

Data and Services Discovery projects - Transformative Data Collections

Title

Percutaneous Coronary Intervention (PCI) Outcomes Registry - Baseline Data

Approach

To achieve our aim of establishing a partially automated collection of baseline data for a Percutaneous Coronary Intervention (PCI) outcomes registry we undertook the following activities:

Consultation with leaders and experts in cardiology and clinical quality registries

The data elements and data dictionary are harmonised with existing Australian (Victorian Cardiac Outcomes Registry (VCOR)) and International (United States National Cardiovascular Data Registry (NCDR)) PCI definitions to enable national and international research comparison, collaboration and interoperability.

An important factor in the success of this project will be clinician engagement. We consulted with leaders within the Sydney Partnership for Health Education, Research and Enterprise Cardiac and Vascular Health Clinical Academic Group (SPHERE – CVH CAG) for expert opinion on the data elements for collection, and to improve scalability of the proposed system design to other cardiac catheter labs across NSW. The proposed system design and specific data elements were shared with the CVH CAG group, Cardiology department heads across South West and South East Sydney Local Health District (SWSLHD, SESLHD) and the Agency for Clinical Innovation (ACI). A teleconference was held that included all project team members, representatives from SWSLHD, Sydney Local health District (SLHD), and the ACI for an in-depth discussion including focus on optimising scalability and application. A further meeting was held with the NSW Ministry of Health, along with ACI and eHealth to discuss project aims, scalability across NSW and interoperability nationally with the planned Australian Cardiac Outcomes Registry (ACOR).

To ensure the scalability and longevity of the project, we accessed best practice information from VCOR and the Australian Commission on Safety and Quality in Health Care (ACSQHC) for clinical quality registry operating and technical guidelines and standards. These guidelines and standards were used to inform the design and governance structure of the project.

Collaboration with the Centre for Big Data Research in Health (CBDRH) at UNSW Sydney

CBDRH have extensive expertise in extraction and analysis of health data and have the infrastructure to host data repositories such as a clinical quality registry in their E-Research Institutional Cloud Architecture (ERICA) platform. CBDRH will host the central data repository in ERICA with project oversight from CBDRH Head Professor Louisa Jorm and Associate Professor Blanca Gallego-Luxan. Dataset governance and operational procedures were discussed. Automated collection of procedural outcomes data through data linkage

performed by the CBDRH with statewide and national health datasets such as the Admitted Patient Data Collection (APDC), the Emergency Department Data Collection (EDDC) and the National Death Index (NDI) for outcomes such as mortality, acute myocardial infarct, stroke, re-vascularization and re-admission are enabled a priori in the present system design.

Exploratory discussions were held with the Prince of Wales Hospital Health Information and Communications Technology (POWH Health ICT) to discuss direct Electronic Medical Record (eMR) data transfer to ERICA, to enable more complex data analyses utilising natural language processing and machine learning.

Collaboration with Health ICT

In order to reduce manual data collection, POWH Health ICT were engaged. The PCI baseline data collection form has been embedded into the POWH eMR with partial auto-population of pathology and medicine data fields.

The project team are currently consulting with POWH ICT to establish an automated transfer of this data from the hospital eMR system to the baseline data collection platform. An interface between the two systems was explored but due to financial and time constraints this was not possible within the scope of this project. Alternatively, a daily extract of data from eMR to the baseline data platform via a Safe File Transfer Protocol (SFTP) is being explored to enable a single user interface for the cardiac catheter lab staff who will be coordinating the data collection.

Development of the baseline data collection platform

Various platforms were considered. Due to considerations around automation of data transfer, data security, scalability to both private and public cardiac catheters across NSW, a custom cloud-based application was developed. Features of the system include:

- A Microsoft AZURE cloud database backend incorporates a high level of data security including individual user authentication
- Compliance with the ACSQHC Security Compliance Guideline for Australian Clinical Quality Registries v1.5 (2013).
- Customisable platform for individual cardiac catheter labs to facilitate embedding into existing local clinical practice
- Auto-population based on past records e.g., in a patient returning for a second cardiac procedure. Prepopulated data fields require repeat contemporary verification.
- Simple, user-friendly interface.
- Future integration with eMR is enabled. This will allow pre-population of data fields based on EMR and reduce work and potential for error
- Interoperability with administrative databases which allows patient identity information to be prepopulated which reduces potential for error
- Data are available in standard csv format as required.
- Regular scheduled data transfer to the central data repository at the CBDRH.

Consultation with clinical staff to embed data collection into existing clinical workflow

An important part of this project is integration of the data collection into existing clinical practice, to reduce duplication, inefficiency and potential for error. Consultation with clinical staff, including local nurse clinicians as an end-user, was undertaken and carefully

considered. One subsequent modification was the decision to expand the scope of the collection to include patients undergoing all invasive procedures performed in the catheter lab. Having one system across all patients would improve workflow and have the additional benefit of expansion of the registry to other interventional cardiac procedures.

Ethics committee approval

An application was made to the South Eastern Sydney Local Health District HREC and is under consideration.

Testing the data collection application

Testing will begin after ethics approval.

FAIR

There is no cardiac outcomes registry in New South Wales. Our pilot registry is based on the principle of a pragmatic, or natural registry that is embedded into clinical practice which optimises efficiency and scalability. As a pilot registry, formal metadata records, unique dataset identifiers, license and usage rights do not apply. The dataset enables future interoperability and accessibility. Complete metadata and provenance information will be created with UNSW as the minting authority. The data will comply with the University's policies and procedures for storage and access. Specific dataset governance rules will also apply.

Collaboration and coverage

This project was able to achieve statewide collaboration and has made significant steps towards enabling a national cardiac procedure outcomes registry. Through the SPHERE-CAG and Agency for Clinical Innovation (ACI) we were able to collaborate with many cardiac catheter labs around NSW in order to establish statewide consensus and engagement amongst clinicians.

Collaboration with Prince of Wales Hospital ICT department has enabled the creation of a partially automated data collection form within eMR that can be replicated in any Cerner eMR around the state.

Collaboration with key stakeholders such as NSW Health and the ACI has enabled the project to make significant steps towards potential statewide adoption of our model for a cardiac procedure outcomes registry.

Collaboration with CBDRH has laid the foundations for the establishment of a central data repository for the proposed PCI registry, including registry infrastructure, operating principals and governance.

Sustainability

This project has created two data collection platforms (the pre-procedural baseline database and the eMR data collection form) that is easily scalable to other sites. The AZUR application can be individualised to minimise impact on existing clinical practices.

The pilot project will be sustained locally with support from the Eastern Heart Clinic. The project team is in exploratory discussions with NSW Ministry of Health and other key stakeholders (individual LHDs, Department Heads, ACI, eHealth, SPHERE, Sydney Health Partners) to discuss support for project expansion to form a NSW cardiac outcomes registry.

Learnings

One of the unexpected challenges in this project was the cost associated with an eMR interface, and so this was not possible to incorporate into the present pilot project. Integration with eMR will be key for Transformative Data Collection in the health sector and will require substantial initial investment in terms of expertise and monies. Investment in secure cloud based data storage for the Commonwealth would also facilitate the growth of Transformative Collections.

Impact

This project has laid the foundations of a state-wide, partially automated cardiac procedure outcomes registry which, which is scalable and sustainable. Cardiac and vascular disease represents highest health burden in developed countries including Australia. A NSW registry (and the national registry) will allow research into outcomes of procedures, variance of practice, and factors which improve patient outcomes to inform health policy and clinical practice. It will also enable registry research and pragmatic trials as well as collaboration in international research.