National Stroke Data Capture Tool

Expressions of Interest
Proposed Technical Build and Platform Support

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Response link:	https://melbourneuni.au1.qualtrics.com/jfe/form/SV_9EVBUYL025winqK
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1. Preamble

This document provides information to vendors who would like to submit an Expression of Interest to build and support a new technology platform for the capture of national stroke data.

The main clinical setting we seek to draw data from is the hospital sector. The main purpose of the data platform is to provide the infrastructure for a national Clinical Quality Registry (CQR) that meets the national Framework requirements[1] and permits time-limited detailed audits of medical records from different health service providers and the collection and reporting of patient care and outcomes.

The data infrastructure should also align with the National Strategy for CQRs and Virtual Registries (2020-2030)[2]. The pillars of this strategy include:
- data can be systematically collected using national health data and terminology standards and definitions
- reporting includes risk adjustment and benchmarking and is designed to build capacity at the site level to consistently collect, enter and transfer data in the same way, at the same time and using identical definitions
- tailored access for a broad range of stakeholders including increased public access to aggregated clinical quality outcomes data by publishing patient-friendly dashboards and data
- interoperability and integration with EMRs and national infrastructure needs to be possible
- use of application programming interfaces (APIs) for automated data extraction, linkage, analysis, and reporting at the national level

2. Background

Multiple organisations collaborate to progress our understanding of stroke care delivery and support improved outcomes for patients who experience a stroke or transient ischaemic attack (TIA).

Variability in the quality of acute stroke care between hospitals, contributes to stroke-related death and disability. To improve patient outcomes, data collection systems aligned with national clinical practice guidelines and standards are needed to inform quality improvement efforts in stroke.

The Australian stroke community have acknowledged the important role data have in monitoring the quality of care.

Since 2007, National Stroke Data, has been collected to enable performance reporting against recommended care. The current platform was established in 2015, as the Australian Stroke Data Tool (AuSDaT), to meet the data collection needs of different stakeholders and to avoid duplication in data capture for different programs using information from the same patient. As part of this process, a National Stroke Data Dictionary was created and has been updated as required (AuSDaT-National-Stroke-Data-Dictionary-March-2021.pdf (australianstrokecoalition.org.au). This document lists all the endorsed data variables available in the AuSDaT, including variable definitions, response options and help notes.

The AuSDaT has been the data collection platform for the following:

- **Australian Stroke Clinical Registry (AuSCR)**
  https://auscr.com.au
  - A minimum dataset captured on consecutive patients with acute stroke and a follow-up survey of patients at 90 days.
  - The data collected guides hospital quality improvement activities.
  - Currently over 150,000 episodes of care captured and 60,000 outcome surveys from up to 83 hospitals).

- **Stroke Foundation Organisational Surveys**
  https://informme.org.au/stroke-data/acute-audits
  - Collects information about the resources available to deliver acute stroke hospitals, such as the availability of stroke unites, imaging services and interdisciplinary staff.

- **Stroke Foundation Acute and Rehabilitation Audits**
  https://informme.org.au/stroke-data/acute-audits
  - Collected in alternate years and involves a retrospective review of up to 40 consecutive patients in each cycle per hospital.
  - Measures adherence to evidence-based processes of care.

Several other short-term projects have also used the AuSDaT to collect data.

The current AuSDaT platform has delivered clear benefits in data entry, the ability to import data from hospitals via different levels of sophistication (manual, partial/full import using EXCEL import templates or directly via an API), export of data at any time, and summarised data reports at any time can be generated. The platform is cloud-hosted on an AWS server within Sydney.

Since 2016, improvements to the tool have been incrementally made and implemented, as required. However, as more hospitals are using the tool, and the number of records entered into the system grows, performance is regularly slow, and the current data model, and the platform in which the tool has been built, is not meeting all the needs of our stakeholders. In particular, clinical staff have less time to directly enter data, and there is an urgent need to be able to extract data from electronic medical records and automate ingestion of data into the tool using APIs. In addition, the methods for collecting AuSCR patient follow up survey data has required manual data entry by a third party reading the paper-forms and this component needs to be modernised and more efficient.

In January 2022, the Stroke Foundation engaged the Checkley Group (now part of Deloitte) to complete a high-level review of the current data collection and workflows of the AuSDaT. This information and user experience surveys we have carried out, have enabled us to identify the functional requirements of an improved system that will better meet the business needs of the Australian stroke sector.

Proposed National Stroke Data Collection Platform High Level Process/Features Map (Figure 1) provides a high level overview of the input and output requirements of the new data capture tool.

3.   Project partners

This project is led by the Stroke Foundation and will be delivered in collaboration with the Florey Institute of Neuroscience and Mental Health (the Florey) and other partners including stroke epidemiologists and CQR experts from Monash University.

4.   The Project

To better meet the Australian clinical, policy and research needs for stroke we seek to establish a modern data collection system (Figure 1) compliant with technical standards and operating principles for CQRs that also aligns with the National Framework for CQRs (https://www.safetyandquality.gov.au/sites/default/files/migrated/Framework-for-Australian-Clinical-Quality-Registries.pdf) to enable the capture of agreed national indicators of stroke care and other variables of interest to users/stakeholders. This new system will better align with our business goals and will adopt modern technology and integration software to improve useability and interoperability with other data capture or reporting systems. We are open to considering systems that are 'off the shelf' or bespoke. Interoperability and use of open source software are essential in ensuring a cost-effective and low maintenance product. We expect the tool to be able to house 200,000 primary records, with an estimated 30,000 new records each year. There is an estimated 200 maximum user load at peak reporting periods.

5.   Submission of EOI Response

To submit an expression of interest please complete the EOI response form (https://melbourneuni.au1.qualtrics.com/jfe/form/SV_9EVBUYL025winqK) by **COB 15/07/2022** with your responses to the below platform requirements (Table 1) attached in response to question 10, outlining at a high level how you will execute the:

1. Build of a new tool via;
2. Customisation of a commercial off the shelf product; or,
3. Software as a service solution.

Please keep uploaded submissions to less than 10 pages and in one of the following formats: MS Powerpoint/Word/Excel or Adobe PDF.

If you would like further information or to discuss the below requirements, please reach out to Marcus: marcus.lester@florey.edu.au (AuSCR Senior Data Manager).

6.   References

1. Australian Commission on Safety and Quality in Health Care, Framework for Australian clinical quality registries. Sydney. ACSQHC, March 2014

2. Department of Health, Maximising the Value of Australia's Clinical Quality Outcomes Data, A National Strategy for Clinical Quality Registries and Virtual Registries 2020 – 2030. Canberra, 2020

Figure 1. Proposed National Stroke Data Collection Platform
High Level Process/Features Map
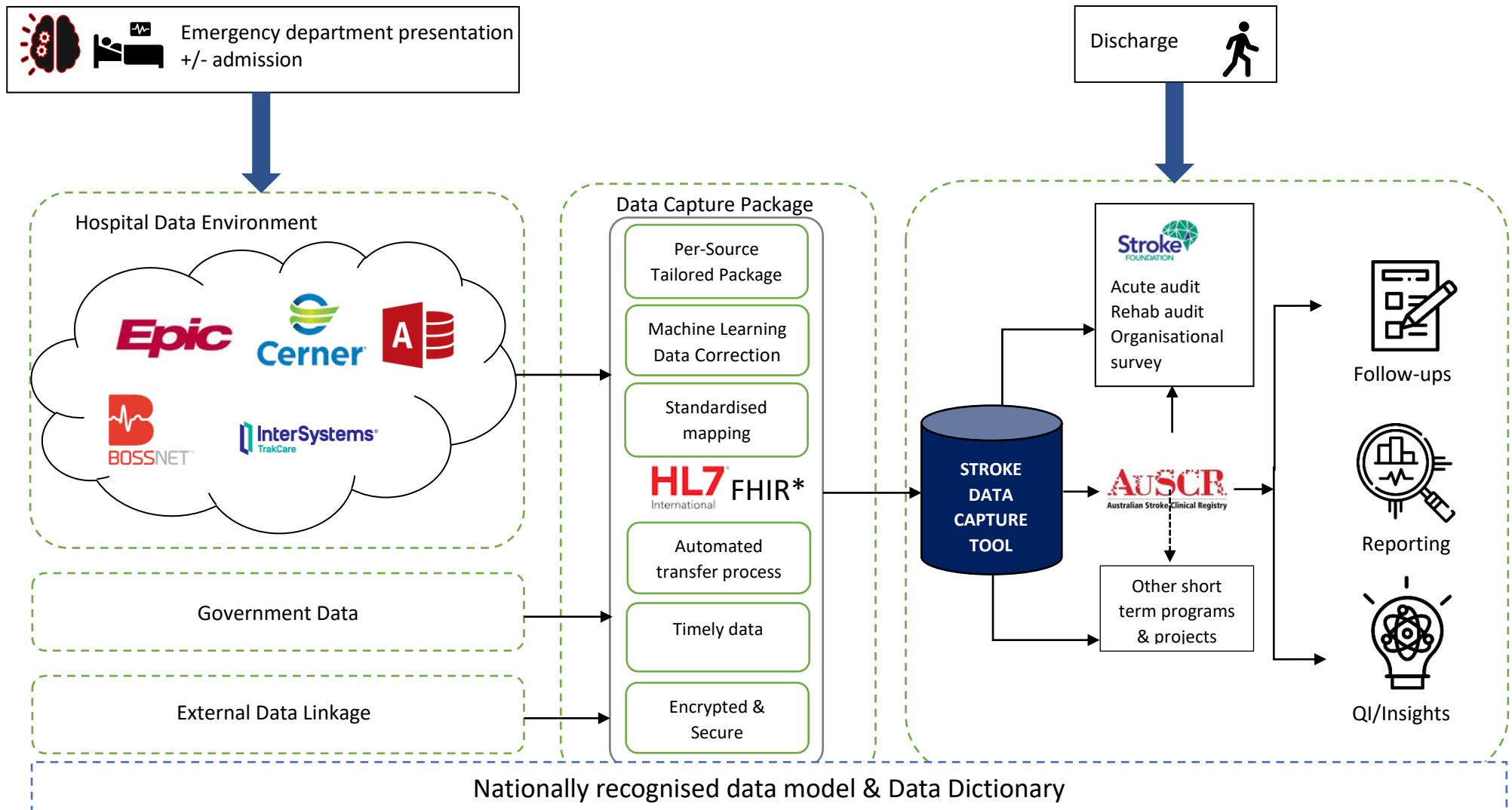
*FHIR (Fast Healthcare Interoperability Resources)
utilised in collaboration with Monash University

Table 1.

PLATFORM REQUIREMENT (HIGH LEVEL)	KEY SPECIFICATIONS
DATA MIGRATION	
	• A comprehensive migration of data, variables and usergroups held in current tool to new platform is required • Access "as usual" for migrated data must be possible for users as per designed UAM (User Access Management)
USER INTERFACE	
	• Interface must be modern and in-line with current CQR's (Clinical Quality Registries). Must work across all browsers and devices commonly used • Interface must be modifiable by staff as needed • User experience must be fluid for all user groups (hospital users, administrative staff, etc.) • Interface must include capability for tooltips, notifications and external links as needed • UI integration with external BI tools
INPUTS	

Data collection	• Multiple pathways
	  – Manual entry via web browser
	  – Imported from source systems, including hospital eMR and centralised government systems, via batch upload and direct feed or APIs using standardised mapping.
	  – Data importing method using a staged approach where the system will have a staging "preview" screen to identify errors before import.
	• Database structure which allows flexibility of adding or removing data elements to meet the needs of stakeholders.
	• Fuzzy logic which allows flexibility with formatting requirements when importing data and the ability to adjust formatting automatically.

Data quality and integrity	• Embedded data checks, logic checks, and business rules. • System generated queries for data quality errors and issues with automatic notification of sites. • Modifiable automated clean-up processes that can be scheduled or initiated manually

Data sharing	• Data elements common between individual programs e.g. AuSCR and SF audits, should only be collected once, and shared between programs.
Data linkage	• Use of statistical linkage keys or personal information variables that enable reliable matching of individuals so that additional data from other sources at different times can be securely added to the case record e.g. National Death Index. • Automated external linkage capabilities
Patient follow-up	• Automated provisioning of surveys (via SMS, email) based on modifiable business rules drawing from primary dataset. Survey lists provisioned for physical mailouts by staff • Automated data capture and collation from digital and scanned paper survey responses • Centralised tracking of survey responses, reminder notifications and completion of the survey (via mail, SMS, phone) for non-responders. • Follow up data to be shared with all sites that have provided care to the patient.
OUTPUTS	
	• Variable extraction capabilities including direct, API and scheduled data extraction • Dynamic reports using BI software, drawing on cleaned data. Full autonomy for team to create/amend/remove reports as needed • "Live" reports using data directly from the tool which provides pre-determined reports of summary statistics
USER ACCESS MANAGEMENT	
	• Full UAM capabilities servicing shared usage of platform between AuSCR and Stroke Foundation • Multi-role functionality for administrative users • UAM accessible via API for external functionality (e.g. BI Solution)
PERFORMANCE	
	• The platform should be designed with future registry integration and increased scale of use in mind • The platform should maintain consistent performance and processing speed during peak periods. (Note: Current platform utilises cloud-hosting) • The platform should have the capability to wind up and down according to peak and quiet usage periods throughout year

SECURITY	
	• Data to be housed in an ISO compliant environment hosted within Australia. • Effective firewall, regularly reviewed security policies, and adhere to all local and national privacy laws and principals. • User interface (web browser) must have adequate security compliance • Backup and disaster recovery procedures. • Regular and adequate testing of all data security procedures in accordance with industry standards.

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