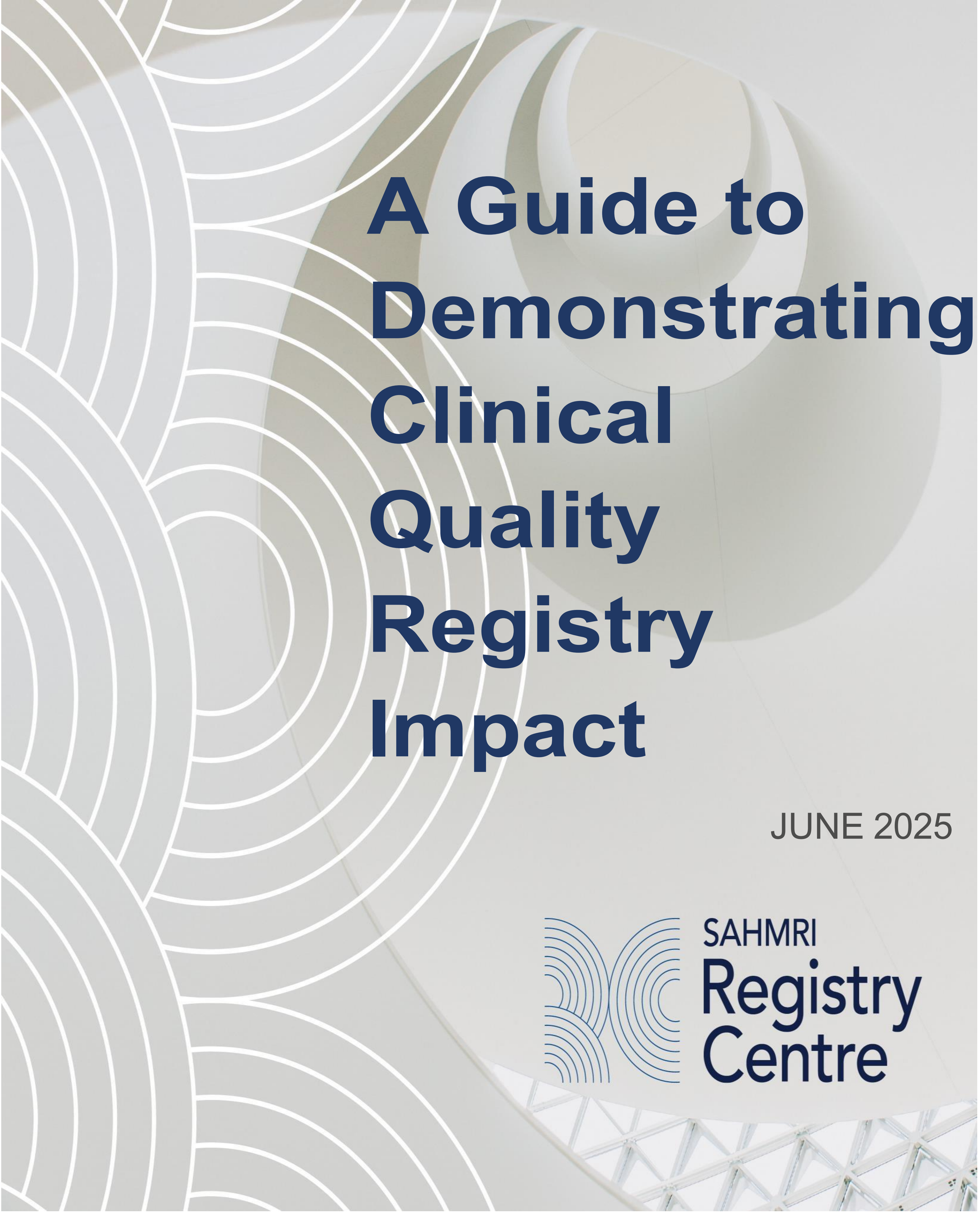

A Guide to Demonstrating Clinical Quality Registry Impact

JUNE 2025

SAHMRI
Registry
Centre

SAHMRI
South Australian Health &
Medical Research Institute

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

Publication Details

Publication Title: A Guide to Demonstrating CQR Impact. Published: 2025

Publisher: South Australian Health and Medical Research Institute https://doi.org/10.58138/4nkh-7x70

Suggested Citation

A Guide to Demonstrating CQR Impact. South Australian Health and Medical Research Institute. June 2025. Version 1. https://www.health.gov.au/resources/publications/a-guide-to-demonstrating-clinical-quality-registry-impact

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INTRODUCTION

Registries play a key role in monitoring patient cohorts, treatment pathways, and outcomes through systematic data collection and reporting. Registry reports are important outputs of this work, providing critical insights and informing policy and practice. However, they often contain complex scientific language and are delivered in formats and channels that are not easily accessible to the public.

The work of registries can have broad impact- influencing clinical practice, supporting evidence-based policy, and improving patient outcomes. Communicating the impact of registries is essential to demonstrate their continued relevance, effectiveness, and value to the healthcare system. Making this communication accessible ensures this value can be understood by researchers, decision makers (i.e. hospital executive, government policy makers) and funding bodies, while also empowering consumers to engage in informed decision-making.

The Clinical Quality Registry (CQR) Framework provides national guidance to support the development, operation, and evaluation of registries that aim to improve healthcare quality and outcomes. It outlines the minimum requirements and best practices for registries to qualify as CQRs, ensuring they collect, analyse, and report data in a way that supports clinical improvement, safety, and health system sustainability. Notably, the Framework highlights the importance of providing communications that meet the needs of all stakeholders, including consumers. While many registries aspire to meet the standards of the CQR Framework, not all currently meet the formal definition of a CQR. Nonetheless, the Framework serves as a valuable benchmark for all registries working toward achieving this status.

The purpose of this document is to provide registries with the knowledge and practical tools to better understand and communicate the impact of their work. This guide includes:

- Key resources to define and identify outcomes and impact
- Links to relevant publications and guidelines
- Practical templates
- Guidance on mapping impacts using a logic model
- Tools to Identify and monitor the evidence of outcomes
- A guide for writing impact statements
- An example of writing a showcase brief
- Guidelines on how to write a case study

DEFINITIONS

Term	Definition
Activities	The actions such as dissemination, collaboration, and consultation that translate & disseminate data and other outputs for stakeholders to adopt and use to make a difference.
Attribution	The role of interventions (i.e. programmes or policies) in producing claimed changes (impact).
AAMRI	The Association of Australian Medical Research Institutes Research Impact working group developed an Impact Framework which includes a list of performance indicators to enable the evaluation of impact. The AAMRI Framework has been developed for medical research institutes and research however has been designed to be dynamic enabling its use for multiple purposes.
End Beneficiary	Stakeholders upon whom the improved or new products, policies, practices, and/or services have an effect.
End user	A research end-user is an individual, community, or organisation external to academia that will directly use or directly benefit from the output, outcome, or result of the research.
Evidence	Statements and sources that prove the impact claims.
Indicators	quantitative or qualitative factors or variables that provide a simple and reliable means to measure achievement and change, track progress to impact, and feed into organisation reporting systems.
Outcome	The way in which an output has been used (adoption/use).
Outputs	Any form of deliverable embodying the data or knowledge for use. Deliverables differ by user and audience and are the direct products and/or services stemming from the registry.
Prospective impact	The anticipated or potential effects and benefits of the activities, outputs, or innovations before they are realised. It involves forecasting the future impact based on current knowledge, methodologies, and expected outputs. Often articulated in project proposals to demonstrate the potential value and relevance of the project.
Reach	The extent and/ or diversity of the beneficiaries of the impact, e.g. constituencies, numbers of groups, as relevant to the nature of the impact. For example, these are usually the numbers of something i.e. downloads, people attending or accessing. It does not tell you if the information was used or anything changed.
Retrospective impact	The actual effects and benefits that have been realised because of the activities, outputs, or innovations after they have occurred. It involves evaluating the outcomes and measuring the real-world changes that have been brought about by the outputs. Used in evaluation stages to assess the effectiveness and impact of completed projects.
Significance	The degree to which impact has enabled, enriched, influenced, informed, or changed the performance, policies, practices, products, services, understanding, awareness, or wellbeing of the beneficiaries.

ACRONYMS

AAMRI	Association of Australian Medical Research Institutes Research Impact
ARC	Australian Research Council
CSIRO	Commonwealth Scientific and Industrial Research Organisation
ICD	International Classification of Diseases
NHMRC	National Health and Medical Research Council
RIA	Research Impact Academy
SAHMRI	South Australian Health and Medical Research Institute

Section 1 - Overview

DEFINING IMPACT

Impact has many definitions as demonstrated by the following:

1. Australian Research Council (ARC)- Research impact is the contribution that research makes to the economy, society, environment, or culture beyond the contribution to academic research. [1]
2. National Health and Medical Research Council (NHMRC) - The verifiable outcomes that research makes to knowledge, health, the economy and / or society. Impact is the effect of the research after it has been adopted, adapted for use, or used to inform further research. [2]
3. 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. [3]
4. OECD - Positive and negative, primary, and secondary long-term effects produced by an intervention, directly or indirectly, intended of unintended.[4]
5. UK Research and Innovation (UKRI) - The Economic and Social Research Council (ESRC) - research impact as the demonstrable contribution that excellent research makes to society and the economy.[5]
6. W. Kellogg Foundation Handbook - impact is the fundamental intended or unintended change occurring in organisations, communities, or systems because of program activities.[6]

LOGIC MODEL FRAMEWORK

Being able to measure and demonstrate impact from registry outputs contributes to building confidence in the value of registries. Articulating this impact is important to ensure that evidence of the value and impact of CQRs is publicly available. This is more than publication, journal quality and funding success as these do not demonstrate real-world impact.

The first step for a registry when determining its impact is to identify its purpose and objectives.

Research Impact Academy (2014) User-Integrated Logic Model (adapted from the Kellogg logic model).

1. OUTPUTS & ACTIVITIES	2. NEXT USERS / AUDIENCE / STAKEHOLDER	3. OUTCOMES (Early impact)	4. INTERMEDIATE Impacts	5. LONG TERM IMPACT
What you produced & how you shared it	Who you delivered the output to	Uptake and adoption (use) of the outputs	Results of the use/adoption of outputs	The consequence of using your output
- Reports - Data sets - Guidelines - Publications - Policy briefs - Newsletter - Tools	- Clinicians - Funders - Administrator - Researchers - Public	- Change quality of care - Research projects - Capacity building	- Reduction in falls - Change in aged care policies - Implement findings	- Improved pt satisfaction/ QALYs - Uptake & use of findings - Reduced hospital stay

Key questions to consider:

1. What inputs activities and outputs are required to achieve the objective?

2. What outcomes is the objective wanting to achieve in the short, intermediate, and long term?

3. What impact domain is influenced by this objective?

Section 2

identifying impact

Mapping the pathway of impact

To effectively demonstrate an impact in a case study, it is important to clearly outline the type of impact achieved, whether it relates to policy, economic outcomes, public health, environmental sustainability, or cultural change. Describe the specific change that occurred and explain how the registry contributed to this outcome. This might include raising awareness, change in clinical practice, informing decision-making, improving services, or shaping public attitudes, ideally with evidence such as testimonials, or measurable outcomes.

A case study requires clearly mapping the process from registry to impact, showing how the work led to a meaningful change. This involves outlining the steps taken to engage stakeholders or the public, communicate findings, and encourage their application. Initial impacts such as increasing awareness or influencing attitudes can pave the way for more significant long-term effects, like changes in behaviour or enhanced well-being.

TYPES OF IMPACT AND EXAMPLES OF OUTCOMES [7],[8],[9]

The key types of impact or impact domains and examples of related outcome indicators are provided below. These indicators will assist registries in determining the impact of the outputs they produce.

Impact Domain	Impact Description	Examples of Outcome Indicators
Knowledge	Adoption, adaption or use of new knowledge by clinicians – further research –basic and fundamental impacts	Raising awareness – clinicians, consumer/ community Dissemination of findings through presentations, media, newsletters Collaboration and sharing data and materials. Recognition of research publications (e.g. citation metrics) Data sharing Contribution to registries or biobanks Uptake of tools and techniques by other registries or researchers Editorials by journals and/or publishers which highlight important papers Invitations to deliver keynote/plenary lectures Invitations to write commentaries and reviews.
Health	Includes improvements in health status and outcomes, health system change, health policy, new therapeutics and diagnostics, disease prevention, changes in health access and behaviour.	Healthcare practitioner choice influenced Improvement in quality of care Lower health burden Increased access to care Reduced mortality and morbidity Adoption of guidelines or tools Improved effectiveness and efficiencies of services or treatments Clinical implementation of guidelines Health policy of program adopted

Impact Domain	Impact Description	Examples of Outcome Indicators
Economic	Reducing healthcare costs and socio-economic benefits, creation of new jobs, new products, commercial outcomes.	Reduced productivity costs and direct health system Improved efficiency of health service delivery Reduced direct health system costs New financing Reduced waste Reduced hospitalization Reduction in usage of Medicare Benefits Schedule/Pharmaceutical Benefits Scheme
Social	Improvements in the health of society, improved access to services, improved social equity, inclusion or cohesion	Improved access to healthcare services Improved social equity, inclusion or cohesion Changes in behaviours and attitudes Improved ability to participate in paid or unpaid occupations Improved ability to participate socially (including empowerment and participation in decision making) Improved health literacy Improved linkage with peer support organisations (Advocacy groups) Improved social determinants of health (New public health education campaigns, improved social support networks)
Environment	Improvements in environmental outcomes	Reduction in toxins and contaminants Changes to the quality of air or water Effect on climate
Cultural	Changes in prevailing values, attitudes, beliefs, discourse and patterns of behaviors	Healthcare practitioner choice influenced Community
Capacity building	This type of impact relates to enhancements in skills and expertise and infrastructure. It reflects the development of capabilities, whether through training, education, or experience, which enable individuals or organisations to perform better or address challenges more effectively.	Training Resource development New networks Changes to skills and expertise Collaboration with other organisations to build capacity
Legislation and policy	Referring to the contribution that the registry has made to new or amended laws, regulations or other policies.	Changes to national regulations and policies Change in practice guidelines New regimes

Section 3 – Demonstrating Impact

GUIDE TO WRITING THE IMPACT STATEMENT.

This page provides a step-by-step guide to assist when writing impact statements.

STEP 1 Problem

Identify and describe the problem that you are attempting to resolve. For example, the use of contrast dye is required to effectively visualise organ function and anatomy during radiological examinations. For a select cohort of patients, the contrast dye can have detrimental effects on their kidney function. Prior to the examination, clinicians need to be able to determine a suitable dose of contrast dye for patients “at-risk” of potential/actual kidney impairment.

STEP 2 Impact logic model

Using your model, select the impact that you want to showcase.

Impact example	
Output / activity	A risk calculator was developed by XXX
Users	Clinicians
Outcomes	Calculator used Appropriate amounts of contrast dye used
Impacts (intermediate/long term)	Less kidney damage Less need for dialysis or kidney transplantation Shorter hospital length of stay Improved patient satisfaction/QALYs

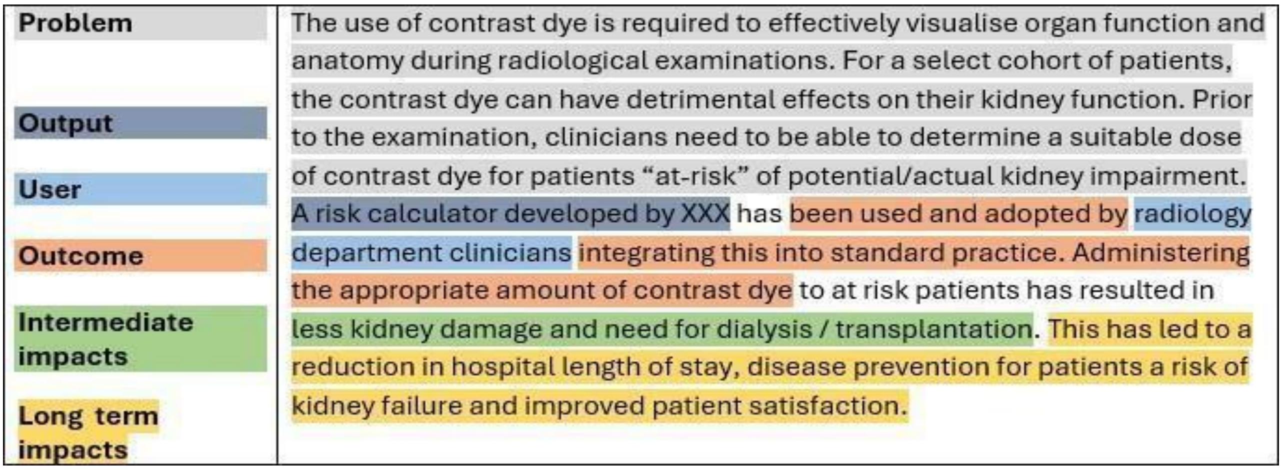
STEP 3 Populate

Using the table below populate each section using the information already available as per Steps 1 and 2 above.

Impact example	
Problem	The use of contrast dye is required to effectively visualise organ function and anatomy during radiological examinations. For a select cohort of patients, the contrast dye can have detrimental effects on their kidney function. Prior to the examination, clinicians need to be able to determine a suitable dose of contrast dye for patients “at-risk” of potential/actual kidney impairment.
Output/activity	A risk calculator was developed by XXX
Users	Clinicians
Outcome (early impact)	The calculator was used and implemented as a standard procedure to determine the appropriate amount of contrast dye to be administered
Intermediate impacts	Less kidney damage Less need for dialysis or kidney transplantation Shorter hospital length of stay Improved patient satisfaction/QALYs
Long term impacts	Reduced hospitalisation and disease prevention for patients at risk of kidney failure

STEP 4 Create the impact statement

When writing your impact statement, consider using key words that demonstrate impact i.e. Influenced, enhanced, adopted, changed, informed, adopted.



Problem **Output** **User** **Outcome** **Intermediate impacts** **Long term impacts**	The use of contrast dye is required to effectively visualise organ function and anatomy during radiological examinations. For a select cohort of patients, the contrast dye can have detrimental effects on their kidney function. Prior to the examination, clinicians need to be able to determine a suitable dose of contrast dye for patients "at-risk" of potential/actual kidney impairment. A risk calculator developed by XXX has been used and adopted by radiology department clinicians integrating this into standard practice. Administering the appropriate amount of contrast dye to at risk patients has resulted in less kidney damage and need for dialysis / transplantation. This has led to a reduction in hospital length of stay, disease prevention for patients a risk of kidney failure and improved patient satisfaction.

CONSOLIDATE THE IMPACT AND EVIDENCE

The purpose of this section is to provide registries with the information and tools to consolidate the information collected and showcase or publish their results. It is important to tailor impact messaging to the intended audience, for example, demonstrating impact to non-clinical stakeholders (such as government, ministers, and media) may require a different approach than communicating with clinical audiences (such as jurisdictions and clinicians).

Showcasing a registry's impact may require the establishment of a process for collection and documentation of its outputs and outcomes. Additionally, continuous monitoring of the outcome/impacts will determine their reach and significance, further supporting the evidence that the output has had an impact.

Claiming the registries attribution to an impact or change is not easy. The outputs produced may be just one factor which has influenced the outcome and led to the impact. Establishing a continuous feedback loop with your stakeholders to monitor the effectiveness and appropriateness of your outputs is one way to verify a link, albeit direct or indirect, between the output and the identified change/impact.

STEP 1 For each impact, document the Reach and Significance

Reach – e.g. 100% of radiology departments across all public hospitals in South Australia

Significance – e.g. the risk calculator has been integrated as standard practice within radiology departments prior to examinations where contrast dye is required.

STEP 2 Document the evidence of the impact

These are statements and sources that prove the impact claims. Types of evidence include:

- Documented evidence of change to policy, regulations, guidelines
- Altimetric and field weighted citations
- Cost savings
- Performance measures
- Change in QALYs
- Patient surveys
- Testimonials
- Stakeholder surveys – clinician, patient, consumer, others

STEP 3 Summarise the impact

Prepare a brief as per the example below which summarises the impact, including its reach, significance, and supportive evidence.

Significance **Reach** **Evidence**	The use of contrast dye is required to effectively visualise organ function and anatomy during radiological examinations. For a select cohort of patients, the contrast dye can have detrimental effects on their kidney function. Prior to the examination, clinicians need to be able to determine a suitable dose of contrast dye for patients "at-risk" of potential/actual kidney impairment. The risk calculator developed by XXX has been adopted and integrated as **standard practice** within **100% of public hospital radiology departments in South Australia**. The use of this calculator has led to less kidney damage and need for dialysis / transplantation, a reduction in hospital length of stay (**cost savings**) and reported **change in QALYs** as **reported by patients** receiving these radiological examinations. Further work is underway to expand the use of the calculator beyond its current reach.

EXAMPLES OF IMPACT STATEMENTS

Leveraging Long-Term ACGR Data to Secure Medicare Support for Corneal Collagen Cross-Linking for Keratoconus

Keratoconus is the leading indication for primary corneal transplantation registered with the Australian Corneal Graft Registry (ACGR) and usually develops in adolescence and young adulthood. Corneal collagen cross-linking (CCXL) was introduced in Australia to halt or delay the progression of keratoconus in the early 2000s. In 2018, CCXL was added to the Medicare Benefits Schedule (MBS). Lacking long-term Australian data, the Medical Services Advisory Committee (MSAC) contacted the ACGR in 2021 to inform its decision on whether CCXL should stay on the MBS. The evidence showed a significant decline in grafts for keratoconus over the preceding 10 years, particularly in recipients under 40. There was also no significant difference in survival of first grafts performed for keratoconus, irrespective of a history of CCXL. The evidence provided by the ACGR supported the utility of CCXL in reducing the need for corneal transplantation for keratoconus and the treatment has remained on the MBS. Access to the rebate makes this treatment available for people who might previously have been unable to access it due to cost and availability.

Integrating CADOSA activity into routine clinical practice

In 2021, the introduction of Cardiac Quality Assessment Officers (CQAOs) into The Queen Elizabeth Hospital's Cardiology Cath Lab improved communication between medical teams, nursing staff, and patients, addressing fragmented information sharing that previously led to missed follow-up appointments and disrupted continuity of care. The CQAOs implemented templates for clinical admission notes and discharge summaries, incorporating CADOSA Registry data, which enhanced workflow and ensured 100% of patients undergoing elective cardiac procedures received discharge summaries. By collaborating with referring cardiologists and attending morning huddles to address workflow issues, the CQAOs contributed to a shift in staff culture, improving documentation, communication, and data capture. These efforts fostered better patient follow-up and interdisciplinary collaboration, ultimately leading to a more efficient, patient-centred healthcare system.

Oz-POTS registry advocates for an ICD code in Australia

Until recently, Australia had not recognised Postural orthostatic tachycardia syndrome (POTS) with its own unique International Classification of Diseases (ICD) code. Without a unique code, POTS is frequently misclassified, leading to poor understanding of the burden of the condition, misdiagnoses, and treatment delays. Data from the Australian POTS Registry (Oz- POTS) has been used by the Australian POTS Foundation (APF) to support advocacy efforts aimed at addressing these issues, highlighting diagnostic delays and the reduced quality of life experienced by those with the condition. The APF successfully lobbied the Independent Health and Aged Care Pricing Authority (IHACPA) for the recognition of POTS. As a result, the unique ICD code is now part of nationally mandated practice, having been adopted into the ICD-10- AM/ACHI/ACS Thirteenth Edition, 2025. This is expected to improve diagnostic accuracy, enable more appropriate treatment for individuals living with POTS, and assist in tracking healthcare costs and resource use.

GUIDE FOR WRITING CASE STUDIES

STEP 1 Headline / Title

Ideally this should be less than 70 characters long and include the registry clinical focus area and outcome/impact story being told.

STEP 2 Introduction / Overview

Lead with an explanation or background of the need/problem/challenge identified and the outcome / impact the registry had from the outputs produced.

STEP 3 Issue / Problem / Question and Challenge

Provide the detail regarding the Issue / Problem / Question, which is to be addressed, and any challenges encountered.

STEP 4 Registry activity and outputs

1. List the registry planned and actual activities relating to the challenge/issue/problem.
2. What registry outputs were produced to address the challenge/issue/problem.

STEP 5 Impact

1. Describe the outcomes achieved. These outcomes can be direct (i.e. would not have happened without input from the registry) or indirect (the registry has contributed but cannot ascertain if the outcome would have occurred without their involvement).
2. For each outcome include the impact domain (health outcome, policy capacity building, social, economic) the registry outputs had on the challenge/issue/problem.

STEP 6 Discussion or Key points

Reiterate the impact of the story and registry value which can suggest future impacts from this case study.

Other tips

Be clear and concise. Readers want to get to the point of the story quickly and easily, and they will be looking to see themselves reflected in the story right from the start.

Provide a big picture. Always make sure to explain who the registry is, their purpose, and how they achieved success in a short introduction to engage the reader.

Use a logic model framework to keep the narrative clear

Leverage graphics. Incorporating infographics, charts, and sidebars can be a more engaging and eye-catching way to share key statistics and data in readable ways.

Offer the right amount of detail. Most case studies are one or two pages with clear sections that a reader can skim to find the information most important to them.

Include data to support claims. Show real results — both facts and figures and quotes — to demonstrate credibility and prove the output works.

Links to case study examples

- NHMRC - Guidelines for producing NHMRC Case Studies
- NHMRC - Impact case studies
- Health Translation SA (July 2021) - Impact-Report-July-2021-WEB-1.pdf (healthtranslationsa.org.au)
- Monash Partners (2021) - Impact-Report
- Monash Partners (2019-2020) Impact-Report-FINAL

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Section 4 – Templates

IMPACT LOGIC MODEL

HEADERS	IMPACT EXAMPLE
Outputs / Activities What you produced & how you shared it	
Users Who you delivered the output to	
Outcomes (early impact) Uptake and adoption (use) of the outputs	
Intermediate impact Results of the use/ adoption of outputs	
Long term impact The consequence of using your output	

Using the logic model template the CADOSA registry example from page 17 is included in the template.

Problem	Fragmented communication between medical teams, nursing staff, referring cardiologists, and patients, leading to missed follow-up appointments and incomplete information sharing. To address this Cardiac Quality Assessment Officers (CQAO) were introduced into The Queen Elizabeth Hospital Cardiology catheterisation laboratory (Cath lab) team, a template for elective clinical admission notes and discharge summaries was developed incorporating data elements of the CADOSA Registry.
Users	Clinicians, including cardiac registrars and nursing staff. Patients undergoing electric cardiac procedures. Referring cardiologists and GPs.
Outcomes	Clinicians and patients received detailed, up to date, patient-centred summaries of symptoms, medications, and medical history. The integration of the CADOSA registry activities into routine clinical practice improves workflow and care quality.100% of patients undergoing elective cardiac procedures receive a discharge summary.
Impact	Improved communication with patients and the medical team, with CQAOs calling cardiologists to ensure follow-up appointments. Shift in staff culture, with CQAOs collaborating with the medical and nursing teams for timely, relevant documentation. Optimised data capture for the CADOSA registry. Enhanced continuity of care through better communication and improved patient follow-up. Improved collaboration within the interdisciplinary team, contributing to a more efficient and effective healthcare system. These efforts fostered better patient follow-up and interdisciplinary collaboration, ultimately leading to a more efficient, patient-centred healthcare system.

IMPACT LOGIC MODEL WITH EVIDENCE

Issue/ Problem / Question	
Outputs / Activities	
Outcomes (early impact)	
Intermediate impact	
Long term impact	
Evidence	
Reach	
Significance	

CASE STUDY

Content Headers

Headline / Title

Ideally this should be less than 70 characters long and include the registry clinical focus area and outcome/impact story being told.

Introduction / Overview

Lead with an explanation or background of the need/problem/challenge identified and the outcome/impact the registry had from the outputs produced.

Issue / Problem / Question and Challenge

Provide the detail regarding the Issue / Problem / Question, which is to be addressed, and any challenges encountered.

Registry activity and outputs

1. List the registry planned and actual activities relating to the challenge/issue/problem.
2. What registry outputs were produced to address the challenge/issue/problem.

Impact

1. Describe the outcomes achieved. These outcomes can be direct (i.e. would not have happened without input from the registry) or indirect (the registry has contributed but cannot ascertain if the outcome would have occurred without their involvement).
2. For each outcome include the impact domain (health outcome, policy capacity building, social, economic) the registry outputs had on the challenge/issue/problem.

Discussion or Key points

Reiterate the impact of the story and registry value which can suggest future impacts from this case study.

Section 5
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