review. Approximately half of these items (n=30, 56%) were then accepted after the second survey, 4% (n=2) excluded, and 40% (n=21) required further discussion (completed during the teleconference). The expert panel deliberated on variables requiring further review, and 86% of these were excluded. However, 14 new variables were proposed and agreed to be added including 'Review of CT completed by telestroke consultant', 'NIHSS score calculated by telestroke consultant', 'Real-time audio-visual communication used between hospital and telestroke consultant' and 'Was other neurosurgical treatment recommended'.

Overall, the final variables were grouped in three themes with 12 categories overall, including: Telestroke Network/Program and details for the Initiating/Spoke Hospital; Telestroke Consultations; and then patient data on Patient characteristics, Presentation to Hospital, General Clinical Care within the First 24 hours, Thrombolysis Treatment, Endovascular Treatment, Neurosurgery Treatment, Processes of Care Beyond the First 24 Hours, Discharge Information and Post-Discharge and Follow-up Data.

Phase 3: Final Item Wording and Response Options

The complete TS-MDS variables and suggested response options are provided in the Supplemental file Data Dictionary. There were 110 variables retained for the minimum dataset covering the telestroke program, the telestroke consultation and the patient's clinical information.

1) Telestroke Program/Network (n=12) and Spoke Hospital items (n=10) which provide contextual information about the service (Supplemental file Data Dictionary, Section 1).

2) Telestroke Consultation patient items (n=17) which provide information specific to each patient's consultation (Supplemental file Data Dictionary, Section 2).

3) Patient Data items (n=71) which provides clinical information specific to each patient's presentation, their clinical care and outcomes (Supplemental file Data Dictionary, Section 3).

Discussion

We have developed a minimum dataset for telestroke (TS-MDS) which provides a consensus-based summary of variables that can be used to monitor and evaluate acute telestroke services in different countries. The final set of variables enables comparisons of consultations, clinical care processes and patient outcomes for new or existing services. Overall, we discarded ~40% of the original variables identified following harmonisation and prioritising those considered of utmost importance to collect. The final set of variables was dominated by those used to describe patients and the care they receive (>65%).

We recognise that, depending upon the resources available to programs, it may be impractical to collect all variables within the TS-MDS. Complete patient episode care data may be in multiple locations (e.g., if patient transferred for treatment). Thus, the time required to collect

these data is anticipated to range between 30-40 minutes, but will vary considerably. For example, depending on each service's acute and patient follow-up data collection systems currently in place (e.g., exporting from established administration data sets would reduce time, if teleconsultation part of medical record), and each patient episode (i.e., smaller data collection if not thrombolysed or neurosurgery treatment not undertaken). Recommendations for response options may be more extensive than currently presented, or the frequency or capacity for collecting outcomes may differ. The majority of items and response options have been collated from established data collection procedures and published program evaluations, however, reliability of the complete data set can be examined in future as services across countries begin to use the TS-MDS. Services are encouraged to provide feedback to the first author. Nevertheless, following the guidance we have provided will ensure more reliable mapping of variables across programs and the ability to pool data from different programs.

It will be important to consider how different models of providing telestroke influence comparisons of patient and consultation data. Therefore, each aspect of telestroke programs (i.e., service configuration, consultations and patient information) remain important to collect. In practical terms, variables pertaining to the Telestroke program/network and the Initiating (spoke) hospitals (i.e., service configuration) could be collected every 2 years as these are unlikely to change regularly. However, variables related to the telestroke consultation and patient should be collected continuously. Additional variables can be collected as required or relevant, at the discretion of each program.

Some services may be specifically interested in one aspect of the telestroke consultations and include additional items in their data collection. There may also be merit in collecting other variables related to telemedicine training and skills. For example, there is a recognised importance of integrating telestroke training into supervised neurovascular fellowships to

increase proficiency and enable benchmarking prior to independent practice in telestroke.[15] Information such as when a program commenced, type of payments or reimbursements, technical support the program receives, type of equipment/software, and whether a program was co-designed with patients may also be relevant. However, we consider these aspects to cover very focussed aspects of telemedicine services that extend beyond the basic 'usual' clinical practice monitoring of service quality and outcomes.

While choice in use of all or some of these variables may occur, this minimum dataset can be considered a baseline for consideration and reporting. We believe that, as a minimum, the service configuration variables for each program should be reported within the first 2-5 years of operation and consultation data that includes sufficient patient information to describe the population and treatments received. The type of video-based activations versus phone or the number of technical incidents that precluded video-based consultation for each patient may also be relevant to collect for monitoring service performance, but these quality assurance metrics have not been recommended here. As an alternative, these aspects are broadly covered in the service configuration reporting. Where possible, 90-day health outcome data should be reported (especially the modified Rankin score). Data linkage may also enable more patient information to be captured without having to duplicate effort and waste resources in collecting information for different purposes.[16] Within Australia, the Victorian Stroke Telemedicine Program will include regular linkage between the Consultation data captured as part of the telestroke program, and data collected through the Australian Stroke Clinical Registry and Ambulance Victoria systems. This linkage will allow confirmation of treatment received in hospital and 90-day outcomes.[17, 18] The dataset may require modification to accommodate pre-hospital telestroke consultations.

Creating a database for the collection of these variables was beyond the scope of this work but details from within the Data Dictionary can be used to form part of future development initiatives. It may also be relevant for stroke quality of care registries, such as the Registry of Stroke Care Quality (RES.Q) developed under the European Stroke Organisation (https://eso-stroke.org/res-q/) to incorporate these variables for routine collection. Other practical aspects such as recommendations for agreements to enable sharing data were also beyond the scope of this initial work. However, submission of anonymised data into a VISTA (Virtual International Stroke Trials Archive)[19, 20] for telestroke could be a future option. There is growing momentum to ensure everyday clinical practice data are made available for secondary purposes so that we maximise uses and avoid data waste.[16, 21] The development of the TS-MDS supports such future endeavours.

Strengths and limitations

We undertook an iterative and inclusive process for receiving feedback. We also searched grey and published literature, as well as obtaining data collection forms from telestroke programs to ensure our initial list of variables was extensive. Reassuringly, when these variables were harmonised the number of variables was able to be reduced significantly, highlighting that many of the variables were already being collected across programs.

For the purposes of developing this TS-MDS, the invited experts were deemed to be a representative panel in the field of stroke and telestroke internationally. The Delphi process is not reliant on a large sample size of experts, but one in which consensus and saturation of information can be reached. Panel size recommendations range from 5-10[22], 10-15[23], 15-20[24] members, dependent upon ensuring representative judgements on the target issue.[25] Our panel was at the upper range, but incorporated clinicians, managers and researchers. The recommended level of concordance also varies in the published literature from 66%[26], 75%[27]

or no less than 78%.[22] We used 80% as the threshold for concordance and to indicate retention of a variable, which was consistent with similar research using panels of experts.[13, 14]

Finally, as with many aspects of medicine, advances in stroke care will mean we need to consider regular reviews of the agreed variables. *We also recognise that mode of transport may be an important area for future research[28, 29] and have included options to collect that data.* As experienced during this study, the advent of endovascular thrombectomy (EVT)[30, 31] becoming routine practice, extended time windows for treatment[32] and greater options for neurosurgical intervention meant the addition of extra variables late in the process of Phase 2. We believe this final set of variables is sufficiently robust to cover the major contemporary aspects of acute telestroke care operating in developed countries, with future work required to identify relevant variables for under developed or developing nations.[3]

Conclusions

The consensus-based, acute telestroke minimum dataset presented in this paper provides a recommended set of variables to evaluate acute telestroke programs in different locations. This information may be useful for new or existing services seeking to monitor their practice or reliably benchmark their quality of care with other telestroke services.

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Table 1. *Results from the three rounds of review within Phase 2, by minimum data set category and total*

Category	Initial number of variables	Survey 1			Survey 2			Teleconferences and review[#]		Final number of variables[#]
		<50%	50-79%*	>80%	<50%	50-79%**	>80%	Accepted	Excluded	
Service configuration										
Details of telestroke network/programs	8	0	5	3	0	2	3	2 + 1 new + 1 split	0	12
Details about initiating hospital	6	0	1	5	0	1	0	1 + 4 new	0	10
Telestroke consultation	14	1	2	11	0	2	0	3 new	2	17
Patient information										
Characteristics	15	7	6	2	0	1	5	0	1	7
Presentation to hospital	26	9	9	8	0	4	5	0	4	5
Hyperacute care										
Thrombolysis treatment	12	3	3	6	1	1	1	0	1	10
Endovascular treatment	12	0	1	11	0	0	1	0	0	13
Neurosurgery Treatment[##]	-	-	-	-	-	-	-	7 new	0	8
General clinical care within first 24 hours	25	7	9	9	1	5	3	0	5	10
Processes of care beyond first 24 hours	18	8	8	2	0	3	5	0	3	7
Discharge information	11	5	2	4	0	1	1	0	1	5
Post-discharge and Follow-up data	12	5	7	0	0	1	6	0	1	6
TOTAL	**159**	**45 (28%)**	**53 (33%)**	**61 (38%)**	**2 (4%)**	**21 (40%)**	**30 (56%)**	**3 (14%) +16 new/split**	**18 (86%)**	**110 Total**

New indicates variable was not part of initial pool identified and added during review process. Split indicates variable that
[#]Final numbers may vary across categories due to items changing categories throughout the consensus process. The final number of variables is the outcome of the full iterative process.
[##]Additional category added during teleconference.

Table 2. *Categories, final number of variables and example questions for the International Telestroke Minimum Dataset*

Categories	Number of variables	Examples
Service configuration (N=22)		
Details of telestroke network/programs	12	Hub-and-spoke, distributed, for profit or not
Details of initiating hospital	10	Hours of operation, stroke unit availability
Telestroke consultation (N=17)	17	Mode, reason, date and time, duration, imaging review
Patient information (N=71)		
Characteristics	7	Age, sex, stroke history
Presentation to hospital	5	Arrived by ambulance, time of arrival
Hyperacute care		
Thrombolysis treatment	10	Thrombolysis recommended, date/time treatment
Endovascular treatment	13	Endovascular treatment recommended
Neurosurgery treatment	8	Type of neurosurgery, date/time treatment
General clinical care within first 24 hours	10	Stroke symptom onset, CT time
Processes of care beyond first 24 hours	7	Follow-up CT, sICH, stroke unit stay
Discharge information	5	Discharge diagnosis, destination
Post-discharge and follow-up	6	Time point, residence, mRS
Total	**110**	

Note: CT=computed tomography scan, sICH=symptomatic intracerebral haemorrhage, mRS= modified Rankin Scale