CQR Advisory Service Pilot Project Report

Cindy Turner and Tamara Hooper

JUNE 2025

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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Executive Summary

Clinical Quality Registries are pioneering the use of health data to drive essential improvements in safety, effectiveness, and appropriateness of care nationally.

Designed to address the growing need for centralised and consistent expert support for CQRs across Australia, the Clinical Quality Registries Advisory Service Pilot (Advisory Service) tested an advisory model aligned with the Australian Framework for National Clinical Quality Registries 2024 (the Framework) from January 2024 to June 2025.

Over a period of 18 months, the SAHMRI Registry Centre project team provided tailored support for the development and enhancement of registries through multiple channels, including email, phone, online, printable resources and face-to-face delivery.

Key deliverables included advice for incoming queries, development of preliminary advisory resources for registries, connecting requestors to existing resources and networks within the sector, testing predetermined access eligibility criteria, refining support mechanisms, tracking service use, and consulting with stakeholders to inform evaluation of the service and future recommendations.

The Pilot confirmed there is strong sector demand for these support services and demonstrated the value of a National CQR Advisory Service to advance health outcomes.

Key findings

- Participants confirmed the value of a centralised national CQR advisory service that provided support and resources and connected enquirers to the sector.
- Such a model has potential to reduce the burden on individual registries throughout Australia and improve the quality and consistency of advice and support provided to researchers, clinicians, policy makers.
- This approach would ultimately enhance CQR's productivity and assisting them in achieving better patient outcomes across the health system.
- Reflecting diversity within the sector and variation in needs, a service which delivers individualised responses would be most effective.
- With the establishment of a formal governance structure and appropriate resourcing the Pilot could be transitioned to a sustainable national service.

Recommendations

Based on the findings of this project, the Registry Centre proposes the following:

Recommendation 1: A National CQR Advisory Service should be implemented to ensure consistency of advice and support provided to a growing CQR sector.

In 2023 there were 106 clinical registries registered on the Australian Register of Clinical Registries. By 2025 this had increased to 133. An Advisory Service would ensure consistency of advice and support to newly established and existing registries.

Recommendation 2: The Service should develop and manage a centralised web-based information resource.

A sector managed web-based resource would provide consistent information and support for registries and those planning to establish a registry. In addition to hosting resources, the service could also communicate education, recruitment and employment opportunities.

Recommendation 3: A formal governance structure for the National CQR Advisory Service should include broad sector representation.

To support the Advisory Service, a formal governance structure should include an Advisory Group with broad representation of required expertise, and a series of expert working groups to advise on resource development.

Recommendation 4: To establish a monitoring and reporting system for the National CQR Advisory Service, that includes a classification matrix of services provided.

Classifying requests will facilitate the analysis and reporting of the service delivered and enable prioritisation of resources for higher demand areas, tailored responses for commonly sought after areas, improve overall resource planning and ensure the service is efficient, scalable and feasible.

Recommendation 5: To implement a request management system to support the National CQR Advisory Service.

A robust request platform will enhance efficiency, assisting with tracking and automated reporting, and provide feedback for ongoing quality improvement.

Recommendation 6: To implement a National CQR Advisory Service communication plan.

The Advisory Service should develop a proactive and targeted communication strategy to maximise engagement and increase visibility, which incorporates digital campaigns, social media outreach, and direct engagement with emerging and existing CQRs.

Recommendation 7: To develop an automated National CQR Advisory Service evaluation system.

The integration of an automatic satisfaction survey into the request management system, which could be sent upon request closure, with reminders and incentives would encourage participation in the feedback loop and inform service improvement.

1. Introduction

The SAHMRI Registry Centre, with funding from the Department of Health, Disability and Ageing (the Department), piloted a national CQR Advisory Service (the Advisory Service) from January 2024 to June 2025. Aligned with the Australian Framework for National CQRs 2024 (the Framework)[1], the Advisory Service provided expert, centralised support to clinicians, researchers and registry teams.

The SAHMRI Registry Centre collaborated with the CQR sector to ensure the Advisory Service supported the work of the National CQR Communication and Collaboration Hub (a collaboration between Monash University, the SAHMRI Registry Centre and the Australian Clinical Trials Alliance).

This report outlines the Pilot's methodology, lessons learned, key challenges, and resulting recommendations to inform the development of a sustainable nationally coordinated CQR Advisory Service.

Goal

To pilot a CQR Advisory Service that leverages the expertise currently within the SAHMRI Registry Centre and tests the viability of transforming this function into an ongoing, sustainable service.

Objectives

1. Develop and test eligibility criteria for access to the CQR Advisory Service
2. Develop and test the mechanisms for delivery of support provided to Registries
3. Monitor and report use of the CQR Advisory Service
4. Coordinate efforts with Monash University and the work of the CQR Communication and Collaboration Hub.

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 interests and capability, and a growing need for interoperability across national systems and data assets. 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 National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030 (the Strategy)[2] and the Australian Commission on Safety and Quality in Health Care, Australian Framework for National Clinical Quality Registries 2024 (the Framework) set the scene for development of Australia's CQRs to a high standard. The release of these documents was accompanied by a funding commitment from the Department of Health, Disability and Ageing to support the National CQR Program in development of the sector and support the implementation of the Framework.

CQRs collect, analyse, and report data to drive improvements in patient care and health outcomes. While the number of CQRs in Australia continues to grow[3], with more than 130 established and emerging CQRs on the Australian Register of Clinical Registries, there is currently limited in-person coordinated national assistance available to those seeking guidance in establishing or expanding their CQRs. As a result, requests for advice on government recommendations, best practices, and shared leanings are often informal, bottom-up, and potentially inefficient. This ad hoc approach places a burden on a small group of frequently consulted experts, risks duplication and can result in inconsistent guidance shaped by personal experience rather than standardised processes and protocols[4].

The South Australian Health and Medical Research Institute (SAHMRI) Registry Centre, a centre of excellence for registries and registry science, was established in 2018. Its mission is to bring together the registry science and operational expertise available among our community, to strengthen the Institute's existing role in the registry space and expand our research capacity and training in this area.

The SAHMRI Registry Centre is a rapidly growing collaboration, consisting of 27 member registries as of 2025. Commencing with mostly South Australian based CQRs, it has expanded to include several major national/bi-national registries, from across the country. Twelve of these are based within SAHMRI.

The purpose of the SAHMRI Registry Centre is to provide a platform to enhance the enormous value of registry data, supporting the utilisation of other important data sources such trials, surveys, biobank data, administrative data sets, and information systems, through data linkage and research collaborations. For further information about the SAHMRI Registry Centre, see SAHMRI | SAHMRI Registry Centre.

The CQR Advisory Pilot aligns with the key goals of the SAHMRI Registry Centre, which include to:

- Provide the best resources for registry building capacity
- Lead registry science through collaborative opportunities for our scientists
- Develop strong international and industry collaborations
- Continue to support a shared learning environment
- Be a leading national and international registry centre.

3. Project Activities

3.1 Planning

3.1.1 Establish Project Governance

The SAHMRI Registry Centre managed the delivery of the Pilot through a project 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, 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 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 Advisory Service project team included the Strategic Director, Project Manager and Project Officer. A 0.5 full time equivalent role was committed to this activity during the 18 month pilot.

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 were undertaken in parallel to each other during the activation of the Advisory Service. These activities included delivery of support, request management, communication strategy, an environmental scan survey, a narrative review, development of resources and design for the evaluation survey including dissemination and analysis of the evaluation survey findings.

3.2.1 SAHMRI Registry Centre Environmental Scan

In May 2024, to help inform the design and development of the advisory service an environmental scan survey was developed and distributed to SAHMRI Registry Centre members to assess their support needs and advice seeking preferences, with 20 member registries responding. The results (Appendix 1) highlighted the need for a centralised advisory service and provided valuable insights that informed resource development.

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 Narrative Review

In October 2024, a narrative review was conducted to identify existing advisory service models across various sectors, including non-health related areas, such as agriculture, information technology, business, and public policy. A systematic search was performed using academic databases (i.e., PubMed Scopus, and Google Scholar) for publications describing advisory service models. The review provided insights into other advisory services' learnings, including personalisation, scalability, and sustainability, offering a strong foundation for the current project.

We determined that there is consistent evidence that the success of advisory services is driven by both macro-level (systemic) and micro-level (individual interaction) factors. Key elements of success include providing timely individual support, ensuring strong communication, and leveraging technology to ensure advice is both accessible and impactful[5].

We found that the incorporation of classification criteria and the service satisfaction feedback respectively enhanced efficient resource allocation and service improvement. Support categories such as request complexity or the level of service user involvement in decision-making could further refine the service's approach to stratification[6].

Whilst these findings are drawn primarily from non-healthcare sectors, they offer valuable underpinning principles for the design and implementation of advisory services generally. The insights gained from the narrative review informed the design of individualised support tailored to the needs of the CQR sector.

3.2.3 Service Promotion

Between January 2024 and June 2024, the Advisory Service was introduced in a passive manner with low key promotion of the services in order to assess sector demand, manage request volume and allow time for establishment of the service. Promotion in the early stages was limited to the Benchmark quarterly newsletter published by the National CQR Communication and Collaboration Hub, Australian Clinical Trials Alliance (ACTA) meetings and webinars (three/year). Fourteen requests were received the initial six month period (January 2024 to June 2024).

As the Advisory Service matured in the second half of 2024 promotional activity slowly increased. Broader awareness was achieved through the ACTA Annual CQR Symposium in December 2024, SAHMRI Registry Centre workshops in 2024 and 2025, the SAHMRI Registry Centre Annual Symposium in March 2025 and word-of-mouth. Even with greater promotion the requests remained consistent and were manageable by the project team who had capacity to answer more requests if required; 27 requests were received between July 2024 and June 2025.

3.2.4 Develop and Test Advisory Service Eligibility Criteria

Eligibility criteria were predetermined during the planning stage to define access to the Advisory Service as outlined in Table 1. The service was implemented with these criteria unchanged from the original project proposal with the expectation that they would be refined and tested throughout the Pilot. The criteria were included in the request monitoring spreadsheet and all requests were allocated against a criterium between services level 1 and 4.

Table 1 Service level eligibility criteria

Service Level 1: Considering Establishing a Registry

• General requests from individuals or organisations considering establishing a CQR, assistance to determine if a CQR is an appropriate tool for their activities, research questions, area.
  • All requestors will be eligible for a one-off consultation session on request – provision of CQR Assessment Checklist tool (to be developed)

Service Level 2: Establishing a New Registry

• Advice and tools to assist establishment of a new CQR
  • Only eligible after completion of the CQR Assessment Checklist has determined that a registry is an appropriate response
  • Provision of high-level step by step guide (to be developed)

Service Level 3: Existing Registry

• Advice and support re further development of existing registries seeking to move their registry closer to meeting the Framework
  • Eligible if registered on the Australian Register of Clinical Registries
  • High level assessment of infrastructure in place e.g., critical policies, standard operating procedures and reporting
  • Advice regarding critical gaps in current practices.

Service Level 4: Advancement of Existing Registry

• Advice and guidance for CQRs seeking to undertake more advanced activities such as strategic planning, registry nested trials, data linkage studies, international collaborations and comparisons, and audit reviews.
  • Eligible if registered on the Australian Commission's Register of Clinical Registries and in receipt of Commonwealth Government Funding.

3.2.5 Develop and Test Support Delivery Mechanisms

Advisory Service requests were received via the SAHMRI Registry Centre's email (registrycentre@sahmri.com) to the Strategic Director, and/or by phone or face to face. Each request was reviewed by either the Strategic Director or the Senior Project Manager, triaged and delivered by the project team via a range of mechanisms, often progressing through:

- Initial contact
- Phone or email response
- Online or face-to-face meetings (discussion/information sharing)
- Presentations
- Assistance with funding awareness, application/grants
- Document preparation assistance
- Provision of printed resources
- Network/sector connection
- Referral

Support provided ranged from tailored advice and resources to escalation for specialist input. Support was matched to the registry's maturity and request topic. The mechanism of support delivery and time required were recorded. Additionally, requestors were often connected into the CQR sector, through the inclusion to mailing lists, invitations to educational opportunities such as the SAHMRI workshops and ACTA CQR Special Interest Group.

3.2.6 Monitor and Report Use of the Service

A Microsoft Excel spreadsheet was used to log requests, capturing key encounter details such as date, contact information, and actions taken. This allowed for follow-up, monitoring of recurring issues, and insights to inform ongoing service improvements.

While a basic tracking process was employed for the purpose of this Pilot, a more tailored and efficient process is recommended for an ongoing Advisory Service.

3.2.7 Best Practice and Registry Support Tools

Throughout the Pilot, a selection of best practice tools was developed to address the needs arising from requests. These resources were shared following or during the online or face to face meetings with requestors. For example, an explanatory presentation preceded the provision of a fact sheet to ensure a good understanding of the importance of the earlier steps such as developing and articulating an agreed purpose for the registry, and the importance of stakeholder engagement. Regular reviews with refinements and updates as required took place to ensure the resources were current and relevant. These resources included:

- 10 Steps – Fact Sheet
- 10 Steps - Presentation
- 10 Steps - Video Presentation
- CQR Cost Drivers
- Feasibility Checklist
- Protocol Template
- In addition, a preliminary set of Standard Operating Procedure (SOP) and Policy templates were produced to share with requestors. These templates require further refinement for future use.

The Advisory Service Pilot resources are supported by complementary resources created through other SAHMRI Registry Centre of Excellence projects such as 'A Guide to Demonstrating CQR Impact', 'CQR Framework Assessment Tool: Reporting' and the 'Impact Case Studies from SAHMRI Registry Centre Member Registries' in addition to existing sector resources.

3.2.8 Satisfaction Survey

In October 2024, a follow-up survey was distributed to 23 users of the Advisory Service. After two follow ups, eight responses were received. The results (Appendix 2) provide insights for process improvement. Specifically, it confirmed that 75% of users thought the service model helped them build skills and knowledge for future use and decision making and 50% found the advice actionable. This feedback also included suggestions that more specific actionable advice could be provided and one that the advice was too high level.

A subsequent follow-up survey has not been undertaken. If an ongoing advisory service were to be established, a regular automated follow-up survey is recommended for all requestors to inform a cycle of continuous improvement to the service.

3.2.9 CQR Sector Consultation

In February 2025, the SAHMRI Registry Centre engaged 20 CQR stakeholders (65% registry managers, 35% other sector experts) from 11 organisations, representing 21 registries from across Australia for a consultation session (Appendix 3). Insights from the consultation contributed to the development of recommendations for a National CQR Advisory Service (see Recommendations).

There was general agreement during the consultation that a centralised easily accessible location for the provision of information and resources was required. The consultation also examined the perceived benefits and limitations of dissemination pathways options for the Advisory Service. Specifically, to ensure resources are broadly available to all users, our stakeholder consultation has identified that:

- Existing pathways for provision of online resources should be utilised and barriers to access (e.g., limited site access or membership requirements) addressed
- New pathways (e.g., sector specific platforms or sites) should be developed and implemented
- A centralised platform for online resources could be explored in future Advisory Service operations. Options for its hosting could include:
    - The Department National CQR Platform website
    - SAHMRI Registry Centre website
    - Individual registry websites
    - A CQR peak body website

The CQR Communication and Collaboration Hub (National CQR Program funded project) was also discussed as a potential resource manager.

3.2.10 Analysis of CQR Advisory Service Pilot Encounters

An analysis was undertaken of Advisory Service encounters to determine the number and type of requests, where the requests came from, and what level and type of resources were provided by the Advisory Service. For extended results of this analysis are in Appendix 4.

4. Findings and Recommendations

4.1 Feedback

4.1.1 Environmental Scan

The environmental scan of the SAHMRI Registry Centre members (Appendix 1) indicated that:

- 5% (N=15) of the 20 respondents received external requests for advice: most seeking peer, academic, or online guidance. Individualised advice was the top support preference.
- 30% (N=6) of the 20 respondents lacked key policy documents (e.g., grant templates, ethics procedures).
- All (N=20) of the 20 respondents nominated the SAHMRI Registry Centre website for centralised resource hosting.

4.1.2 Service Satisfaction Survey

Those who received a service prior October 2024 were asked to complete a follow-up survey (Appendix 2). The survey was done in the 9th month of the project, and the response rate was 35%. This survey was not repeated. While the feedback from the survey data was limited it identified areas for improvement and could be valuable if repeated in future iterations of the Pilot Advisory Service.

- 88% (N=7) of the 8 respondents found the service useful and would use it again.
- 75% (N=6) of the 8 respondents were satisfied with the response times and felt it supported skill or knowledge development.
- 63% (N=5) of the 8 respondents were satisfied with the service.
- 50% (N=4) of the 8 respondents said the advice was directly actionable for their goals.

4.1.3 CQR Sector Consultation

Of the 20 CQR stakeholders who participated in the sector consultation 85% (N=17) supported development of a National CQR Advisory Service.

Respondents suggested that a National CQR Advisory Service: ‘fosters community and collaboration and standardisation’.

Of the 20 CQR stakeholders, 65% (N=13) had between 1 and 5 requests for information or support from outside of their organisation each month, with one experiencing between 6 and 10 requests per month and one between 11 and 15, only 5 of the participants did not regularly respond to external requests. Several participants suggested that a National CQR Advisory Service would be helpful at any point along the life cycle of registries.

Participants also expressed their willingness to contribute going forward.

> Sector consultation participant:
>
> ‘We are all so busy with our own deliverables but I’m sure most, if not all of us, would love to see more CQRs established and would happily provide support where we could, to grow the sector. Having a service would give us a unified voice and greater visibility’.

Participants reported that a National Advisory Service would benefit all registries in Australia to work more cohesively and efficiently. They also suggested that the Advisory Service is essential to disseminating knowledge about CQR processes and procedures, updates to CQR frameworks and goals, as well as potentially being an intermediary between CQRs and Government.

- 65% (N=13) out of 20 participants generally receive 1-5 requests per month.
- 85% (N=17) out of 20 participants supported a National Advisory Service.
- 88% (N=14) out of 20 participants indicated a strong interest in future engagement.

The sector consultation participants were also asked what they thought was the best online mechanism for providing access to information and resources. There was a mixture of responses from the group although the Commonwealth CQR webpage featured in 17 of the 18 responses:

- 21% (N=6) of the 28 participants indicated a Commonwealth CQR webpage only
- 21% (N=6) indicated a combination of new CQR Sector webpage, the Commonwealth CQR webpage, ACTA, or independent entity
- 14% (N=4) indicated either a new CQR Sector page or the Commonwealth CQR webpage
- 7% (N=2) Independent entity or using all interested bodies agreed to by the sector

In conclusion, our environmental scan, narrative review, service feedback survey and CQR sector consultation indicated an individualised consistent source of CQR advice, support and resources was valuable and needed. Whilst it was clear that a centralised web-based repository with resources, inclusive of communication of education opportunities, recruitment and employment as well as hosting resources, was considered valuable, it was less clear where this should be hosted. There was strong support from the sector for use of the Department’s webpage, but a sector managed web-based repository could also be viable.

Recommendation 1: A National CQR Advisory Service should be implemented to ensure consistency of advice and support provided to a CQR growing sector.

In 2023 there were 106 clinical registries registered on the Australian Register of Clinical Registries. By 2025 this had increased to 133. An Advisory Service would ensure consistency of advice and support to newly established and existing registries.

Recommendation 2: A centralised web-based resource should be developed and managed by the National CQR Advisory Service for the provision of information and resources for registries and those planning to establish a registry.

A sector managed centralised web-based resource or service that supports communication of education opportunities, recruitment and employment as well as hosting resources is considered worthy of further exploration.

4.2 Governance

The Advisory Service Pilot governance was SAHMRI based. However, for future planning, participating stakeholders were asked how such service could achieve maximum accessibility and inclusivity. The consensus was that an overarching National Advisory Group is required, and that membership should include individuals with a mix of expertise, backgrounds, and affiliations. Broad representation within an Advisory Group would help mitigate potential conflicts of interest, particularly if a National CQR Advisory Service continues to be hosted within one centre. It was also suggested that this Advisory Group should provide operational and strategic advice and facilitate the dissemination of the Advisory Services activities.

The consultation also suggested the establishment of an expert pool to support the Advisory Service. The majority (83%) of those consulted suggested they would be interested in participating in this expert pool. Such an expert pool could be employed in several of the Advisory Services activities, including resource development, mentorship programs, and future piloting activities.

The proposed governance model is provided in Appendix 5.

Recommendation 3: A formal governance structure for the National CQR Advisory Service should include broad sector representation.

To support the Advisory Service, a formal governance structure should include an Advisory Group with broad representation of required expertise, and a series of expert working groups to advise on resource development.

4.3 Access Eligibility Criteria

The initial access eligibility criteria (Appendix 6) for the Advisory Service was designed to support and manage referral volume. When used to categorise the type of request they unintentionally caused confusion as the level of eligibility did not always match the type of request i.e. a mature high functioning registry could still make a request regarding funding sustainability; whether a registry was recorded on the Australian Register of Clinical Registries was not applied as a requirement for access to the service.

Sector experts engaged through the consultation endorsed a more flexible classification matrix rather than criteria to determine access eligibility (Appendix 7). It was hoped that this new approach would provide better information about the nature and type of requests and enable tailored responses, improve resource planning, and facilitate targeted solutions into the future. It is expected that the matrix will continue to be refined as the service evolves.

To test the usability of the Classification Matrix it was retrospectively applied to the requests already received.

The classification matrix was based on three levels of registry maturity and eight support themes. When applied it became evident that an additional level was required for where there was no current registry in place i.e. the request was about consideration of establishing a registry.

The support themes suggested registry maturity levels are combined in the Request Classification Matrix in Appendix 7.

Themes:

1. Governance
2. Implementation/expansion/operations
3. Funding
4. Regulatory approval/policy requirements and compliance
5. Data collection and management
6. Architecture/design
7. Feedback and reporting
8. Healthcare improvements.

Request levels:

1. Considering establishing a registry - no registry in place
2. Early set-up: Establishing a registry, securing resources, and addressing foundational challenges.
3. Operational improvement: Actively managing a registry and seeking operational enhancements.
4. Advanced/ongoing: Established registries with more complex requests, focused on refinement, benchmarking, and collaboration with other mature registries.

Recommendation 4: To establish a monitoring and reporting system for the National CQR Advisory Service, that includes a classification matrix of services provided.

Classifying requests will facilitate the analysis and reporting of the service delivered and enable prioritisation of resources for higher demand areas, tailored responses for commonly sought after areas, improve overall resource planning and ensure the service is efficient, scalable and feasible.

4.4 Tracking and Communication Systems

A Microsoft Excel spreadsheet was used to track requests throughout the Pilot. It was modified at various stages as gaps in data collection or functionality were identified. This process highlighted the value of adaptable tracking tools and provided key lessons for future implementations. Future iterations could implement a centralised, automated system to capture real-time request details, enforce required fields, trigger alerts, and track follow-ups. Such a system would streamline operations, improve coordination, ensure timely responses and integrate an automated follow-up message allowing the recipient to provide feedback.

Recommendation 5: To implement a request management system to support the National CQR Advisory Service, which will enhance its efficiency, tracking and feedback for ongoing quality improvement.

A robust request platform will enhance efficiency, assisting with tracking and automated reporting, and provide feedback for ongoing quality improvement.

4.5 Communication Strategy

The communication strategy used during the Pilot was largely passive. This approach aimed to allow time for the service to develop, manage uncertain request volumes and manage limited resources amid indeterminate demand and future funding. However, it also inadvertently limited the service's visibility and likely affected the uptake rate (N=41). It is important to note that services such as this take time to develop a level of awareness and gain trust within the sector. Participants in the sector working group consultation had not generally referred requests to the service (10%, N=2) despite 65% (N=13) being aware of the service.

Future promotion should clearly communicate the scope and limitations of the Advisory Service to manage expectations. This could include a multi-channel strategy, leveraging social media, newsletters (e.g., SAHMRI, universities, ACTA), the National Health and Medical Research Council (NHMRC) website, conferences, and platforms like the ACTA CQR Special Interest Group and Commonwealth websites, will broaden reach. To engage new and non-registry audiences, additional efforts such as keynotes, webinars, and op-eds in academic journals are advised. This approach will increase visibility and attract a broader user base, particularly those considering new registry development. Including CQR representatives in the governance committee and working groups will facilitate the effective promotion and advocacy of the service.

Recommendation 6: To implement a National CQR Advisory Service communication plan.

The Advisory Service should develop a proactive and targeted communication strategy to maximise engagement and increase visibility, which incorporates digital campaigns, social media outreach, and direct engagement with emerging and existing CQRs.

4.6 Feedback on Service Evaluation

The Advisory Service satisfaction survey conducted during the 9th month of the service had a relatively low response rate (N=8) which limited the generalisability of the reported findings and were interpreted with caution. Specifically, the responses indicated a preference for specific, practical, and layperson-friendly support over high-level advice. Some respondents noted that the resources needed further development, underscoring the need to refine materials based on user feedback. To strengthen future service provision, more engaging and accessible feedback collection methods could be explored. This could include automated surveys or alternative data collection tools to boost participation and enable a more comprehensive assessment of the service's effectiveness and areas for improvement.

Recommendation 7: To develop an automated National CQR Advisory Service evaluation system.

The integration of an automatic satisfaction survey into the request management system, which could be sent upon request closure, with reminders and incentives would encourage participation in the feedback loop and inform service improvement.

5. Discussion

The CQR Advisory Service Pilot successfully demonstrated a clear demand for such service, with 41 requests responded to between January 2024 and June 2025. Feedback from all sources (SAHMRI Registry Centre Environmental Scan, Satisfaction Survey and Sector Consultation) indicated an individualised service model was preferred. An analysis of the Advisory Service's encounters and an evaluation of Pilot processes, incorporating feedback from service users and sector experts, has led to actionable recommendations to support its full-scale implementation and national rollout.

Advisory Service requests remained relatively constant throughout the Pilot, with 14 requests received in the first six months (January 2024 to June 2024), 12 in the second six months (July 2024 to December 2024) and 15 in the last six months (January 2025 to June 2025). The majority of requests originated from South Australia (N=26), followed by Victoria (N=7).

The SAHMRI Registry Centre effectively responded to the broad range of requests, delivering in-person consultation (either face to face or virtual) to 90% of requestors, structured presentations to 22%, and emailing correspondence and resources to all.

Notably, 71% of requests the Advisory Service received were from an established CQR and 32% were related to the establishment of a new registry. This highlights the potential of the service to intervene early in the establishment of a registry, greatly increasing the potential for new registries to be established in line with the guidance of the Strategy and the Framework.

This service fosters national collaboration, ensures consistent messaging, and over time, has the potential to ease the resource burden associated with responding to individual registry requests and importantly provide a more consistent approach to advice and support provided within the sector.

6. Conclusion

The CQR Advisory Service Pilot confirmed the value, need and potential for a national, centralised support model for CQRs. As expected for a pilot service there were some challenges; despite these the Pilot delivered targeted support, engaged stakeholders, and laid the foundation for a scalable, Framework-aligned service. With a relatively small investment in staffing, systems, and governance, the Pilot Advisory Service was well positioned to support the delivery of consistent national guidance within the CQR Sector.

The variation in needs and requests received by the Advisory Service suggests individualised support has greatest benefit.

This is supported by our analysis which showed that of 41 requests received, 95% (N=39) led to at least one meeting either face to face or online, resulting in the resolution of the incoming requests and queries.

It is also supported by the academic literature from other sectors, which proposes that personalised service, with individual interaction that fosters community and collaboration and standardisation, is key to success.

Accordingly, this report outlines key recommendations for an individualised responsive National CQR Advisory Service and strategies that would improve the services provided in the Pilot, particularly in request stratification, tracking and monitoring systems, evaluation processes, and promotional strategies.

In consultation with the CQR working group, targeted recommendations were developed to address these areas and support the transition from a pilot to a sustainable national service. This includes the establishment of a formal governance structure.

Successful implementation will require adequate resourcing, including dedicated and experienced staff, to ensure the service's effectiveness and long-term viability.

A National CQR Advisory Service, as recommended by the findings of this report, has the potential to reduce the burden on individual registries throughout Australia and improve the quality and consistency of advice and support provided to researchers, clinicians, policy makers, ultimately enhancing CQR's productivity and assisting them in achieving better patient outcomes across the health system.

7. Appendices

Appendix 1 Environmental Scan Survey Results

Member registries were asked to:

1. Indicate if researchers, clinicians or others come to them for registry advice and if they were able to provide them with the required advice

Response: 75% (n=15) of survey respondents indicated they are asked for advice and can provide the advice required.

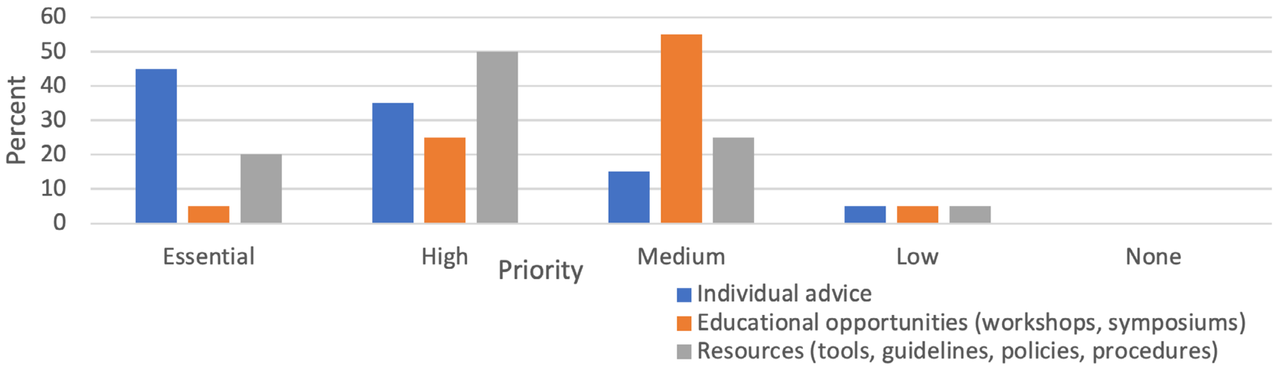
2. Provide examples of where they seek advice / support

Table 2 Examples of where registries seek advice and support

Registries seek advice/support	Results (N, %)
Other registries	18, 90%
Academics	14, 70%
Internet search (publications)	14, 70%
Department of Health and Aged Care	7, 35%
Other e.g. registry sector experts, professional societies, guidelines, international organisations, WHO.	3, 15%

3. Prioritise their preferences with regards the type of support

Figure 1 Preference of registries for the types of support



4. Share if they have policies and procedures

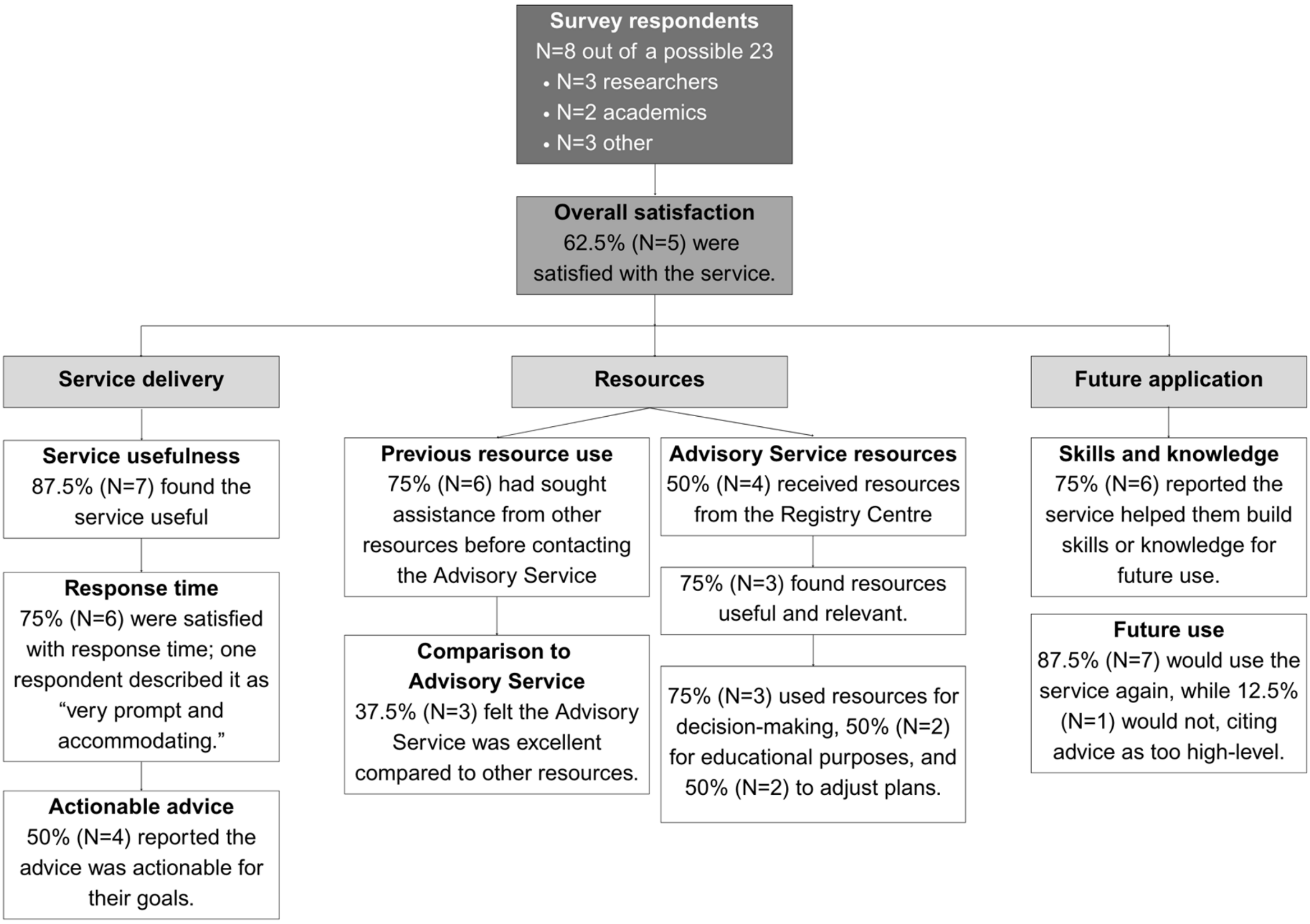
Response: Approximately 30% (n=6) indicated they don't have the policies and procedures required to operate their registry

5. Indicate a suitable location which would ensure access to supporting documents or templates

Table 3 Resource hosting locations

Document hosting locations	Results (N, %)
Other registries	20, 100%
Academics	2, 10%
Internet search (publications)	2, 10%
Department of Health and Aged Care	1, 5%
Other e.g. registry sector experts, professional societies, guidelines, international organisations, WHO.	0, 0%

Appendix 2: Satisfaction survey results



Survey respondents
N=8 out of a possible 23
- N=3 researchers
- N=2 academics
- N=3 other

Overall satisfaction
62.5% (N=5) were satisfied with the service.

Service delivery

Service usefulness
87.5% (N=7) found the service useful

Response time
75% (N=6) were satisfied with response time; one respondent described it as “very prompt and accommodating.”

Actionable advice
50% (N=4) reported the advice was actionable for their goals.

Resources

Previous resource use
75% (N=6) had sought assistance from other resources before contacting the Advisory Service

Comparison to Advisory Service
37.5% (N=3) felt the Advisory Service was excellent compared to other resources.

Advisory Service resources
50% (N=4) received resources from the Registry Centre

75% (N=3) found resources useful and relevant.

75% (N=3) used resources for decision-making, 50% (N=2) for educational purposes, and 50% (N=2) to adjust plans.

Future application

Skills and knowledge
75% (N=6) reported the service helped them build skills or knowledge for future use.

Future use
87.5% (N=7) would use the service again, while 12.5% (N=1) would not, citing advice as too high-level.

Appendix 3: Demographics of CQR Consultation Participants

CQR Consultation Participants Demographics	Respondents (N, %)
Role	
Manager	13, 65%
Director/Chair	2, 10%
Coordinator	2, 10%
Project Officer	2, 10%
Academic Lead	1, 5%
Organisation	
Monash University	6, 30%
South Australian Health and Medical Research Institute	3, 15%
Thoracic Society of Australia and New Zealand	2, 10%
Neuroscience Research Australia	2, 10%
The University of Notre Dame Australia	1, 5%
University of Wollongong	1, 5%
University of Melbourne	1, 5%
The Florey Institute	1, 5%
Australian and New Zealand Intensive Care Society	1, 5%
DayCOR II Ltd	1, 5%
Australian Bragg Centre for Proton Therapy and Research	1, 5%
Registry*	
Aplastic Anaemia and Other Bone Marrow Failure Syndromes Registry (AAR)	1, 5%
Australian Breast Device Registry (ABDR)	1, 5%
Australian Early Psychosis Collaborative Consortium Clinical Quality Registry (AEPCC CQR)	1, 5%
Australian & New Zealand Dialysis & Transplant Registry (ANZDATA)	2, 10%
Australia New Zealand Eye & Tissue Donation Registry (ANZETD)	1, 5%
Australian & New Zealand Living Kidney Donation Registry (ANZLKD)	1, 5%
Australian and New Zealand Hip Fracture Registry (ANZHFR)	1, 5%
Australian & New Zealand Heart Transplant Registry (ANZHTR)	1, 5%
Australian and New Zealand Intensive Care Society (ANZICS) Registry	2, 10%
Australian & New Zealand Lung Transplant Registry (ANZLUNG)	1, 5%
Australian & New Zealand Organ Donor Registry (ANZOD)	1, 5%
Australian and New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS) Database	1, 5%
Australasian Pelvic Floor Procedure Registry (APFPR)	1, 5%

CQR Consultation Participants

Demographics	Respondents (N, %)
Australasian Rehabilitation Outcomes Centre (AROC)	1, 5%
Australasian Severe Asthma Registry (ASAR)	2, 10%
Australian Particle Therapy Clinical Quality Registry (ASPIRE)	1, 5%
Australian Stroke Clinical Registry (AuSCR)	1, 5%
Burn Registry of Australia and New Zealand (BRANZ)	1, 5%
Day Case Anaesthesia Outcomes Recording (DayCOR)	1, 5%
National Gynae-Oncology Registry (NGOR)	1, 5%
Upper Gastrointestinal Cancer Registry (UGICR)	1, 5%

*Participants may represent more than one registry

Appendix 4: Analysis of service access data

CQR Advisory Service Pilot

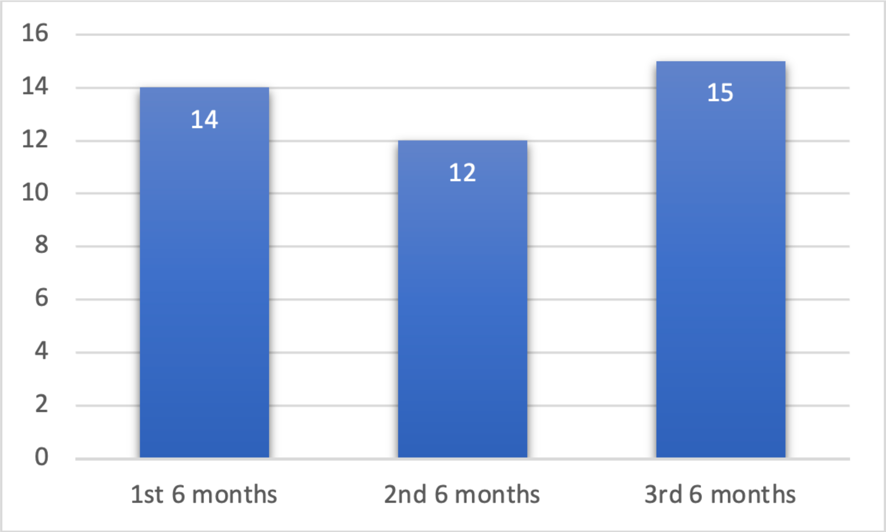
Analysis of Service Access Data

1. Usage Patterns

Volume and Trends of Requests

The Pilot had a soft launch, giving the service time to establish and the team time to build and develop resources. There were 41 requests, remaining relatively consistent in number over the duration of the Pilot. During this time other registries and experts presumably have continued to field requests and the volume of these is unknown.

Figure 1 Number of Request by Period

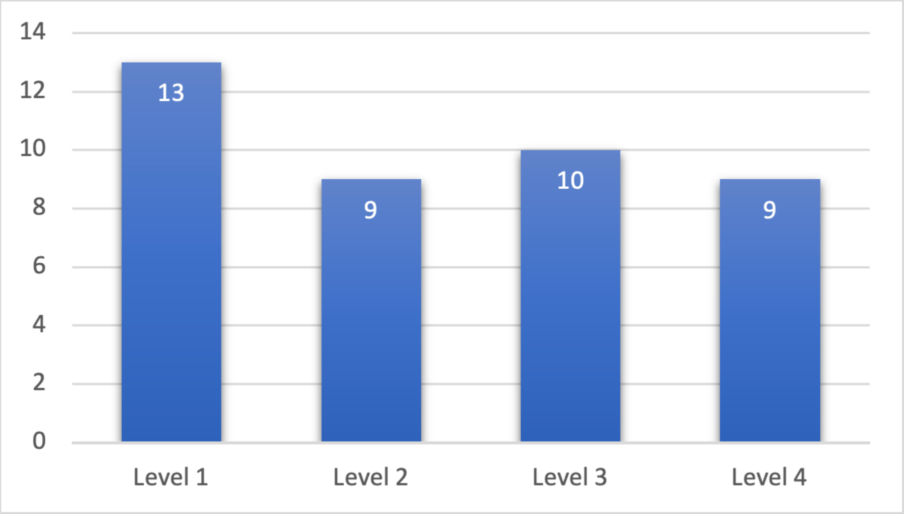


**Period of request 6 monthly (middle period include Christmas/NY break)*

Enquiry Level

Enquiries at level one received the highest number of requests – these were not already connected to an existing registry but related to the development of a new registry.

Figure 2 Number of requests by Level of Request



Level 1: Considering establishing a registry (no registry in place)

Level 2: Establishing a new registry

Level 3: Existing registry

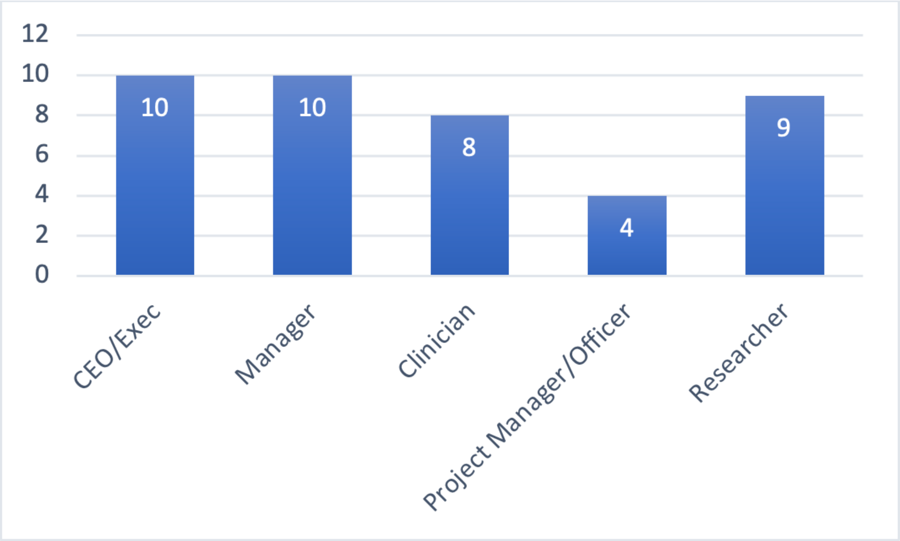
Level 4: Advancement of existing registry

2. User Demographics

The intended target group

Whilst many requestors had dual or multiple roles they were classified into their primary role related to a CQR for the purpose of the request. Based on the breadth of roles it would appear the service was reaching a broad range of requestors within the target group.

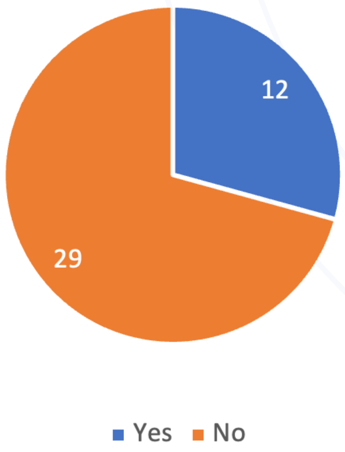
Figure 3 Requests by Role



Link to an existing Registry

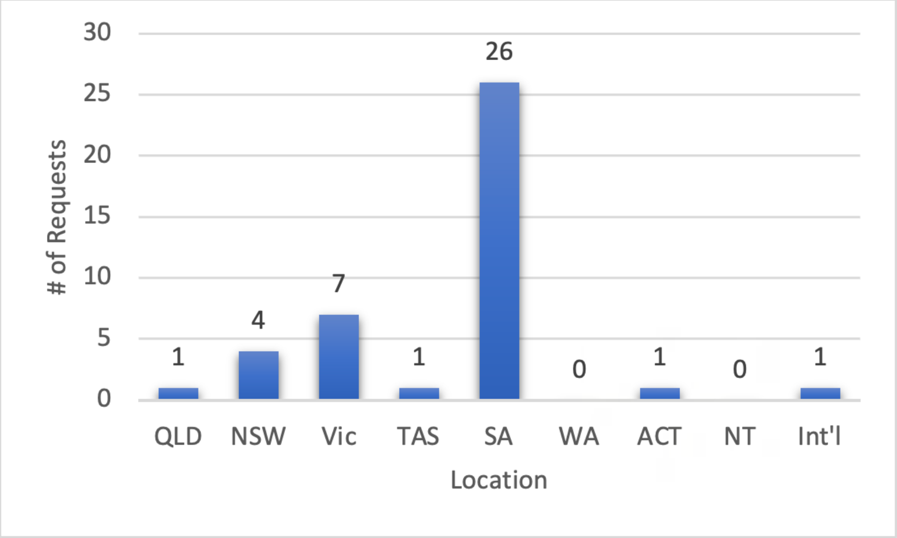
Of the 41 enquiries 12 (31%), were from a registry already included on the Australian Register of Clinical Registries.

Figure 4 Registered on the Australian Register of Clinical Registries



Location of Requestor

Figure 5 Request # by Location



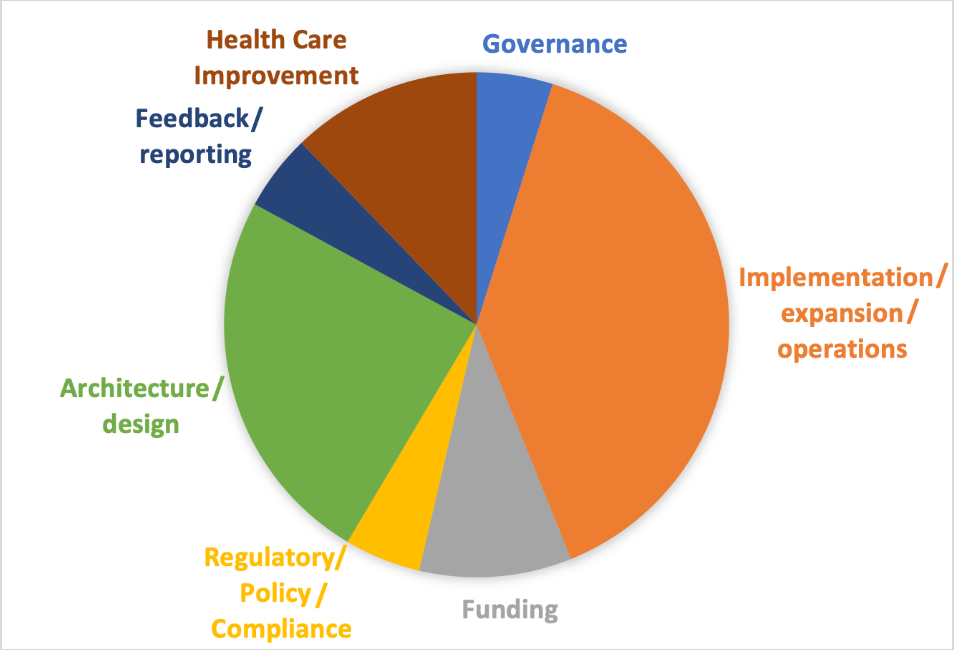
**One request was International – from Malaysia*

3. Nature of requests

Requests by Theme/Topic

Although many requests started with an initial topic they frequently expanded and covered multiple topics; requests were classified into a primary theme for the purposes of this analysis.

Figure 6 Number of requests by theme of request

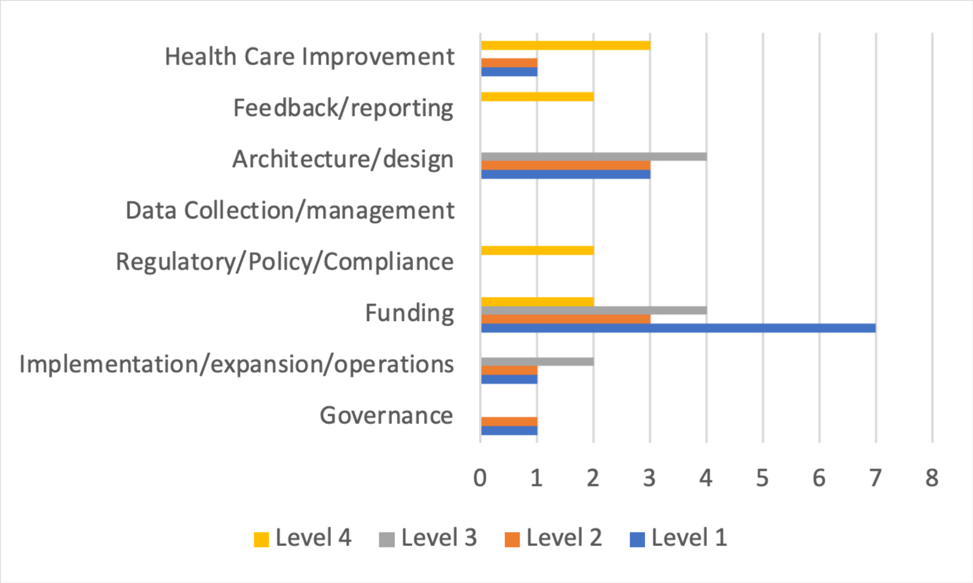


**No requests were received where the primary theme was data collection/management, however, this was covered as a secondary topic in many discussions.*

Theme by level of request

The spread of requests over the 4 levels were generally aligned with the appropriate request level. For example, most Level 1 enquiries related to funding a registry, and some to registry design. Level 2 requests were spread across governance, implementation, funding and architectural design, similarly Level 3 requests focused on implementation, funding and architectural design. Level 4 requests were a little different to other levels in that they covered themes of funding, regulatory/policy/compliance or feedback/reporting.

Figure 7 Topic/ theme by level of request



Complexity

Of the 41 requests received 95% (N=39) led to at least one meeting (either face to face or online) of which the duration was generally 1 hour. Only two requests were able to be addressed solely by email and none solely by phone.

Number of Contacts per Request

All requestors had at least two contacts. Of the 41 requests, 36% (N=15) required three or more contacts and 12% (N=5) received four or more contacts.

These contacts included further meetings, emails, phone calls, discussions, presentations or additional provision of resources or referrals.

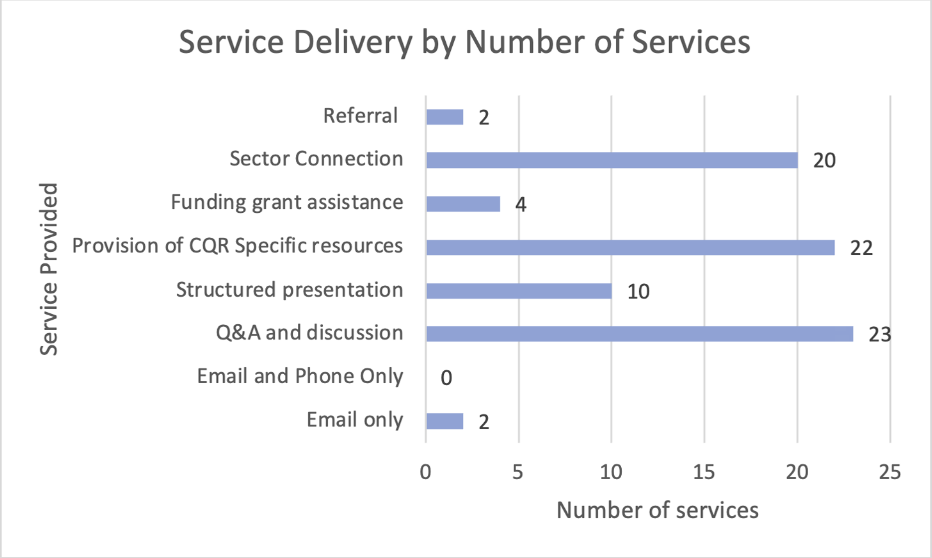
4. Mechanism of service delivery

Types of Service Provided

Services were delivered via:

- Email communication only
- Email and phone communication only
- Question and Answer, information sharing
- Structured presentation
- Provision of CQR Specific Resources
- Grant funding assistance
- Sector connection
- Referral

Figure 8 Service delivery type by number of services



**A single request may have received more than one service type*

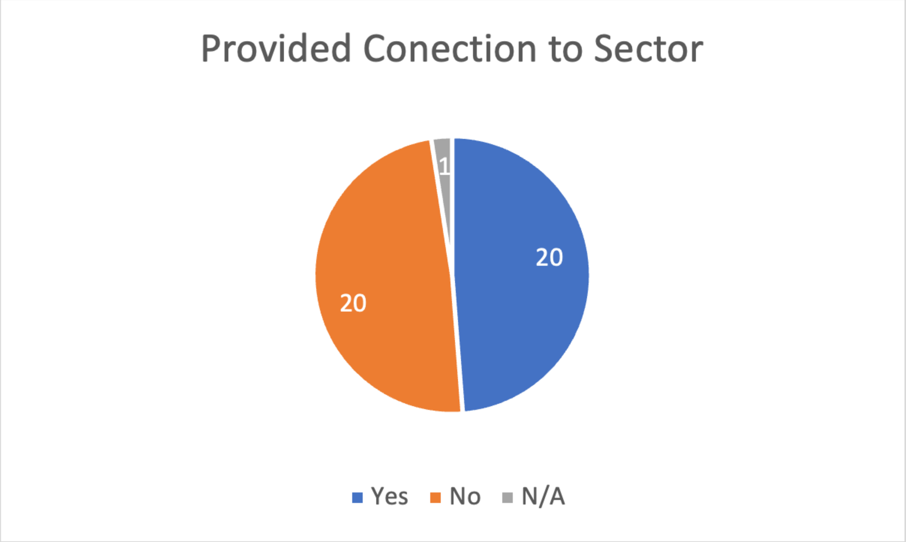
For many who accessed the service, learning there was a thriving and supportive sector with a range of experts available was highly valuable. At instigation, it was not fully understood what an important part of the service providing this connection would be. Many requestors were pleased to find a centralised source of information and support that they had not previously been aware of. Many had been working isolated from support and expressed significant levels of frustration. Indeed, 32% (N=13) of requests were classified as Level 1 which indicated they were enquiring about the potential establishment of a new registry, so were likely new to the sector. Separately, 71% (N=29) of the requests came from a source not related to a registry already recorded on the Australian Register of Clinical Registries, which indicates they were likely not connected to the CQR sector (a service user could be connected to a registry included on the National Register of Clinical Registries and be seeking advice or support to establish a new registry). Enquirers were eager to talk directly to experts about their challenges and were extremely grateful for the opportunity to discuss issues, develop strategies and make connections throughout the sector for ongoing support.

Connected to sector/network

Of the 41 requests 46% (N=20) were provided a connection into the CQR sector for ongoing support, education or information. Connecting enquirers into the CQR Sector to enable them to take advantage of opportunities offered and expertise within the sector was considered a high priority; many felt isolated and were unaware of support that was available to them. Connection provided included adding enquirers to the Benchmark mailing list, referral to the ACTA CQR Special Interest Group, referral to Monash University, invitation to sector events i.e. ACTA Registry Symposium, SAHMRI Annual Symposium, education opportunities that included workshops, forums or invitations to join the SAHMRI Registry Centre. The purpose of this was to ensure requestors had other sources of support beyond the Pilot Advisory Service.

Figure 9 Requestor Connection provided to the CQR Sector

Connecting enquirers to the sector was considered an important function; generally, when this was not done, it was because the enquirer was already connected.

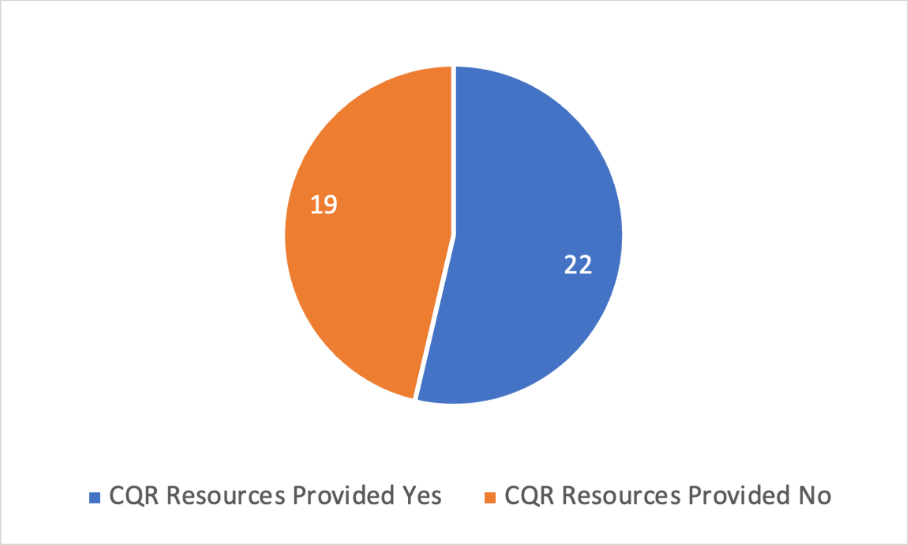


**N/A= One International request*

CQR Resources Provided

More than half of those making requests received CQR resources, including some already available in the sector, such as the Framework and the Strategy, and others that were developed specifically to address their needs.

Figure 10 Resources provided



5. Project workload and resources

Human Resources allocated to project: Total 0.5FTE / 17 months combination of Strategic Director, Project Manager and Project Officer.

- 41 Requests
- 76 Individuals
- 68 Hours of direct support

Note:

  - Indirect support not recorded
  - Time spent in project planning and implementation not recorded
  - Time spent preparing resources or presentations not recorded
  - Time in administration not recorded

6. Alignment with SAHMRI Registry Centre purpose

The SAHMRI Registry Centre, a centre of excellence for registries and registry science, was established in 2018 to bring together the registry science and operational expertise available among our research community, to ultimately strengthen the Institute's existing role in the registry space and expand our research capacity and training in this area.

A rapidly growing collaboration, the SAHMRI Registry Centre currently consists of 27 member registries. Member registries are based in South Australia and other states; 12 are based within SAHMRI, including several important national/bi-national registries.

The SAHMRI Registry Centre provides a platform to enhance the enormous value of registry data, supporting the utilisation of other important data sources such trials, surveys, biobank data, administrative data sets, and information systems, through data linkage and research collaborations.

Key goals align with the work of the CQR Advisory Pilot and the Framework. They are to:

- Provide the best resources for registry building capacity
- Lead registry science through collaborative opportunities for our scientists
- Develop strong international and industry collaborations
- Continue to support a shared learning environment
- Become a leading national and international registry centre.

The delivery of the CQR Advisory Service Pilot enabled the SAHMRI Registry Centre to extend its work beyond member registries and foster a broader national approach to enhancing the value of registries and registry data in Australia.

Appendix 5: Proposed Governance Structure: National CQR Advisory Service

Proposed Governance Structure		
Governance	Role	Members
National Advisory Group	Provide strategic direction, oversight, and alignment with the Strategy and the Framework. Develop key messaging, define support categories and themes, monitor progress, and report on impact.	Representatives from jurisdictions, central government, high functioning CQRs and research.
Expert working groups	Support the National CQR Advisory Service in the development of sector resources. Contribute to, writing, review and edit resource content.	Individuals with diverse expertise and affiliations.

Appendix 6: Eligibility Criteria

Eligibility Criteria		
Level	Support	Eligibility
1	General requests from individuals or organisations considering establishing a CQR, assistance to determine if a CQR is an appropriate response.	All requestors will be eligible for a one-off consultation session on request.
2	Advice and tools to assist establishment of a new CQR.	Only eligible after completion of the CQR Assessment Checklist and it has been determined that a registry is an appropriate response. Provision of high-level step by step guide.
3	Advice and support re further development of existing registries seeking to move their registry closer to meeting the Australian Framework for CQRs.	Eligible if registered on the Australian Registry of Clinical Registries. High level assessment of infrastructure in place e.g., critical policies, standard operating procedures (SOPs) and reporting. Advice regarding critical gaps.
4	Advice and guidance for CQRs seeking to undertake more advanced activities such as registry nested trials, data linkage studies, international collaborations and comparisons, strategic planning, audit review.	Eligible if registered on the Australian Commission's, Registry of Clinical Registries and in receipt of Commonwealth Government Funding.

Appendix 7: Request Classification Matrix

Request Classification Matrix				
Support Themes	**Not a Registry**	**Maturity of Registry**		
	1. Considering developing a registry	2. Early Set-Up	3. Established Registry - Operational Improvement	4. Advanced/Ongoing
Governance	Bringing expertise and stakeholders into the consultation.	Steering/Advisory Structure Site Governance Ethics Stakeholder Engagement	Stewardship Expansion nationally/ interstate Stakeholder Engagement Consumer Engagement	International Collaboration Research Projects Strategic planning
Implementation/ Operations	Feasibility Appropriateness	Establishment Defining purpose Sector Connection CQR Team development Advice/support Sector Connection Understanding Impact Roles/responsibilities **Resource provision:** National frameworks Protocol Template Establishment 10 Steps Establishment Feasibility Checklist Cost Drivers Document development SOPs	Expansion/addition of modules Resource allocation Quality Improvement Sector Connection Monitoring Impact Benchmarking activities, Managing data breaches **Resource provision**: Protocol Template SOPs Policy Templates	Project Development International Collaboration Resource allocation Quality improvement Bi-national data storage and governance Reporting Impact **Resource provision:** Contracts and payments SOPs Policies
Funding	Cost Drivers	Explore funding options	Sustainable funding Funding models Funding expansion activities Reporting Impact	Commonwealth funding Ongoing funding Funding models – industry/government contributions
Regulatory /Policy /Compliance	Ethics Site Governance	Consent models Informed consent Privacy Qualified privilege	Consent Models Informed consent Qualified privilege	Complex Data linkage Clinical trials Data sharing Accreditation/standards

Request Classification Matrix				
Support Themes	**Not a Registry**	**Maturity of Registry**		
	1. Considering developing a registry	2. Early Set-Up	3. Established Registry - Operational Improvement	4. Advanced/Ongoing
		Indigenous Data Governance	Indigenous Data Governance	Changing regulations Qualified privilege Indigenous Data Governance
Data Collection and Management	Determining dataset (MDS)	Development Minimum Dataset (MDS) Data collection feasibility Data dictionaries PROMs Data Management	Review Minimum Datasets (MDS) Quality Indicators Recruitment strategies Data Management Data quality Registry Nested Clinical Trials PROMs collection and reporting	Additional Cohort Studies Automation of data collection Data completeness Data linkage Data quality Registry Nested Clinical Trials Analytics MDS for Benchmarking
Architecture/Design	Platform and system	Functionality/system requirements of CQR Hosting Storage	Automation Reporting System development/ Enhancement Hosting	Data extraction Interoperability EMRs
Feedback and Reporting	Stakeholder requirements	Annual Reports Jurisdiction reports Reports and dissemination Consumer Translations	Public Reporting Quality review Reports and dissemination Benchmarking Consumer public reporting	Quality review External Review Reports and dissemination Benchmarking Consumers International collaboration; sharing knowledge Reporting Impact
Healthcare Improvement	Clarify Purpose	Jurisdiction connection Clinician body connection	Local Policy development Identifying outliers and unwarranted variation	Policy development Identifying outliers and unwarranted variation Jurisdiction engagement Commonwealth Engagement Clinical Guidelines Health Policy Change

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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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SAHMRI
South Australian Health & Medical Research Institute

SAHMRI
Registry Centre