Discussion Paper - A national cardiac outcomes registry

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Background

The Australasian Cardiac Outcomes Registry Ltd (ACOR) (and its sub-contractor the South Australian Health and Medical Research Institute (SAHMRI)) was contracted in July 2014 to undertake the design, establishment, maintenance and administration of the CDR.

ACOR and SAHMRI have developed the infrastructure, governance and policy documents, a dataset and approached hospitals nationally to contribute to the CDR.

The Commonwealth Department of Health contracted HeathConsult Pty Ltd in June 2017 to undertake an independent review of the CDR. Data limitations, low update of participating sites, issues with engaging key stakeholders, role confusion and issues with local governance and ethics approval processes were identified as key for resolution (see Attachment A).

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Attachment A

HealthConsult Review of the Cardiac Devices Registry

An independent review of the CDR was undertaken to assess the effectiveness of the arrangements, identify options to improve or modify the arrangements, and provide advice on strengthening future performance. The Department contracted HealthConsult Pty Ltd to undertake the review in June 2017 and the final report was provided on 26 October 2017.

The report identified:

CDR Strengths

- Ability to link with other registries: it has been designed with the ability and functionality to link with existing registries including with other existing cardiac databases such as state based registries;
- Stringent security protocols: all patient identified data is submitted through the Secure Report Depot, which is in line with best practices as per the CQR operating principles, and
- Quality infrastructure for data provision: The CDR has a governance structure in place, accessible data collection forms, a documented minimum data set with documented data definitions, a detailed user manual and a number of Policies and Standard Operating Procedures.

Key Issues

- Data limitations: The CDR does not meet the requirements of the Australian Commission on Safety and Quality in Health Care (Commission) *Operating Principles for Clinical Quality Registries*. It is therefore unable to analyse the device data in a way that is relevant for stakeholders, including clinicians and patients.
- Low uptake of participating sites: As at mid-2017, the CDR had 1194 patient records in the CDR provided by 43 clinicians across six sites. This represents less than five percent of eligible sites contributing data.
- Engagement with key stakeholders: The CDR has not been able to leverage the success of State and Territory based registries.
- Role confusion: The majority of stakeholders are not sure if the CDR is a patient recall register or a CQR.
- Local governance and ethics approval processes: These processes have significantly impacted on timeframes.

Response to review findings

The Department and ACOR have agreed that, in response to the review findings, a new federated model may be a solution to achieve a cardiac devices, procedures and outcomes registry with the support and engagement of cardiologists, cardiac surgeons, hospitals and other stakeholders.