Public Reporting Project Report

Cindy Turner, Tamara Hooper and Elsie Nunu

JUNE 2025

SAHMRI
South Australian Health & Medical Research Institute

SAHMRI Registry Centre

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This report has been developed by the South Australian Health and Medical Research Institute Registry Centre with funding provided by the Australian Department of Health, Disability and Ageing through the National Clinical Quality Registry Program.

Acknowledgment of country

SAHMRI acknowledges Aboriginal and Torres Strait Islander people as the first peoples of Australia and the longest continuous living culture in the world. We recognise the injustices of the past and that Aboriginal and Torres Strait Islander people do not experience the same equality of rights and life expectancy as other Australians. We respect the resilience of Aboriginal and Torres Strait Islander people in the face of adversity.

Publication Details

Publication Title: Public Reporting Project Report.
Published: 2025

Publisher: South Australian Health and Medical Research Institute
https://doi.org/10.58138/atzr-m406

Suggested Citation

Public Reporting Project Report. South Australian Health and Medical Research Institute. June 2025. Version 1.

https://sahmri.blob.core.windows.net/communications/PublicReportingProjectReport.pdf

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Contents

Executive Summary

Timely, accurate, and accessible reporting by registries is critical to improving transparency and healthcare quality.

In January 2024, the SAHMRI Registry Centre commenced a series of activities as part of the Registry Centre of Excellence Project, aimed at supporting national best practice in registry science and enhancing the visibility and value of registries.

The projects were guided by the *Australian Framework for National Clinical Quality Registries 2024*[1] and the *National Strategy for Clinical Quality Registries and Virtual Registries 2020-2030*[2].

One of these initiatives, the Public Reporting Project, was dedicated to improving reporting practices among SAHMRI Registry Centre members.

The project included a formative evaluation of current reporting practices, a workshop with SAHMRI Registry Centre members focused on the Framework's guidance, expert consultations across the CQR sector, and the development of a practical tool to assess and support registry reporting practices.

Key findings

The SAHMRI Registry Centre has laid a foundation for enhancing public reporting practices across its member registries in alignment with national frameworks and strategies.

Through stakeholder engagement and the development of practical tools, the SAHMRI Registry Centre has identified barriers and gaps in reporting and supported registries in understanding and aligning with best practice standards.

Recommendations

Based on its findings the SAHMRI Registry Centre has developed the following recommendations, which would require registries to the supported and adequately resourced to implement:

Recommendation 1: Registries should create and maintain feedback loops with stakeholders to ensure continuous improvement and relevance of reported information.

To maximise the impact of their stakeholder reports, registries are supported to develop a feedback loop with their stakeholders to inform their communication and dissemination strategies where targeted audiences, reporting formats, schedules, and other processes are well defined. Reports should be regularly reviewed to ensure maximum reach and highest utility.

Recommendation 2: To develop shared resources that support reporting and utilise the expertise of mature registries to strengthen sector-wide capability.

Creating shared resources that leverage the knowledge and experience of mature registries can aid those with limited capacity to meet best practice reporting requirements.

Recommendation 3: To increase sector investment in reporting and analytics infrastructure that enables routine, ad hoc, and real-time reporting.

Improving infrastructure for routine, ad hoc, and real time reporting is recommended for long term improvement in registry data access and usability. Improving infrastructure and achieving automation require investment in data governance, data sharing agreements, and interoperability between CQRs.

Recommendation 4: A centralised CQR web platform should be developed to host resources that assist with reporting activities.

Engagement with key stakeholders revealed there is a desire across the CQR sector for resources to be readily available in a centralised location. A central online platform would require investment in resources for its establishment and maintenance.

Recommendation 5: Registries should prepare lay summaries of findings and outputs and involve consumers in their development where appropriate.

Consumers are a significant stakeholder for registries. It is therefore important that outputs and findings which are often complex and technical are made more accessible and meaningful. This would be a step toward supporting informed consumer decision-making.

Recommendation 6: Registries should review and update governance structures and policies to incorporate Indigenous Data Sovereignty principles where applicable.

To enable the provision of reports on equitable healthcare outcomes for Aboriginal and Torres Strait Islander people, registries are encouraged to review their governance structure and policies to incorporate Indigenous Data Sovereignty principles. This process should focus on the rights of Indigenous nations over data about them and working with peak bodies to support these efforts https://www.maiamnayriwingara.org/.

Recommendation 7: Registries should engage meaningfully with diverse consumer groups to ensure their reports address the needs of priority populations.

There is an opportunity for registries to better align with the Strategy’s priorities on equitable healthcare reporting to address health inequities. To ensure the collection, monitoring and reporting of data meets the needs of priority groups, registries should engage with diverse consumer groups that reflect the needs of women, people in regional/remote areas, people with a disability, socio-economically disadvantaged groups, and culturally and linguistically diverse communities.

1. Introduction

The South Australian Health and Medical Research Institute (SAHMRI) Registry Centre was established in 2018 as a centre of excellence for registries and registry science. As of 2025, it brings together a collaboration of 27 member registries encompassing a broad range of health topics.

In January 2024, the SAHMRI Registry Centre commenced a series of activities under the Registry Centre of Excellence Project, aimed at supporting national best practice in registry science and enhancing the visibility and value of registries, in line with the Framework and the Strategy. As one of these key initiatives, this project focused on improving public reporting practices across the CQR sector. This report outlines the delivery of the project, its key challenges, lessons learned, and recommendations to support best practice public reporting across registries.

Funded by the Department National Clinical Quality Registry Program, the Public Reporting Project aimed to build capacity for best practice reporting among registries. The project included consideration of how resources could be shared to reduce costs for individual registries, and how the skills and experience of more mature member registries could be leveraged to increase the knowledge and capacity among developing registries.

Goal

To increase best practice public reporting (including for consumers) across multiple registries.

Objectives

1. Work with SAHMRI Registry Centre member registries to improve best practice reporting
2. Translate registry findings into a set of best practice resources
3. Determine the pros and cons of using different vehicles to host CQR public reports/consumer tools

2. Background

Clinical registries are an increasingly critical component of a learning health care system, collecting clinically relevant data regarding specific diseases or health events. In Australia, a clinical quality registry (CQR) is a specialised type of registry that systematically monitors and reports on the appropriateness and effectiveness of health care, within defined clinical domains, to drive improvements in safety and quality. Reporting to stakeholders is an integral role of CQRs, ensuring their work is visible to those who provide and receive care. Effective reporting serves as a catalyst for improvements in healthcare.

The importance of timely, high-quality reporting by CQRs is highlighted in the Australian Commission on Safety and Quality in Healthcare (the Commission) *Australian Framework for National Clinical Quality Registries 2024* (the Framework).[1] The Framework outlines best practice guidance for feedback and reporting. Briefly, the Framework's recommendations for best practice reporting is that CQR data collections should be routinely analysed and timely reports (with recommended frequency) disseminated to its intended audiences. Further, it recommends that registry findings should be risk adjusted where possible, aggregated, and structured processes for peer review and dissemination put in place to ensure fairness, accuracy, utility and accountability. Complementing this, the Department of Health, Disability and Ageing (the Department) *National Strategy for Clinical Quality Registries and Virtual Registries 2020-2030 (the Strategy)*[2] outlines national priorities for improving the collection, monitoring, and reporting of CQR data. The Strategy seeks to enhance the value and impact of CQRs and ensure government investments are maximised in prioritised areas.

3. Project Activities

The following activities were undertaken to determine what would increase best practice reporting and identify the most suitable location for hosting registry reports and resources.

3.1 Planning

3.1.1 Establish Project Governance

The SAHMRI Registry Centre managed the delivery of the project through a governance structure that included:

The SAHMRI Registry Centre Advisory Group

The Advisory Group meets quarterly with the purpose of advising and providing guidance on the work of the SAHMRI Registry Centre, specifically in the achievement of its key goals. This group consists of a representative from each of the 27 member registries. Quarterly updates on each project were provided to the Advisory Group. Depending on the stage and requirements of each project there were varying levels of involvement from individual registries.

The SAHMRI Registry Centre Executive Group

The SAHMRI Registry Centre Executive Group which meets monthly consists of the:

- SAHMRI Chief Operating Officer and Director Health Policy Centre at SAHMRI
- Strategic Director SAHMRI Registry Centre
- Director ROSA and Joint Academic Lead of the SAHMRI Registry Centre
- Executive Director ANZDATA and Joint Academic Lead of the SAHMRI Registry Centre.

The Executive Group were involved in the original project concepts and application. They provided project advice and recommendations.

Project Teams

Each of the projects had their own project team responsible for the delivery of the project and varied between projects depending on the requirements. Often team members were working across more than one project. Team members include the:

- Strategic Director SAHMRI Registry Centre
- Project Manager
- Project Officer(s)

Project Plans

A plan was developed for each project as aligned with the contract deliverables. Each plan was reviewed monthly.

3.1.2 Establish Project Team

The Reporting project team included the Strategic Director, Project Manager and Project Officer. A 0.7 full time equivalent role was committed to this project.

3.1.3 Finalisation of Project Plan

The project plan was finalised in March 2025.

3.2 Implementation

Key implementation activities are presented sequentially; however, activities were undertaken in parallel. These activities included an environmental scan survey, member workshop, CQR sector consultation, participation in a jurisdiction review and development of resources and design to assess reporting alignment with the Framework.

3.2.1 SAHMRI Registry Centre Environmental Scan

Development of the survey tool

As part of a formative evaluation, the SAHMRI Registry Centre developed a survey to conduct an environmental scan of registry characteristics and reporting practices. An iterative process in the survey development was undertaken. It was guided by the Commission Framework for Australian clinical quality registries Second Edition (the Framework second edition), the Strategy, and consultation with SAHMRI Registry Centre contacts and representatives from the Department Clinical Quality Registry Section. The survey questions can be found in Appendix 1 SAHMRI Registry Centre Member Survey . Questions focused on identifying the barriers and facilitators to best practice reporting, in line with guidance provided in the Framework. The survey also asked registries to specify their preferred location for hosting supporting documents or templates.

Survey administration and sample characteristics

The survey was administered via Research Electronic Data Capture (REDCap) and distributed to member registries in May 2024. A user guide was also developed to provide members with the rationale and instructions on how to complete the survey. The survey was distributed to 22 SAHMRI Registry Centre members who are based both within SAHMRI (n=9) and externally (n=13) (see Appendix 2). Four registries did not respond to questions relating to reporting due to their recent establishment.

Analysis of the results

Survey responses were exported to Microsoft Excel where analyses were performed.

Analyses and interpretation of the results as well as the provision of recommendations was supported by the Framework, which was officially released following the development of the survey. Registries' compliance was evaluated based on whether they delivered the required reports at the recommended frequency with the necessary analysis included, as per Table 1 of the Framework. Appropriate reporting is contingent upon the focus and purpose of the CQR and therefore, overall compliance has been evaluated within this context.

Individual Registry Feedback

SAHMRI Registry Centre members were subsequently provided with individual reports detailing the results of the survey and how their registry compared to others. A series of recommendations based on the survey findings were also provided in each report. They included general recommendations for all registries as well as more tailored recommendations for each registry.

3.2.2 Development of the Action Plan

Following the analysis of the environmental scan an action plan was developed to address gaps and shortfalls and increase access to public reporting (see Appendix 3 for strategies and actions).

3.2.3 Reporting Workshop

Following the release of the Framework, the SAHMRI Registry Centre convened a workshop with its member registries in September 2024 to provide an update on the new reporting recommendations. In addition to this update, participants were asked to self-asses their registry's alignment to the Framework recommendations and reflect on the barriers and enablers to reporting. Participants were also asked to indicate the current and desired future state of their registry in terms of its level of functioning and maturity. Responses were collected via Microsoft Forms. The workshop was conducted using a hybrid model, with in-person attendance at the SAHMRI Auditorium complemented by online participation via Zoom. The workshop was attended by 23 participants who represented a total of 14 member registries (See Appendix 4).

3.2.4 CQR Sector Working Group Consultation

In February 2025, the project team consulted with 20 CQR experts from across Australia. This consultation was conducted to guide the development of the SAHMRI Registry Centre CQR Advisory Service and to explore preferences for a platform to host CQR public reports and resources. The advantages and disadvantages of the various options were assessed.

The group included participants from Monash University and the Australian Clinical Trials Alliance (ACTA) CQR Special Interest Group (SIG), representing a breadth of high-level knowledge of registry sector operations. In this consultation, participants were asked about their preferred locations to host registry reports and related resources such as templates. This focus group complemented the previous findings from both the May 2024 survey and September 2024 Reporting Workshop.

3.2.5 SA Health Jurisdiction Review

As jurisdictional leads in South Australia, the Department for Health and Wellbeing and Commission on Excellence and Innovation in Health conducted a workshop and landscape survey of clinical registries within their local health networks. The goal was to inform recommendations to the Health Chief Executives' Council (HCEC) of the short- and long-term objectives for clinical registries in the 21st Century. The rationale underpinning the review included the following:

- There are many health registries in SA of varying size and purpose
- Valuable clinical information is collected and reported but is not always used effectively to improve patient outcomes or make strategic decisions
- There is a lack of a clear overarching strategy for prioritisation, establishment and use of registries
- An apparent disconnect exists between the information use by clinicians and that used by other decision makers.

SAHMRI Registry Centre staff were invited to provide their strategic expertise and knowledge to the collaboration by contributing to the workshop and survey.

3.2.6 Development of a CQR Reporting Assessment Tool

The release of the Framework provided the SAHMRI Registry Centre team with the guidance to frame discussions with its member registries.

The project team developed a CQR Reporting Assessment Tool to assist registries to identify, evaluate and measure their current reporting practices against the Framework and the Strategy. The assessment tool includes eight sections with questions to guide self-assessment. The tool will be available to download from the SAHMRI Registry Centre website and the National CQR Platform.

Although the recommendations within the Framework apply to national CQRs and those with the potential to be expanded nationally, it does not preclude other clinical registries who wish to apply the guidance of the Framework.

Recognising the value of its guidance, the SAHMRI Registry Centre actively encourages member registries to align their operations with the Framework.

Concurrently, the Commission is leading a process to create a self-assessment tool enabling registries to measure themselves against all sections of the Framework. The SAHMRI Registry Centre is working with the Commission on this by sharing the content of the CQR Reporting Assessment Tool and contributing their expertise to the development of the new tool.

4. Findings and Recommendations

The following section summarises the project's findings and provides recommendations aimed at improving public reporting capacity and practice within the CQR sector.

4.1.1 Stakeholder Utilisation of Reports

The environmental scan showed seven registries (44%) would like to provide stakeholder reports but are unable to, due to a lack of report automation, insufficient staffing resources, complexity of data and lack of expertise.

Consultations across the SAHMRI Registry Centre highlighted the importance and challenges of meeting stakeholders' diverse needs. Many registries did not know if the reports they send are read, utilised or understood. There was a clear need for an improved feedback loop between registries and those they are reporting to, as well as a strategic approach to disseminating reports to ensure they reach the target audience.

Recommendation 1: Registries should create and maintain feedback loops with stakeholders to ensure continuous improvement and relevance of reported information.

To maximise the impact of their stakeholder reports, registries are encouraged to develop a feedback loop with their stakeholders to inform their communication and dissemination strategies. Target audiences, reporting formats, schedules, and other processes should be well defined and regularly reviewed to ensure maximum reach and highest utility of the reports.

The SAHMRI Registry Centre proposes that supporting resources be developed. This may include a guide to developing a report dissemination strategy and establishing feedback loops with stakeholders to monitor uptake.

4.1.2. Reporting in Alignment with the Framework

Of the 19 participants providing a response in the Reporting Workshop, seven (37%) indicated that they were currently a high functioning registry while eight (42%) reported that in the future they would like to develop to a high functioning/mature CQR.

Findings from the environmental scan and the workshop reveal consistent barriers and enablers to reporting in line with the Framework.

Commonly identified barriers to recommended reporting included insufficient staffing, lack of statistical resources, infrastructure limitations and lack of report automation. Registries also indicated a lack of funding was a factor hampering innovations such as the development of dashboards and applications.

Workshop recommendations for enabling best practice reporting included stakeholder input, funding, template sharing and high case ascertainment. They also reported that statistician expertise was a resource that could be shared among registries. Commonly identified enablers from the environmental scan included access to a statistical resource and an upgrade to their infrastructure/database.

The SAHMRI Registry Centre Environmental Scan found a high level of compliance with the Framework's recommended reporting frequency. All registries reported compliance with the recommended reporting frequency for routine annual CQR, unit, clinician, provider, and device and therapeutics. There was lower compliance for jurisdiction and public reports due to factors such as insufficient data. There was variation in the types of analyses provided in ad hoc versus routine reports and over half of the registries indicated that a statistical resource (n=10, 63%) or infrastructure upgrade (n=9, 56%) would help their registry to provide these data analyses in their reports.

For CQRs, the Framework is an important resource for all registries aiming to further their quality and maturity. It provides support and guidance as they work towards achieving their purpose and providing maximum value to the Australian health system.

In creating shared resources for registries, leveraging the expertise of mature registries can aid those with limited capacity, and may enable data analytics, peer review and consumer engagement to meet other best practice reporting requirements. For example, the SAHMRI Registry Centre identified a need to develop a tool to help assist registries to assess their reporting against the Framework. The project team subsequently developed the CQR Reporting Assessment Tool. Future resources may be identified and developed by the Department in partnership with experts in the CQR sector.

Recommendation 2: To develop shared resources that support reporting and utilise the expertise of mature registries to strengthen sector-wide capability.

Creating shared resources that leverage the knowledge and experience of mature registries can aid those with limited capacity to meet best practice reporting requirements.

Noting improved reporting infrastructure would support closer alignment to the Framework, many registries would require additional investment from the Department or other external funding to overcome limitations to meeting reporting guidelines and ensure ongoing sustainability.

Recommendation 3: To increase sector investment in reporting and analytics infrastructure that enables routine, ad hoc, and real-time reporting.

Improving infrastructure for routine, ad hoc, and real time reporting is recommended for long term improvement in registry data access and usability. Achieving automation and improving infrastructure likely requires investment in data governance, data sharing agreements, and interoperability between CQRs.

4.1.3 Hosting CQR Reports and Resources

Resources. The environmental scan and the CQR stakeholder consultation revealed differing preferences for where CQR resources should be hosted. Challenges in deciding on the vehicle to host resources include sustainability, trust and credibility.

The scan of SAHMRI Registry Centre members indicated a preference for resources to be hosted on the SAHMRI Registry Centre website, while those in the sector consultation preferred the Department National CQR Program webpage. The findings from both suggest that there is a desire for resources be more centralised.

Participants in the sector consultation suggested that using an existing Department website may be a reliable path, whereas establishing a new site presents risks such as underfunding and lack of clarity in governance and maintenance.

Reports. There is no consensus on whether registry reports should also be on a centralised location or the value of this. However, since reports are specific to health areas, it is reasonable to assume it would be more appropriate for them to be located on a site related to that specific health area rather than in a central platform.

Recommendation 4: A centralised CQR web platform should be developed to host resources that assist with reporting activities.

Engagement with key stakeholders revealed there is a desire across the CQR sector for resources to be more centralised. A central online platform will require investment into resources for its establishment and maintenance.

4.1.4 Lay Summaries and Consumer Involvement

Environmental scan results showed that nine registries (56%) included a lay summary designed for consumers or the general population in their reports. Fewer than half of these (44%, n=4) reported involving consumers in lay summary development. Three registries (43%) indicated it is their preference to include a lay summary in their reports. Challenges such as a lack of resources and time, as well as access to appropriate consumer groups prevent registries from including lay summaries.

Given that most (65%, n=13) SAHMRI Registry Centre members identified consumers as a major stakeholder, the gap in consumer engagement represents an opportunity to increase efforts to involve and consult with consumers to develop lay summaries as an element of public reports. Involving consumers in the translation of registry outputs can help to ensure that public reports and accompanying communications meet their purpose, and are usable, accessible and clear for their intended audience. However, it is evident that there are funding and human resource constraints which prevent registries from doing so. Therefore, expecting consumer involvement in all registries as standard practice may not yet be achievable. Developing shared resources for CQRs may overcome challenges to co-design, especially by facilitating access to consumers. For example, as part of its Consumer-Friendly Information (CoFI) Project, the SAHMRI Registry Centre has developed a user guide for registries to follow when translating registry outputs into consumer-friendly resources: A registry guide to co-designing consumer friendly resources. SAHMRI | Resources

Recommendation 5: Registries should prepare lay summaries of findings and outputs and involve consumers in their development where appropriate.

Consumers are a significant stakeholder for registries, and it is important that outputs and findings which are often complex and technical are made more accessible and meaningful to this group. This would be a step toward supporting informed consumer decision-making.

4.1.5 Reporting on Equitable Healthcare Outcomes

According to the environmental scan, most registries (85%, n=17) reported that they collect Aboriginal and Torres Strait Islander identifiers, 65% (n=13) have ethics approval* to collect these data, but only four (26%) reported on equitable healthcare outcomes for Aboriginal and Torres Strait Islander people.

A mechanism is in place in 35% (n=7) of registries to ensure the priorities of women, people in regional/remote areas, people with a disability, socio-economically disadvantaged groups, and culturally and linguistically diverse communities are considered in data collection, monitoring, and reporting. Only four (26%) registries produce an equitable healthcare outcomes report that includes these different cohort groups.

**Registries which have mandatory reporting do not require ethics approval however, they do collect Aboriginal and Torres Strait Islander identifiers.*

The environmental scan identified gaps in the provision of equitable healthcare outcome reports for Aboriginal and Torres Strait Islander populations, despite efforts to collect relevant identifiers. The lack of reporting is mirrored for other priority populations, suggesting that registries could better align with the Strategy's priorities on equitable healthcare reporting to address health inequities.

Implementing this can be complex and there is not yet standard guidance for CQRs. However, registries could work with peak bodies such as the National Aboriginal Community Controlled Health Organisation, Australian Institute of Aboriginal and Torres Strait Islander Studies and the Lowitja Institute which are well placed to provide informed, community-centric approaches to the governance of Indigenous data.[3] Also, the Department National Clinical Quality Registry Program has a project underway that will develop best practice guidance on embedding Indigenous data sovereignty and data governance principles into national CQRs. The guidance material is expected mid-2026.

Recommendation 6: Registries should review and update governance structures and policies to incorporate Indigenous Data Sovereignty principles where applicable.

To enable the provision of reports on equitable healthcare outcomes for Aboriginal and Torres Strait Islander people, registries are encouraged to review their governance structure and policies to incorporate Indigenous Data Sovereignty principles[4]. This process should focus on the rights of Indigenous nations over data about them and working with peak bodies to support these efforts https://www.maiamnayriwingara.org/.

Recommendation 7: Registries should engage meaningfully with diverse consumer groups to ensure reports address the needs of priority populations.

There is an opportunity for registries to better align with the Strategy's priorities on equitable healthcare reporting to address health inequities. To ensure the collection, monitoring and reporting of data meets the needs of priority groups, registries should be encouraged and supported to engage with diverse consumer groups that reflect the needs of women, people in regional/remote areas, people with a disability, socio-economically disadvantaged groups, and culturally and linguistically diverse communities.

5. Discussion

The SAHMRI Registry Centre's delivery of the Public Reporting Project has laid a foundation for enhancing public reporting practices across registries in alignment with national frameworks and strategies. Through stakeholder engagement and the development of practical tools, the SAHMRI Registry Centre has supported registries to understand and embrace self-assessment against best practice standards. The SAHMRI Registry Centre has also gained an insight into the current reporting practices of its members, identified the barriers and enablers to best practice reporting in alignment to the Framework, and developed an understanding of the needs and preferences of key stakeholder groups for vehicles that host CQR reports and related resources.

Gaps in registry reporting were demonstrated by the environmental scan, particularly for the provision of equitable healthcare outcomes reports. Only four (26%) registries produce an equitable healthcare outcomes report for women, people in regional/remote areas, people with a disability, socio-economically disadvantaged groups, and culturally and linguistically diverse communities. Likewise, only four (26%) reported on equitable healthcare outcomes for Aboriginal and Torres Strait Islander people despite most indicating that they collect Aboriginal and Torres Strait Islander identifiers.

Engagement with member registries revealed barriers to recommended reporting including insufficient staffing, lack of statistical resources, infrastructure limitations, and inadequate funding. They also encountered challenges such as addressing the diverse needs of stakeholders and receiving little to no feedback on whether the reports they distribute are read or used. Meeting such challenges would require sustained investment in infrastructure and accessible, centralised resources, as well as ongoing collaboration with key stakeholders to ensure reports are relevant and impactful. With time and continued support registries could be enabled to align with the guidance provided in the Framework and the Strategy and thus work toward achieving their core purpose.

There are some caveats in the project's findings. For example, it is unclear whether the findings can be generalised to all Australian registries, as SAHMRI Registry Centre members may not be representative of the broader registry landscape. However, the perspectives and responses of several national large CQRs as well as smaller more regional registries have been captured, showing a spread of registries' experiences.

6. Conclusion

High-quality and transparent CQR reporting is essential for driving continuous improvement in clinical care and ultimately enhancing patient outcomes across the Australian healthcare system. As the registry sector continues to evolve, there is a growing need to be able to provide reports to a wide variety of stakeholders, in a manner that is timely, accurate and intentional. The SAHMRI Registry Centre is well positioned to provide continued support that enables registries to align their reporting with best-practice national guidance.

The SAHMRI Registry Centre is committed to improving the reporting capability of CQRs to influence care delivery nationally and advance the health of Australians. The Centre aims to continue its support through future efforts such as its ongoing program of educational workshops and annual SAHMRI Registry Centre symposiums.

The recommendations arising from this project highlight key opportunities to strengthen registry reporting, including centralised resource sharing, consumer involvement, clinician and stakeholder engagement, and support for Indigenous Data Sovereignty through governance and policy. Continued collaboration and investment will be essential to sustain momentum and ensure that registries can deliver clear, meaningful, accessible, and actionable information to improve healthcare delivery.

7. Appendices

Appendix 1: SAHMRI Registry Centre Member Survey Questions

Please review the list of report types and indicate (a) if it is produced and (b) how often it is produced.

	Annual	Biannual (twice per year)	Quarterly	Monthly	Ad hoc	Other	Not applicable (registry has not produced this report type)
Clinical and registry findings	☐	☐	☐	☐	☐	☐	☐
Jurisdiction (state) and private hospital	☐	☐	☐	☐	☐	☐	☐
Unit level*	☐	☐	☐	☐	☐	☐	☐
Clinician, Provider (association)	☐	☐	☐	☐	☐	☐	☐
Device and therapeutic	☐	☐	☐	☐	☐	☐	☐
Public (incl consumer)	☐	☐	☐	☐	☐	☐	☐

***** Unit level - hospitals, hospital departments, local or regional health services or other healthcare organisations

Please list any "other" types of reports your registry produces and the frequency.	
Please select the types of analysis provided in your reports. *(more than one may apply)*	The proportion of eligible people participating in the registry against a target indicator | Descriptive reporting of process or outcome variance | Risk adjustment | Benchmarking performance | Assessment of outcome data against minimum procedure volume | Post-market surveillance of devices and of new and existing technologies where relevant | Cost effectiveness assessment, cost-utility and cost-benefit | Annual clinical outcomes | Annual corporate outcomes | Identification of outliers and unexplained variance| Clinical interpretation of findings | Equitable healthcare outcome report for Aboriginal and Torres Strait Islander people |Equitable healthcare outcome report for different cohorts (women, regional/remote, disabilities, socio-economically disadvantaged groups, diverse cultural and linguistic backgrounds) | Other (specify)

What prevents your registry from including the above types of analysis in your reports?	Low priority | Registry does not collect (ethnicity, CALD, geographic location, disability, socioeconomic) cohort identifiers | Complexity of data, lack of expertise (access to statistician) | Lack of report automation | Insufficient staffing resources | Lengthy approval process for review and release of reports | Other (specify)
What would help your registry provide the above types of analysis in its reports?	Statistical resource | Infrastructure (database) upgrade to include cohort identifiers | Dedicated report review group for routine and ad hoc reports | Other (specify)
Are there reports that you would like to provide but are unable i.e. a specific stakeholder group?	Yes | No
If yes, what prevents your registry from providing other stakeholder reports?	Low priority | Complexity of data, lack of expertise (access to statistician) | Lack of report automation | Insufficient staffing resources |Lengthy approval process for review and release of reports | Other (specify)
If yes, what help would enable your registry to provide other stakeholder reports?	Statistical resource | Infrastructure (database) upgrade to include cohort identifiers | Dedicated report review group for routine and ad hoc reports | Other (specify)
Does your registry contain findings which you have not been able to report?	Yes | No
If yes, what prevents your registry from reporting findings?	Low priority | Complexity of data, lack of expertise (access to statistician) |Lack of report automation | Insufficient staffing resources | Lengthy approval process for review and release of reports | Other (specify)
If yes, what help would enable your registry to report its findings?	Statistical resource | Infrastructure (database) upgrade to include cohort identifiers | Dedicated report review group for routine and ad hoc reports | Other (specify)
Do any of the reports include a lay summary designed for consumers or the general population?	Yes | No
If yes, were consumers involved to determine the most suitable and useful formats for the report and accompanying communications?	Yes | No
If no, is it the registry's preference to include a lay summary (consumers, general population)?	Yes | No
If no, what would help your registry achieve the inclusion of a lay summary?	Yes | No
Does your registry have processes and capacity to provide stakeholders with additional analysis and ad hoc reports, on request, within a reasonable period of time?	Yes | No
Does your registry have a secure web interface which provides approved users with access to routine and ad hoc reports?	Yes | No
If no, is a secure web portal something your registry would like to know more about?	Yes | No
Are authorised users able to generate and configure real time reports using their own unit's/institution's/jurisdiction's data?	Yes | No
If no, would your registry like to know more about automated real time reports?	Yes | No

Appendix 2: SAHMRI Registry Centre Member Characteristics - Survey Respondents

Registry name	Acronym	Affiliation	Geographic coverage	Contribution*	Consent
Australian Corneal Graft Registry	ACGR	Flinders University	Australia	Voluntary	Opt-in
Australian and New Zealand Audit of Surgical Mortality	ANZASM	Royal Australasian College of Surgeons	Australia	Mandatory	Combination
Australian and New Zealand Dialysis and Transplant Registry	ANZDATA	SAHMRI	Australia, New Zealand	Voluntary	Opt-out
Australian and New Zealand Emergency Laparotomy Audit - Quality Improvement	ANZELA-QI	Royal Australasian College of Surgeons	Australia, New Zealand	Voluntary	Waiver
Australia and New Zealand Eye and Tissue Donation Registry	ANZETD	SAHMRI	Australia	Voluntary	Combination
Australian and New Zealand Heart Transplant Registry	ANZHTR	SAHMRI	Australia, New Zealand	Voluntary	Opt-out
Australian and New Zealand Living Kidney Donation Registry	ANZLKD	SAHMRI	Australia, New Zealand	Voluntary	Opt-in
Australian and New Zealand Lung Transplant Registry	ANZLUNG	SAHMRI	Australia, New Zealand	Voluntary	Opt-out
Australian and New Zealand Organ Donor Registry	ANZOD	SAHMRI	Australia, New Zealand	Mandatory	Combination
Australian and New Zealand Registry of Advanced Glaucoma	ANZRAG	Flinders University	Australia, New Zealand	Voluntary	Opt-in
Australia and New Zealand Vasculitis Quality and Disease Registry	ANZVASC-QDR	Monash University / Monash Health	Australia, New Zealand	Voluntary	Opt-in
Australasian Registry of Electrocardiograms in National Athletes	ARENA	SAHMRI / University of Sydney	Australia	Voluntary	Combination
The Australian Particle Therapy Clinical Quality Registry	ASPIRE	SAHMRI	Australia, New Zealand	Voluntary	Opt-out
Breast Surgeons of Australia and New Zealand Quality Audit	BQA	Royal Australasian College of Surgeons	Australia, New Zealand	Mandatory	Opt-out
The Kidney Health Registry	Kidney health	SA Health	South Australia	Voluntary	Opt-out
Registry of Senior Australians	ROSA	Flinders University	Australia	Data linkage	Combination
South Australian Prostate Cancer Clinical Outcomes Collaboration	SA-PCCOC	SA Health	South Australia	Voluntary	Opt-out
South Australian Birth Defects Register	SABDR	SA Health	South Australia	Mandatory	Waiver
South Australian Cerebral Palsy Register	SACPR	SA Health	South Australia	Mandatory	Opt-in
Transcatheter Aortic Valve Implantation	TAVI	SAHMRI	Australia	Voluntary	Opt-out

**The survey did not enquire about the specifics of mandatory contributions of data to the registries.*

Appendix 3: Action Plan

Strategies

Strategies for addressing gaps and shortfalls included:

- Creation of comparative reports for participating registries
- Develop recommendations to assist registries to evaluate practices and increase best practice reporting
- Hold discussions with registries to
  - Evaluate where opportunities exist to share resources
  - Discuss barriers
  - Determine what resources would aid registries in closing the gap/shortfall
- Raise awareness regarding education sessions

Actions

To assist registries, the SAHMRI Registry Centre actioned the following strategies:

- Provision of individual reports to participating registries with
  - Ability to review and compare themselves against aggregated results.
  - Recommendations to assist registries to evaluate practices and increase best practice reporting.
- Informal discussions 1:1
  - Resources and requirements to meet gaps.
  - Feedback loop to discuss report and plan for enhancements.
- Workshop/seminar to
  - Focus on the reporting guidance in the Framework.
  - Identify reporting barriers and enablers.
  - Evaluate opportunities to share resources.
- Education opportunities
  - SAHMRI monthly statistical education sessions.
- Guide/tool development
  - Reporting assessment tool.
  - Standard operating procedures.

Appendix 4: Participants of the reporting workshop

Registry name (acronym)	Participants
Australian and New Zealand Audit of Surgical Mortality (ANZASM)	1
Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)	4
Australian and New Zealand Emergency Laparotomy Audit - Quality Improvement (ANZELA-QI)	2
Australia and New Zealand Vasculitis Quality and Disease Registry (ANZVASC-QDR)	1
Australasian Registry of Electrocardiograms in National Athletes (ARENA)	1
The Australian Particle Therapy Clinical Quality Registry (ASPIRE)	2
Breast Surgeons of Australia and New Zealand Quality Audit (BQA)	2
Coronary Angiogram Database of South Australia (CADOSA)	3
Flinders Kidney Health Registry	1
Lily Registry (SA registry for eating disorders)	1
Registry of Senior Australians (ROSA)	1
South Australian Prostate Cancer Clinical Outcomes Collaboration (SA-PCCOC)	1
The Australasian Shunt Registry	1
Transcatheter Aortic Valve Implantation (TAVI) Registry	2

8. References

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SAHMRI

Creating Healthier Futures

SAHMRI exists to help people lead healthier lives. South Australia's flagship not-for-profit health and medical research institute is driven by research excellence that delivers rapid improvements in the prevention, diagnosis, and treatment of disease.

This is achieved through four health themes – Aboriginal Health Equity, Women and Kids, Precision Cancer Medicine and Lifelong Health.

Home to a leading Aboriginal and Torres Strait Islander research unit, the Wardliparingga Aboriginal health research team is focused on achieving equitable outcomes by responding to community priorities, reflecting our commitment to improving the health and wellbeing of Indigenous communities, which is vital for a healthier future for all.

Designed for collaboration, our landmark building is at the heart of South Australia's Biomedical ecosystem, uniting hospitals, universities and research entities in interdisciplinary partnerships.

Located in the agile, 20-minute city of Adelaide, SAHMRI is embedded in the state's creative, legal and government precincts, inspiring innovation and accelerating the speed to market of discoveries.

Cost effectiveness combined with Australia's R&D tax incentives make SAHMRI a preferred partner for international collaborations.

Our translational impact is profound and growing. We've influenced health policies such as laws on vaping, established a centre of excellence for registries to house health-advancing data, discovered lifesaving therapies such as a treatment for Chronic Myeloid Leukaemia, and developed the evidence-based Omega-3 test and treat program to help prevent preterm births.

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