CQR Value and Impact Project Report

Tamara Hooper, Elsie Nunu and Cindy Turner

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SAHMRI
South Australian Health & Medical Research Institute

SAHMRI Registry Centre

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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.

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Contact Us

For further details or feedback contact
registrycentre@sahmri.com, SAHMRI | SAHMRI Registry Centre

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Executive Summary

The Clinical Quality Registry (CQR) Value and Impact Project, delivered by the SAHMRI Registry Centre and funded by the Department of Health, Disability and Ageing, was established to address the growing need for CQRs to effectively demonstrate their value to the Australian health system and their impact on healthcare delivery and patient outcomes.

The SAHMRI Registry Centre identified variability across its member registries in how they monitor, evaluate, and demonstrate their impact. Discussions revealed that more mature registries, with greater resources, generally had greater capacity and were more likely to publish their outcomes.

While most registries track at least one performance or output metric, inconsistency in knowledge, capability, monitoring and practices limits the sector's ability to communicate value effectively. This presents risks to stakeholder engagement, funding sustainability, and the potential for registries to influence health policy and decision-making.

Moreover, gaps were revealed in the provision of reports on equitable healthcare and outcomes, highlighting an opportunity to improve the impact of registry data on the delivery of health care for priority populations. Addressing these challenges requires a sector-wide commitment to building capability through structured education, practical tools, and shared resources.

In this project, the SAHMRI Registry Centre has engaged with experts on impact, provided targeted support, and facilitated opportunities for shared learning for its member registries and the sector more broadly. The SAHMRI Registry Centre has also worked closely with its members to develop 13 impact case studies demonstrating a breadth and depth of registry impact.

The SAHMRI Registry Centre remains committed to supporting the registry sector and fostering a collaborative environment where registries can thrive and deliver meaningful improvements to healthcare quality and equity across Australia. Reflecting the key findings of this report, nine key recommendations have been developed.

Key findings

- The Project highlighted an urgent need for clinical quality registries to strengthen their ability to measure and communicate impact.
- Addressing current gaps in capability, consistency, and equity is essential to ensure registries remain relevant, sustainable, and influential in shaping healthcare outcomes.
- By developing sector-informed impact guidance, enhancing education and tools, and embedding equity and strong governance into routine practice, the registry sector can better monitor and demonstrate its value.
- Continued alignment with national initiatives will support a more cohesive, capable, and future-ready registry landscape across Australia.

Recommendations

Recommendation 1: Evidence of registry impact on health outcomes should be published to promote the profile and value of CQRs in Australia and support their sustainability.

For CQRs to be competitive and ensure their sustainability in a tight funding market they need to be able to demonstrate their value and impact. Publishing this evidence would also help demonstrate the contributions of registries to clinicians, policy makers, and other important stakeholders which could foster further support for the sector.

Recommendation 2: To develop a fit-for-purpose impact framework specifically for CQRs.

A practical impact framework co-designed with the sector would support registries to measure and communicate impact that is relevant, and reflective of the real-world contributions of CQRs in ways that resonate with funders, policymakers, clinicians, and the broader health system.

Recommendation 3: Delivery of an ongoing program of structured and practical education forums to increase the capability of the registry sector to monitor, measure and demonstrate their impact.

Successfully embedding practice change into daily operations requires building capability, confidence, and capacity within the registry to ensure consistency. This involves equipping staff with comprehensive education, knowledge, and practical tools.

Recommendation 4: The Guide to Demonstrating CQR Impact should be adopted by registries to assist in identifying, measuring, and communicating their impact.

The use of a practical, tested, and sector-informed tool supports registries when developing clear and compelling impact narratives, strengthening their strategic position, and contributing to improved engagement with stakeholders and decision-makers across the health system. This must include implementation of a feedback loop to determine the usefulness and clinical relevance of their reporting.

Recommendation 5: To develop a series of dedicated tools and accompanying resources for the Guide.

The creation of practical, adaptable tools and resources will assist registries to monitor and measure their impact. These need to be aligned with the real-world requirements of the sector to build capacity and support continuous improvement.

Recommendation 6: Registries should engage meaningfully with diverse consumer groups to ensure registry findings and outputs 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.

Recommendation 7: To establish sector-wide guidance and tools to assist registries to embed equity indicators into routine operations and reporting.

All registries are encouraged to review the collection of equity indicators, and the provision of vulnerable groups reports as per their purpose. Embedding these practices into routine operations supported by appropriate guidance and tools would enable registries to ensure the data that is collected is included consistently in reports on vulnerable populations.

Recommendation 8: 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 9: SAHMRI Registry Centre members should align with the 2024 Framework and use the self-assessment tool to evaluate their performance.

Together, the Framework and tool provide registries with the resources to identify areas for improvement, plan enhancements, monitor progress, and demonstrate their value and impact.

1. Introduction

The CQR Value and Impact project aimed to strengthen the value of CQRs and better demonstrate their impact across the sector. The SAHMRI Registry Centre partnered with its member registries to develop impact case studies and delivered a practical, educational program to build sector capability in demonstrating and communicating their value and impact.

This report outlines the project's delivery, its key challenges, lessons learned, and the SAHMRI Registry Centre's recommendations, to support registries to convey the importance of their work.

Goal

To develop and compile a registry analysis including a series of case studies, and evaluation metrics that demonstrate the value and impact of member registries.

Objectives

1. To include an assessment of the usefulness and clinical relevance of registry reporting and outputs amongst SAHMRI Registry Centre members
2. Develop a series of case studies/impact stories
3. Design and undertake an assessment to determine whether registries capture information that can used to assess access equity, in care access and outcomes for different patient cohorts, including Aboriginal and Torres Strait Islander people to inform a centre level report.

2. Background

The Clinical Quality Registry (CQR) sector is entering a significant period of transformation. This shift is driven by increasing digitisation, integration with electronic medical records, expanded data linkage, and a growing need for interoperability across national systems and data assets. As systematic monitors of healthcare quality, CQRs are essential in driving improvements in safety, effectiveness, and appropriateness of care. They have pioneered the use of health data to enhance outcomes and are well positioned to lead Australia's national effort toward a more data-enabled healthcare system.

The Department of Health, Disability and Ageing (the Department) National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030[1] (the Strategy) and the Australian Commission on Safety and Quality in Health Care (the Commission) Australian Framework for National Clinical Quality Registries 2024 (the Framework) are critical in guiding the development of Australia's CQR sector and to enhance the value and impact of CQRs and ensure government investments are maximised in prioritised areas.

Demonstrating the value and impact of CQRs to key audiences including the general public, clinicians, health services, policymakers, and other stakeholders is essential. Doing so not only supports the role of registries in improving clinical care and informing health policy, but also reinforces confidence in the value of CQRs across the sector.

In a highly competitive funding environment, CQRs must be able to clearly articulate their value to secure ongoing sustainability. Registries that can identify and communicate their impact effectively are better positioned to attract and maintain support.

However, identifying, attributing, and clearly articulating impact is particularly challenging. CQR activities span a broad range of areas, including sector reporting, quality improvement, post-market surveillance, and research. These activities are governed by varying expectations with guidance provided in the Framework.[2] The diversity in the CQR purpose, governance, and outcomes adds layers of complexity to measuring and attributing their impact effectively.

3. Project Activities

3.1 Planning

3.1.1 Establish Project Governance

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

The SAHMRI Registry Centre Advisory Group

The Advisory Group met 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 consisted 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 form individual registries.

The SAHMRI Registry Centre Executive Group

The SAHMRI Registry Centre Executive Group which meets monthly, and 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, tailored to meet each project's requirements. Often team members were working across more than one project. Team members included 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 0.5 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 of the CQR Advisory Service Pilot

Key implementation activities are presented here numerically; however, activities were undertaken in parallel. These activities included planning the annual symposium, an environmental scan survey, desktop review of the literature, education program, development of resources, review of equitable healthcare and outcome reporting, and creation of case studies and impact statements.

3.2.1 SAHMRI Registry Centre Advisory Group

The SAHMRI Registry Centre Advisory Group has been in operation since 2022. At the commencement of this project the group included 33 members. 94% (n=31) are involved in the day-to-day management of a registry. This group was initially engaged to provide insights and feedback on the project plan, contribute to the discussion regarding the 2024 SAHMRI Registry Centre Symposium theme ‘Impact and Value’ and to respond to the request for abstracts detailing impact. Throughout the project, the SAHMRI Registry Centre project team kept the group informed with regular updates and sought their guidance and feedback on key issues.

3.2.2 Registry Centre Environmental Scan

As part of a formative evaluation for the four SAHMRI Registry centre of excellence projects an environmental scan (survey) of SAHMRI Registry Centre members was conducted. Questions were informed by the Strategy (principles and priorities),[1] and guidance contained in the Framework’s Second Edition. The survey was developed iteratively, involving consultation with the SAHMRI Registry Centre Advisory Group and representatives from the Department’s Clinical Quality Registry Program. Survey questions focused on registry characteristics, the methods currently used by registries to demonstrate impact, and the existing mechanisms, structures and policies that support the collection of data and the reporting of equitable healthcare delivery and outcomes. The survey questions can be found in Appendix A.

Survey administration and sample characteristics

The survey was administered via REDCap and distributed to member registries in May 2024. A user guide explained the rationale and provided members with instructions on how to complete the survey. The survey was distributed to 22 SAHMRI Registry Centre members based within SAHMRI (n=9) and externally (n=13). Registry characteristics and respondents are included in Appendix B.

Analysis of the results

Survey responses were exported to Microsoft excel where analyses were performed. See Appendix B.

Reciprocal reporting

Following the analysis of the environmental scan, each respondent received an individual report outlining their survey results, comparisons with other registries, and tailored recommendations based on the findings. Due to potential sensitivities, these reports have not been shared beyond the individual registries.

3.2.3 SAHMRI Registry Centre Symposium 2024

In March 2024, the SAHMRI Registry Centre hosted its Annual Scientific Symposium, highlighting the value and impact of CQRs. Member registries were invited to submit 300-word abstracts showcasing how their registry had acted as a ‘catalyst for change’. The SAHMRI Registry Centre supported interested members to identify impacts and develop their abstracts. Completed submissions were reviewed by the Symposium Organising Committee, with feedback provided to authors ahead of the event.

Eight registries presented at the Symposium - see Appendix C for the list of registries and their presentation title.

3.2.4 Development of Resources

The SAHMRI Registry Centre has developed the following resources for the CQR sector:

- The Guide to Demonstrating CQR Impact 3.2.6
- A collation of case studies and impact statements 3.2.9

These materials have been provided to the Department. Intended for the public domain, they serve as evidence of the value and effectiveness of registry-driven quality improvement initiatives across the healthcare system.

In addition to these resources an education workshop program as outlined in 3.2.8 was developed.

3.2.5 Reporting Workshop

Objective 1 of this project relates to assessing the usefulness and clinical relevance of registry reporting and outputs amongst SAHMRI Registry Centre members. It was first necessary to understand the current reporting status of member registries. The SAHMRI Registry Centre convened a workshop with its member registries in September 2024 to provide an update on the new reporting recommendations in the recently released Framework. 23 participants representing 14 member registries were asked to self-assess their registry’s alignment to the Framework recommendations and reflect on the barriers and enablers to reporting. They were also asked to indicate the current and desired future state of their registry in terms of its level of functioning and maturity. With this knowledge in hand, a series of one-on-one meetings with individual registries determined the impact of their reporting processes.

3.2.6 Guide to Demonstrating CQR Impact

Stage 1 Draft guide: ‘How to write impact statements and impact cases studies’

Working with registries in preparation for the symposium highlighted a gap in understanding around identifying and effectively communicating impact. In response, a user guide was developed to support member registries. This resource provided information on impact, links to relevant publications, and templates to assist in the development of case studies.

Stage 2 Desktop review of the literature

In September 2024, a targeted literature review was conducted to support the writing of case studies, compliment the information in the draft guide and address the following question: How can registries effectively demonstrate their impact, and what existing impact categories and frameworks, particularly from fields such as research, could be adapted to better assess and communicate their value in future impact case studies? The insights further confirmed the lack of frameworks and resources directly applicable to registries.

Stage 3 Further enhancements to the guide

The project team further refined the user guide to increase its focus on impact. They drew on a research impact framework, member feedback, and insights acquired in developing the education forum. This enhanced guide provided member registries with a practical resource, offering information on impact concepts, examples, and templates for case study development. It also served as a foundational tool for the project team when working directly with registries. Using this guide, the team successfully partnered with 13 registries to co-develop 13 detailed case studies and 16 impact statements. See Appendix D.

3.2.7 Engaging with Impact Experts

The SAHMRI Registry Centre team engaged with three expert groups, the Research Impact Academy, Grow Impact, and the Association of Australian Medical Research Institutes (AAMRI), to explore opportunities for addressing the gap in understanding impact within the registry sector. These discussions aimed to identify potential synergies with the broader research impact sector and to determine whether any existing national work could be adapted for use by registries. It was confirmed through this engagement that no registry-specific impact frameworks currently exist. However, the Research Impact Academy expressed a willingness to adapt their existing training modules to better suit the registry context.

3.2.8 Education Forums (workshops)

Informal discussions with members and preparations with registries for the symposium identified the need for further support. These interactions revealed varying levels of understanding, measurement and demonstration of registry impact.

Workshop aims

The SAHMRI Registry Centre collaborated with the Research Impact Academy to refine the content and aims of the workshop. These were to provide participants with:

- An understanding of the fundamentals of impact, including impact types and indicators
- Methods for identifying indicators of successful uptake of registry outputs
- Approaches to capturing and measuring registry impact
- Strategies for effectively communicating impact and value

Member workshop on impact and value

In August 2024, the SAHMRI Registry Centre hosted a half-day Fundamentals of Impact workshop for its members. A total of 26 participants from 12 registries attended the workshop and shared positive feedback. See Appendix E for the results.

Delivered broader CQR sector workshops on impact and value at the ACTA Clinical Registry Symposium

Following the success of the initial Fundamentals of Impact workshop, the SAHMRI Registry Centre was invited to deliver workshops at the Australian Clinical Trials Alliance (ACTA) 2024 Clinical Trials and Registries Symposium in December 2024. While the structure and style of the workshops remained consistent, the content was further refined to include more robust examples tailored specifically to the registry sector.

56 participants attended the two half-day sessions, including individuals directly employed within registries as well as representatives from government, industry, and clinical settings who work closely with registries. See Appendix E for the results.

3.2.9 Development and the Collation of Impact Case Studies

A total of 13 cases studies and 16 accompanying impact statements have been collated to illustrate the significant contributions of clinical quality registries.

Working individually with each member registry to support crafting and submission of case studies

Beginning in November 2024, all 22 SAHMRI Registry Centre members were invited to participate in writing a short case study. The SAHMRI Registry Centre project team worked one-on-one with 13 registries to identify areas of impact and prioritise one significant impact to develop into an impact case study. Using a modified research logic model , the team first collaborated with each registry to develop an impact statement, which then informed the structure and content of the impact case study. A structured guideline was used throughout to support consistent case study development. An iterative review process between the registry and the team ensured the accuracy of the impact statement and its related case study before final approval.

Development of impact statements

Impact statements and supporting evidence play a critical role in demonstrating value and differentiating registries, particularly in the context of competitive funding and grant applications. It is essential that impact statements are clearly articulated, comprehensive, and easy to understand. Using the methodology developed for the education forums and the Guide to Demonstrating CQR Impact the 12 registries were supported to develop impact statements. This activity formed part of the broader case study development process. The resulting impact statements provided registries with clear, tailored evidence of their impact.

See Appendix D for the final list of case studies and impact statements.

3.2.10 Review Of Equitable Healthcare and Outcome Reporting

Concurrent with the process of assessing impact for a CQR, an assessment was undertaken to determine whether centre registries collect information regarding access equity, in care access and outcomes for different patient cohorts. This information was collated from the environmental scan (3.2.2), informal discussions, and feedback gathered during a dedicated workshop focused on evaluating the reporting recommendations of the Framework. The assessment specifically examined:

- Equitable healthcare and outcomes for different patient cohorts, including women, people living in regional and remote areas, people with disabilities, people from socio-economically disadvantaged groups and people from diverse cultural and linguistic backgrounds, as appropriate, in line with the Strategy.

- Outcomes for Aboriginal and Torres Strait islander people, and comparisons between Indigenous and non-Indigenous Australians where possible, in line with the Strategy.

3.2.11 Development of an Assessment Tool to Measure Performance

The SAHMRI Registry Centre, in collaboration with representatives from the CQR sector, is participating in an initiative led by the Commission to develop a CQR Self-Assessment Tool. The first iteration of this model will serve as a foundational tool to assess registry performance, identify gaps, and highlight areas requiring focused effort. It will also guide registries in planning future activities and provide a strategic roadmap to support their continued development and maturation.

4. Findings and Recommendations

The following section summarises the project's findings and provides recommendations aimed at enhancing the value and impact of Australian registries.

4.1.1 CQR Sustainability

The SAHMRI Registry Centre Environmental Scan (Appendix B) revealed that 45% (n=9) of its members receive funding from more than one source. The ability to demonstrate value and impact is critical to CQR sustainability, particularly in a competitive funding and policy environment where recognition and sustained engagement from stakeholders are essential. The Framework emphasises the importance of stakeholder engagement, governance, communication, and sustainability. It discusses how failure to engage and communicate value can undermine support and funding for CQRs.[1]

There is increasing need for CQRs to seek alternative sources of funding as seen with 25% (n=5) of SAHMRI Registry Centre members relying on grant funding to support their core operations. Recent changes to grant assessment criteria specifically placed emphasis on clearly articulated impact statements which reinforces the importance of registries being able to effectively define, demonstrate and publish their impact. Failure to communicate the value and impact of registries can lead to under-recognition of their role within the health sector, limit stakeholder engagement, and ultimately affect the sustainability and relevance of the CQR sector.

Recommendation 1: Evidence of registry impact on health outcomes should be published to promote the profile and value of CQRs in Australia and support their sustainability.

For CQRs to be competitive and ensure their sustainability in a tight funding market they need to be able to demonstrate their value and impact. Publishing this evidence also helps demonstrate the contributions of registries to clinicians, policy makers, and other important stakeholders which can foster further support for the sector.

4.1.2 Limited Knowledge and Understanding of Impact and Value

This project revealed varying levels of knowledge regarding impact and consistency in how registries enable the evaluation of their outcomes and impacts. This presents an opportunity to enhance knowledge through targeted education and the development of supporting resources.

Activities undertaken early in the project to prepare case studies for the Annual Symposium clearly identified that there were varying levels of knowledge and understanding around how to identify and effectively communicate impact and value. The literature review, consultations with key experts (Research Impact Academy, Grow Impact, and AAMRI), and further feedback from the registry sector highlighted a clear gap: while numerous frameworks exist for defining and measuring research impact, they lack relevance to the unique context of CQRs, further contributing to the lack of knowledge and understanding.

Registries face a key challenge – the absence of a structured, sector-validated impact framework tailored to their context means there is not a consistent approach to impact assessment. Existing definitions (Table 1) are often research-focused, inconsistent, and not easily applicable to the diverse functions of CQRs. In addition, the complexity of choices in how impact could be reported has created further challenges for registries seeking to demonstrate their value.

Table 1. Definitions of Research Impact

Organisation	Definition
National Health and Medical Research Council (NHMRC)	The verifiable outcomes that research makes to knowledge, health, the economy and/or society and stresses that impact occurs after research is adopted or adapted for use[7].
Organisation for Economic Co-operation and Development (OECD)	The positive and negative, primary and secondary long-term effects produced by an intervention, directly or indirectly, intended or unintended.[8]
Australian Research Council (ARC)	The contribution that research makes to the economy, society, environment or culture beyond the contribution to academic research.[9]
New Zealand Ministry of Business, Innovation & Employment (NZ MBIE)	A change to the economy, society or environment beyond contribution to knowledge and skill in research organisations[10].
UK Research and Innovation (UKRI) - The Economic and Social Research Council	The demonstrable contribution that excellent research makes to society and the economy[11].
W. Kellogg Foundation Handbook	The fundamental intended or unintended change occurring in organisations, communities or systems as a result of program activities.[4]

To address this gap and equip registries with the knowledge and tools they needed to identify, measure, and communicate impact, educational workshops were developed and implemented across the sector. Pre-workshop, of the 59 respondents 39% (n=23) indicated they were slightly familiar with impact concepts followed by somewhat familiar (29%, n=17), moderately familiar (20%, n=12), and not at all familiar (12%, n=7). Feedback from the workshop showed an improvement in participants' knowledge and understanding of impact. There was a strong interest in repeated sessions to consolidate learning and a desire for practical, actionable guidance to support the consistent implementation, measurement, and monitoring of impact.

Despite these efforts, only a small proportion of the registry sector had the opportunity to participate in the educational forums, and a knowledge gap remains for the majority of the sector. To address this gap, the project undertook modification to an existing research impact framework. Elements of this adapted framework have been incorporated in the Guide to Demonstrating CQR Impact, providing a practical support tool for registries seeking to strengthen their approach to measuring and demonstrating impact. There is, however, some argument that further work could be done to make this a more specific CQR Impact Framework incorporating consistent terminology and provide guidance for identifying, measuring, and communicating impact.

Recommendation 2: To develop a fit-for-purpose impact framework developed specifically for CQRs.

A practical impact framework co-designed with the sector, will support registries measure and communicate impact that is relevant, and reflective of the real-world contributions of CQRs in ways that resonate with funders, policymakers, clinicians, and the broader health system.

4.1.3 Inconsistent Approach to Monitoring and Measuring Impact

Throughout the project, it became clear that many registries either do not have established processes for monitoring and measuring impact or apply them inconsistently. The environmental scan found that 53% (n=9) of SAHMRI Registry Centre members currently do not measure the impact of their outputs (reports), although most expressed a strong interest in learning how.

Key challenges include the absence of systems to assess the effectiveness and relevance of registry outputs, difficulty in closing the stakeholder feedback loop, and the complexity of demonstrating attribution since registry outputs are often just one of many influences on outcomes.

Without consistent monitoring and measurement practices, registries found it difficult to take the next steps to demonstrate and articulate their impact in meaningful ways.

Workshop feedback reinforced this issue and highlighted the need for practical tools to help registries evaluate the reach and effectiveness of their outputs. Being able to determine whether information reaches the right stakeholder, at the right time, in the right format, and with relevant content is central to addressing the feedback loop and demonstrating value. Until registries are able to routinely monitor and measure impact, including implementation of a feedback loop, it is not possible to determine the usefulness and clinical relevance of their reporting.

This inconsistency underscores the need for a more structured approach to evaluating the clinical relevance of registry outputs. Many registries lack the tools and frameworks to assess whether their data is being used effectively by clinicians, health service leaders, and policymakers. Addressing this gap is essential to ensuring that registry outputs are not only clinically meaningful but also actionable.

The development and adoption of the Framework provides a foundation for registries to assess and improve the relevance of their reporting. Embedding routine feedback mechanisms and engaging end-users in the design and dissemination of outputs will further enhance clinical utility.

As stated earlier, the project team developed the Guide to Demonstrating CQR Impact. The guide was refined throughout the project based on user input and experience gained from its application in a real-world setting. This ensured it was tailored to the specific needs and realities of the registry sector. As a practical, tested, and sector-informed tool, it can support registries in developing clear and compelling impact narratives, strengthening their strategic position, and contributing to improved engagement with stakeholders and decision-makers across the health system.

Recommendation 3: Delivery of an ongoing program of structured and practical education forums to increase the capability of the registry sector to monitor, measure and demonstrate their impact.

Successfully embedding practice change into daily operations requires building capability, confidence and capacity within the registry to ensure consistency. This involves equipping staff with comprehensive education, knowledge, and practical tools.

Recommendation 4: The Guide to Demonstrating CQR Impact should be adopted by registries to assist in identifying, measuring, and communicating their impact.

The use of a practical, tested, and sector-informed tool supports registries when developing clear and compelling impact narratives, strengthening their strategic position, and contributing to improved engagement with stakeholders and decision-makers across the health system. This must include implementation of a feedback loop in order to determine the usefulness and clinical relevance of their reporting.

4.1.4 Demonstrating Value and Impact

An important way to demonstrate impact is achieved through the development of impact statements and impact case studies that illustrate the breadth and depth of registry contributions to health outcomes, clinical practice, and policy.

The project found that the process of creating these outputs (16 impact statements and 13 impact case studies, Appendix D) not only produced tangible examples of registry impact but also helped to build internal capability and confidence among registry staff. Whilst it was clear there was value in this process not all registries took up the opportunity to prepare an impact case study. There were varying reasons for this, including that some registries felt they didn’t have the capacity in staff or resources, and a small number felt they were still in establishment phase and not yet ready to document impact. Registries also expressed that there were limited tools or supports to make this possible in an efficient manner that would not require additional human resources on their part.

Recommendation 5: To develop a series of dedicated tools and accompanying resources for the Guide.

The creation of practical, adaptable tools and resources will assist registries to monitor and measure their impact. These need to be aligned with the real-world needs of the sector to build capacity and support continuous improvement.

4.1.5 Vulnerable Cohorts

An opportunity exists for registries to strengthen governance and reporting frameworks to support the collection, monitoring and transparent reporting of equitable healthcare outcomes for vulnerable cohorts.

The environmental scan (Appendix B) conducted as part of this project revealed significant gaps in how registries are addressing equity in healthcare delivery and outcomes. These findings highlight a critical need for reflection and action across the sector to ensure that registry data meaningfully informs the delivery of equitable healthcare across Australia.

Among SAHMRI Registry Centre members, 85% (n=17) reported collecting Aboriginal and Torres Strait Islander identifiers. However, when asked about their capacity to respond to the needs of diverse cohorts including women, people living in regional or remote areas, people with disabilities, socio-economically disadvantaged groups, and culturally and linguistically diverse (CALD) communities only 35% (n=7) of registries indicated that they have mechanisms in place to consider the priorities of these populations in the collection, monitoring, reporting, and use of their data.

Moreover, only four (26%) registries currently produce equity-focused outcome reports: two reporting outcomes for Aboriginal and Torres Strait Islander people, and the other two addressing outcomes across broader priority population groups. This represents a missed opportunity to use registry data to assess and improve access, experience, and outcomes of care for all Australians.

These findings point to key areas for improvement across the sector, especially in strengthening the ability of registries to collect, analyse, and report equity-related data. Addressing these gaps is essential to achieving a health system that delivers fair and equitable outcomes for all, regardless of background or circumstance. The findings and analysis have been included in the 2024 SAHMRI Registry Centre Annual Report, released in March 2025 and available on the SAHMRI Registry Centre website. Both this project and the Public Reporting Project, had the same findings and recommendation in this area.

Recommendation 6: Registries should engage meaningfully with diverse consumer groups to ensure registry findings and outputs 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.

Recommendation 7: To establish sector-wide guidance and tools to assist registries to embed equity indicators into routine operations and reporting.

All registries are encouraged to review the collection of equity indicators, and the provision of vulnerable groups reports as per their purpose. Embedding these practices into routine operations supported by appropriate guidance and tools will enable registries to ensure the data that is collected is included consistently in reports on vulnerable populations.

4.1.6 Indigenous Data Governance and Sovereignty

Findings from the environmental scan revealed that while four member registries have implemented an Indigenous data sovereignty policy and have a governance structure that includes engagement with Indigenous peoples, only two registries produce a report which compares outcomes between

Indigenous and non-Indigenous Australians as per the Strategy. This highlights a significant gap in ensuring that registry processes are aligned with Indigenous data rights and the principles of Indigenous leadership, ownership, control, and accountability[12]. Without strong Indigenous-led governance and data stewardship, registries risk undermining trust and missing opportunities to produce culturally safe and meaningful insights that can support improved health outcomes for Aboriginal and Torres Strait Islander peoples.[13]

Recommendation 8: 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 Islanders, registries should review their governance structure and policies to incorporate Indigenous data sovereignty principles.[13,14] 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/. Registries may require additional support, resourcing and education to undertake this work.

4.1.7 CQR Performance Metric

Insights from the environmental scan revealed that approximately half (n=8) of member registries reported that their outputs have the greatest influence on hospital, clinic, or system-wide quality improvement (QI) programs. In relation to tracking impact, 47% (n=8) of registries monitor report downloads, and all but one registry (n=16) track at least one performance or output metric. These findings highlight the considerable variability across registries in how they monitor, evaluate, and demonstrate the utility of their outputs.

To cater for the different assessment metrics between registries, the Commission is leading the development of a self-assessment tool aligned with the Framework. This tool will provide registries with a structured approach to evaluate their performance and enhance their capabilities. Through its involvement in the development of this tool, the SAHMRI Registry Centre will inform and support its member registries, advocating for its application to assess and strengthen their own CQRs.

Recommendation 9: SAHMRI Registry Centre members should align with the 2024 Framework and use the self-assessment tool to evaluate their performance.

Together, the Framework and tool provide registries with the resources to identify areas for improvement, plan enhancements, monitor progress, and demonstrate their value and impact.

5. Discussion

The Value and Impact Project, delivered by the SAHMRI Registry Centre, has revealed several critical gaps within the CQR sector that require a flexible and responsive approach. These gaps reflect the evolving needs of registries and the increasing demand for them to demonstrate their value in a clear, consistent and meaningful way. For registries to fulfil their role effectively, they must be able to articulate their impact in ways that resonate with a broad range of stakeholders, including funders, health service leaders, clinicians, policymakers, and the wider community.

A key finding of the project was the considerable variation in how registries understand, monitor, evaluate, and communicate their outcomes. This inconsistency limits the sector's ability to demonstrate its collective value and poses risks to stakeholder engagement, funding sustainability, and policy influence. Addressing this challenge requires a sector-wide commitment to building capability through structured education, practical tools, and shared resources. The inclusion of education forums and the development of the Guide to Demonstrating CQR Impact, offers a valuable starting point for registries seeking to showcase their contributions. Additional feedback from the sector indicates a strong need for tools and resources suitable for implementation into core operations that support the routine monitoring of outputs and the measurement of impact.

Central to strengthening the sector is the need for registries to routinely publish and communicate their impacts. The SAHMRI Registry Centre worked closely with its members and finalised the release of 13 impact case studies. During the discussion with registries those who are more mature with more resources tend to have more capacity and are more likely to publish their outcomes. This is of importance as it not only enhances transparency and accountability but also supports the strategic positioning of registries within the health system. However, expansion of this across the sector cannot be achieved without further investment in building the knowledge and capability required to undertake impact assessment and communication effectively.

The absence of a fit-for-purpose impact framework was identified as a significant gap. A framework that is co-designed with the sector would provide the necessary structure, language, and guidance to support registries in identifying, measuring, and communicating their impact. Such a framework would also promote consistency across registries and ensure alignment with national expectations, ultimately contributing to the long-term sustainability of the sector.

Equity emerged as a universal priority that must be embedded into all aspects of registry operations. SAHMRI Registry Centre members indicated 85% (n=17) collect Aboriginal and Torres Strait Islander identifiers and 35% (n=7) have mechanisms in place to consider the needs of diverse populations. Moreover, only four (26%) registries currently produce equity-focused outcome reports: two reporting outcomes for Aboriginal and Torres Strait Islander people, and the other two addressing outcomes across broader priority population groups. Registries are encouraged to review and update their governance arrangements to ensure they are inclusive, ethical, and aligned with principles of Indigenous data sovereignty. This includes ensuring Aboriginal and Torres Strait Islander leadership and collaboration with relevant peak bodies. Strong governance structures are essential to supporting these efforts.

6. Conclusion

The Value and Impact Project has provided critical insights into the current state and future needs of the CQR sector in Australia. It has highlighted the importance of a flexible, responsive, and equity-informed approach to strengthening registry capability and sustainability. The findings underscore the need for registries to clearly articulate their value and impact in ways that resonate with a broad range of stakeholders.

Addressing the identified variability in knowledge, practice, and reporting requires a coordinated effort to build sector-wide capability. This includes the development of a fit-for-purpose impact framework, the adoption of practical tools and resources, and the delivery of structured education to embed good practice into routine operations. Publishing and communicating impact must become a core function of registries to ensure their continued relevance, visibility, and influence.

Equity must be embedded across all aspects of registry work from governance and data collection to reporting and stakeholder engagement. Strengthening governance structures, particularly in relation to Indigenous data sovereignty, and engaging with diverse consumer groups are essential steps toward more inclusive and impactful registry practices.

Finally, continued alignment with national initiatives, such as the CQR maturity model and self-assessment tool, will support a more consistent, innovative, and sustainable registry sector. The SAHMRI Registry Centre remains committed to supporting these efforts and fostering a collaborative environment in which registries can thrive and contribute meaningfully to healthcare improvement across Australia.

7. Appendices

Appendix A – Environmental scan (survey): focus, questions and respondents

Impact

Focus

- Whether or not registries measure the impact of their outputs.
- What measures registries have to indicate reports are being reviewed.
- The areas where registry outputs have informed, changed or provided support.
- The communication methods registries used to share their impact.

Questions

Table 2. Survey questions - Impact

Question	Response option
Does your registry measure the impact of its output? If no, is your registry interested in learning more about how it can measure its impact?	Yes | No Yes | No
What measures does your registry have to indicate the reports are being reviewed? *(more than one may apply)*	Download metrics | Increase in ad hoc requests following the release of routine reports | Request from recipient for clarification or further information | None, the registry does not measure this |Other (specify)
Please select all options where registry outputs have informed, changed or supported any of the following: *(more than one may apply)* *Strategy Pillar 2 (Priority 9)*	Hospital/clinic or system-wide QI programs | Shared patient-clinical decision making in the hospital/clinic setting | Hospital/clinic or system-wide policy | Integrated into government data systems e.g. AIHW, jurisdictional datasets | Enhanced skills, expertise or infrastructure | Reduced healthcare costs | Improved efficiencies of health services | Improved access to healthcare services | Improved health literacy among the community | Improved social determinants of health | Improved social equity, inclusion, or cohesion | Community empowerment and participation in health decision making | Influenced healthcare practitioner choice | None | Other (specify)
Please select all communication methods your registry uses to share its impact. *(more than one may apply)*	Case studies/stories | Testimonials | Interactive web content | Podcasts | Infographics | Reports | Social media |Publications | None | Other (specify)

Reporting On Equitable Healthcare and Outcomes

Focus

- Whether or not registries collect variables which would inform equitable reports.
- Determine if mechanisms, structures and policies exist to support collection of data and reporting of outcomes in different cohort groups.

Questions

Table 3. Survey questions - Reporting on equitable healthcare and outcomes

Question	Response option
Does your registry collect Aboriginal and Torres Strait Islander identifiers? Strategy Pillar 5 (Priority 21)	Yes | No
Does your registry have in place an Indigenous Data Sovereignty policy in line with this statement? *Indigenous Data Sovereignty refers to the right of Indigenous peoples to exercise ownership over Indigenous data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous data[12].*	Yes | No | NA
Does your registry have a governance structure which includes engagement with Indigenous peoples to determine how Indigenous data is collected, accessed and used? *Indigenous Data Governance refers to the right of Indigenous peoples to autonomously decide what, how and why Indigenous data are collected, accessed and used. It ensures that data on or about Indigenous peoples reflects our priorities, values, cultures, worldviews and diversity[12].*	Yes | No
Are there mechanisms in place to ensure the priorities of women, regional/remote, people with a disability, socio-economically disadvantaged groups and culturally and linguistic diverse communities are considered in the collection, monitoring, reporting and use of the data? Strategy Pillar 1 (Priority 3)	Yes | No | NA
Please select the types of analyses provided in your reports **1.** Equitable healthcare outcome report for Aboriginal and Torres Strait Islander people **2.** Equitable healthcare outcome report for different cohorts (women, regional/remote, disabilities, socio-economically disadvantaged groups, diverse cultural and linguistic backgrounds)	Yes | No

Appendix B – Environmental scan (survey): results

SAHMRI Member Characteristics

Table 4. SAHMRI Registry Centre Member geographic coverage

Geographical coverage	Results (N, %)
National (only)	6, 30%
Australia and New Zealand	10, 50%
South Australia (only)	4, 20%

Table 5. SAHMRI Registry Centre Member funding sources

Funding	Results (N, %)
Commonwealth DHAC	6, 30%
State-based	4, 20%
Grant	5, 25%
Local Health Service	2, 10%
Participating Sites	2, 10%
Other • Aged care industry partners • Australian Organ and Tissue Donation Authority (DonateLife) • NZ Te Whatu Ora (Health Ministry) • Kidney Health Australia • ANZSN • Organ and Tissue Authority • Supported by an unrestricted grant from Pharma • Charitable funding, Hospital research foundation, Movember • Paid membership body i.e. BreastSurgANZ, Urological society (SA)	10, 50%

Table 6. SAHMRI Registry Centre Member major stakeholders

Major stakeholders	Results (N, %)
Contributing Clinicians	20, 100%
Consumers	13, 65%
General community	12, 60%
Researchers	12, 60%
Heads of Units (hospital)	11, 55%
Hospital Executive	8, 40%
Hospital Clinical Governance	8, 40%
Regulatory bodies (HREC, TGA)	6, 30%
Policy makers	5, 25%
Peak bodies	5, 25%
Clinical colleges	4, 20%
Other (Clinical/Professional Societies/Bodies, Aged care sector)	4, 20%
Industry (manufacturers)	2, 10%

**Multiple responses were permitted for this question therefore column percentages do not add up to 100.*

Impact

Respondents

Table 7. Registries that responded to survey questions, and their acronyms

Organisation	Definition
National Health and Medical Research Council (NHMRC)	The verifiable outcomes that research makes to knowledge, health, the economy and/or society and stresses that impact occurs after research is adopted or adapted for use[7].
Organisation for Economic Co-operation and Development (OECD)	The positive and negative, primary and secondary long-term effects produced by an intervention, directly or indirectly, intended or unintended.[8]
Australian Research Council (ARC)	The contribution that research makes to the economy, society, environment or culture beyond the contribution to academic research.[9]
New Zealand Ministry of Business, Innovation & Employment (NZ MBIE)	A change to the economy, society or environment beyond contribution to knowledge and skill in research organisations[10].
UK Research and Innovation (UKRI) - The Economic and Social Research Council	The demonstrable contribution that excellent research makes to society and the economy[11].
W. Kellogg Foundation Handbook	The fundamental intended or unintended change occurring in organisations, communities or systems as a result of program activities.[4]

Results

Member registries were asked to:

1. Indicate if they currently measure the impact of the outputs that they produce.

Table 8. Do registries measure impact

Currently measure impacts	Results (N, %)
Registries which measure the impact of their outputs	8, 47%
Registries which don't measure impact but would like to learn more	9, 100%

2. Provide examples of where their outputs have informed, changed or supported improvements in clinical practice and patient outcomes.

Table 9. Examples of where outputs have informed, affected, changed or provided support

Areas of impact*	Results (N, %)
Hospital/clinic or system-wide Quality Improvement programs	8, 50%
Hospital/clinic or system-wide policy	6, 38%
Shared patient-clinical decision making in the hospital/clinic setting	5, 31%
Enhanced skills, expertise or infrastructure	5, 31%
Improved efficiencies of health services	5, 31%
Improved health literacy among the community	4, 25%
Community empowerment and participation in health decision making	4, 25%
Influenced healthcare practitioner choice	4, 25%
Integrated into government data systems e.g. AIHW, jurisdictional datasets	3, 19%
Improved social equity, inclusion, or cohesion	3, 19%
Improved access to healthcare services	2, 13%
Reduced healthcare costs	2, 13%
Improved social determinants of health	1, 6%

3. Identify how they know their reports are being reviewed

Table 10. Metrics used to measure the review of reports

Output review metrics*	Results (N, %)
Download metrics	8, 47%
Request from recipient for clarification or further information	7, 41%
Increase in ad hoc requests following the release of routine reports	6, 35%
Other • Incidence of clinical management issues over time • Mortality rates over time. • Survey of report recipients for feedback. • HREC confirm receipt of report. • Open report rate only • Number of commissioned reports yearly • Tracking of the number of annual requests for individualised Outcome Monitoring System reports among South Australian aged care providers (residential and home care package providers).	6, 35%

**Multiple responses were permitted for this question therefore column percentages do not add up to 100.*

4. Indicate what methods the registry uses to communicate impact

Table 11. Communication methods used by registries to demonstrate value and impact

Communication methods*	Results (N, %)
Reports	14, 78%
Publications	14, 78%
Infographics	5, 28%
Social media	5, 28%
Other - presentation	2, 22%
Case studies/stories	3, 17%
Testimonials	1, 6%
Interactive web content	1, 6%
Podcasts	0, 0%

**Multiple responses were permitted for this question therefore column percentages do not add up to 100.*

Reporting On Equitable Healthcare and Outcomes

Respondents

Table 12. Registries that responded to questions related to collection and reporting of equitable healthcare and outcomes

Registry Name (Acronym)
Australian Corneal Graft Registry (ACGR)
Australian and New Zealand Audit of Surgical Mortality (ANZASM)
Australia and New Zealand Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI)
Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)
Australia and New Zealand Eye & Tissue Donation Registry (ANZETD)
Australia and New Zealand Living Kidney Donation Registry (ANZLKD)
Australia and New Zealand Organ Donor Registry (ANZOD)
Australian and New Zealand Heart Transplant Registry (ANZHTR)*
Australian and New Zealand Lung Transplant Registry (ANZLUNG)*
Australia and New Zealand Registry of Advanced Glaucoma (ANZRAG)
Australian and New Zealand Vasculitis Quality and Disease Registry (ANZVASC-QDR)*
Australasian Registry of ECGs of National Athletes (ARENA)*
Australian Particle Therapy Clinical Quality Registry (ASPIRE)
BreastSurgAnz Quality Audit (BQA)
Kidney Health Registry
Registry of Senior Australians (ROSA)
South Australian Birth Defects Register (SABDR)
South Australian Cerebral Palsy Register (SACPR)
South Australian Prostate Cancer Clinical Outcomes Collaboration (SA-PCCOC)
Transcatheter Aortic Valve Implantation Registry (TAVI)

**Did not provide a response to question 3 – registry in early establishment phase*

Results

Member registries were asked to indicate if they:

1. Collect Aboriginal and Torres Strait Islander identifiers and have in place Indigenous data sovereignty and governance.

Table 13. Identifiers, policy and governance - Aboriginal and Torres Strait Islander peoples

Identifiers, policy and governance structure	Results (N, %)
Collect Aboriginal and Torres Strait Islander identifiers	17, 85%
Indigenous data sovereignty policy	4, 20%
Governance structure which includes engagement with Indigenous peoples to determine how Indigenous data is collected, accessed and used	4, 20%

2. Have mechanisms in place to collect, monitor and report on the priorities of women, regional/remote, people with a disability, socio-economically disadvantaged groups, diverse culturally and linguistic diverse communities.

Table 14. Mechanisms in place to collect, monitor and report on different cohorts

Mechanisms different cohorts	Results (N, %)
Collect, monitor and report using existing mechanisms for different cohort groups	7, 35%

3. Report on equitable healthcare and outcomes

Table 15. Equitable healthcare outcomes included in reports

Reporting	Results (N, %)
Aboriginal and Torres Strait Islander people	4, 20%
Different cohorts (women, regional/remote, disabilities, socio-economically disadvantaged groups, diverse cultural and linguistic backgrounds)	4, 20%

**16 member registries provided a response to this question*

Appendix C – 2024 Symposium abstracts

Table 16. Registry abstracts presented at the 2024 Annual Symposium

2024 Symposium Abstracts	
Registry Name	Presentation Title
Australian and New Zealand Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI)	Using near-time quality improvement to change emergency laparotomy care in Australia
Australian Particle Therapy Clinical Quality Registry (ASPIRE)	Developing the Australian Particle Therapy Clinical Quality Registry – ASPIRE, learnings from one registry to another
Australian Corneal Graft Registry (ACGR)	The evolving treatment of keratoconus
Australia & New Zealand Dialysis & Transplant Registry (ANZDATA)	BEST-Fluids for better outcomes[14].
The Registry of Senior Australians (ROSA)	Impact on Knowledge and Policy to Monitor and Improve Aged Care Quality
South Australia Prostate Cancer Clinical Outcomes Collaboration (SA-PCCOC)	Reporting Real -World Data on Prostate Cancer Treatment Outcomes for Consumers: The Prostate Cancer Report Card
Coronary Angiogram Database of South Australia (CADOSA)	The Personalising Acute Myocardial Infarction Care to improve Outcomes (PAMICO) Project
Australia & New Zealand Dialysis & Transplant Registry (ANZDATA)	Using Registry data to drive change: access to transplantation for Aboriginal and Torres Strait Islander people.

Appendix D – Final case studies and impact statements

Table 17. List of cases studies and impact statements

Impact case studies and statements		
Registry name	Case study title	Impact statement title
Australian Corneal Graft Registry (ACGR)	Harnessing Long-Term **ACGR** Data to Secure Medicare Support for Corneal Collagen Cross-Linking for Keratoconus	Leveraging long-term **ACGR** Data to secure Medicare support for Corneal Collagen Cross-Linking for Keratoconus
Australian and New Zealand Audit of Surgical Mortality (ANZASM)		Developing a tool to identify non-technical errors in surgical care using **ANZASM**
Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)	1. The BEST-Fluids Trial: An **ANZDATA** registry-based trial to optimise transplant fluid selection 2. Improving Access and Waitlisting for Kidney Transplantation through the **National Indigenous Kidney Transplantation Taskforce (NIKTT)**	
Australia and New Zealand Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI)	Driving practice change to improve preoperative risk assessment compliance in emergency laparotomy: The **ANZELA–QI** impact at Midland and Bunbury Hospitals	
Australia and New Zealand Organ Donor Registry (ANZOD)	Improving utility and equity of kidney allocation by harnessing ANZOD and ANZDATA	
Australasian Registry of ECGs of National Athletes (ARENA)	The role of **ARENA** in enhancing sports cardiology guidelines	
Australian Particle Therapy Clinical Quality Registry (ASPIRE)	**ASPIRE**'s Role in Building Capacity and Fostering Effective Partnerships with Nursing Staff	
Coronary Angiogram Database of South Australia (CADOSA) Registry	1. Integrating **CADOSA** activity into routine clinical practice 2. **CADOSA** supports future workforce capacity through student development	
Dental Implant Registry (DIR)	Streamlining dental implant procedures with the **DIR**	
Australian Postural Orthostatic Tachycardia Syndrome Registry (Oz-POTS)	**Oz-POTS** registry advocates for an International Classification of Diseases (ICD) code in Australia	
Registry of Senior Australians (ROSA)	Leveraging Existing Data to Generate Evidence and Inform National Aged Care Policy and Reforms: **The Registry of Senior Australians (ROSA)**	1. Expansion of the Quality Indicator Program and **ROSA's** role in aged care reform 2. Leveraging the **ROSA** to address overuse of antipsychotics in aged care 3. Identifying the risks associated with long wait times through the **ROSA** to promote timely access to home care
South Australian Birth Defects Register (SABDR)	A linkage study using **SABDR** data and its application in shaping South Australian clinical practice	

Appendix E – Education forum evaluation

Results

Before and after the workshop, participants were surveyed and asked to indicate how familiar they were with the concept of impact. 79 participants attended the three workshops. We received a 75% (n=59) response rate to the pre workshop survey and 58% (n=46) response rate to the post workshop survey.

Table 18 shows the level of familiarity with impact prior to the workshop.

Table 18. Participant levels of familiarity with impact prior to the workshop

Number of responses	***Extremely familiar***	***Moderately familiar***	***Somewhat familiar***	***Slightly familiar***	***Not at all familiar***
N= 59	0, 0%	12, 20%	17, 29%	23, 39%	7, 12%

Following the workshop, 46 participants reported the following average confidence ratings:

- 7 out of 10 for identifying the types of impact
- 7 out of 10 for identifying indicators of early, intermediate and long-term impacts
- 7 out of 10 for communicating the impact of the registries' outputs and activities

Direct Quotes

Workshop attendees provided positive feedback, noting:

- The content was very relevant for my upcoming Investigator Grant application
- I will be amending the wording on my grant application following the workshop
- Clear framework and real-world examples
- Registry relevance
- Very interactive and well presented. The examples helped a lot with understanding the concepts.
- Very clear information and I found the terminology very helpful.

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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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