Consumer Friendly Information CoFI Pilot Project Report

A SAHMRI Registry Centre project to co-design patient-friendly resources with consumers

Sarah Eley and Cindy Turner

JUNE 2025

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Acknowledgement 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

The *Consumer-Friendly Information (CoFI) Pilot Project* developed and implemented a consumer co-design and dissemination process to translate registry outputs into accessible, consumer-friendly resources that support healthcare decision-making.

Partnering with three mature registries and the CoFI Consumer Group, the project successfully co-designed a range of resources: two lay summaries of academic papers, an information booklet, an infographic, a video, and an animation. These were disseminated through consumer-informed channels and registry stakeholder mapping.

Participating registries were clear that whilst they saw the value of the resources for consumers, they would not have had the expertise or resources to undertake this work without the external capability provided by this pilot project. Data obtained from the environmental scan of SAHMRI Registry Centre members showed that 88% (n=7 out of 8 respondents) indicated that a lack of staffing resources was a barrier for them. With competing demands on registry resources, it is therefore important to consider how registries can be enabled to undertake the work required to translate registry output into consumer-friendly versions.

To help address the lack of internal skills and resources, a key output of this project is the User Guide, which has been developed to support and upskill registries to create consumer-friendly resources. The guide includes step-by-step instructions, templates, practical tools, and learnings informed by the pilot experience.

The CoFI pilot suggests that registry outputs can benefit consumers' healthcare when translated into accessible formats; further evaluation of the impact of these resources would be a valuable exercise to confirm and prioritise investment in translation capability.

Key findings

- The CoFI project demonstrated that consumers highly value the translation of registry outputs into accessible, useful resources, and appreciate being meaningfully involved.
- Embedding this work into routine registry practice will require dedicated funding, staffing, support and sector education.
- The practical tools developed through this project will better position registries to partner with consumers and translate their outputs into resources that genuinely improve healthcare experiences.

Recommendations

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

Recommendation 1: Registries are encouraged to adopt a consumer co-design process to translate relevant registry findings into consumer resources as part of their core business.

Sharing registry findings with the public in consumer-friendly formats and locations will assist patients and their families in navigating health and life challenges.

Recommendation 2: Build sector-wide understanding of the value of consumer-friendly resources in improving patient outcomes to expand translation activity across the registry sector.

Given that 25% of registries surveyed reported translating outputs into consumer-friendly resources as a low priority, without education on the broader societal benefits and a commitment to improving health outcomes, registries may not prioritise effective, consumer-friendly communication of findings.

Recommendation 3: Registries be appropriately funded and resourced to embed co-design and translation of consumer-friendly resources into core business.

To enable sustained engagement in co-design, registries require adequate funding, staffing and support, without which the creation of meaningful consumer resources is unlikely to occur.

Recommendation 4: Registries adopt the 'A registry guide to co-designing consumer friendly resources' to support the translation of registry outputs.

This practical resource will equip teams to avoid common challenges, build consumer resources efficiently, streamline processes and foster meaningful collaboration between registries and consumers.

Recommendation 5: That a comprehensive evaluation of the impact and usefulness of consumer resources developed from registry data be conducted.

Such evaluation is important to demonstrate effectiveness to the registry sector, justify ongoing investment, and guide improvements that maximise benefits for consumers and the broader community.

1. Introduction

The SAHMRI Registry Centre, with funding from the Department of Health, Disability and Ageing (the Department), delivered the CoFI project between January 2024 to June 2025. Aligned with the *Australian Framework for National CQRs 2024 (the Framework)*[1], CoFI aimed to create and disseminate understandable and reliable information from registries.

Partnering with three mature registries (the Australian Corneal Graft Registry (ACGR), the Registry of Senior Australians (ROSA) Research Centre, and the Transcatheter Aortic Valve Implantation (TAVI) Registry), this consumer co-design project piloted the collaborative development of consumer-friendly resources from registry outputs, to support healthcare decision-making.

This report outlines the project's delivery, lessons learned, its key challenges, and the SAHMRI Registry Centre's recommendations.

Goal

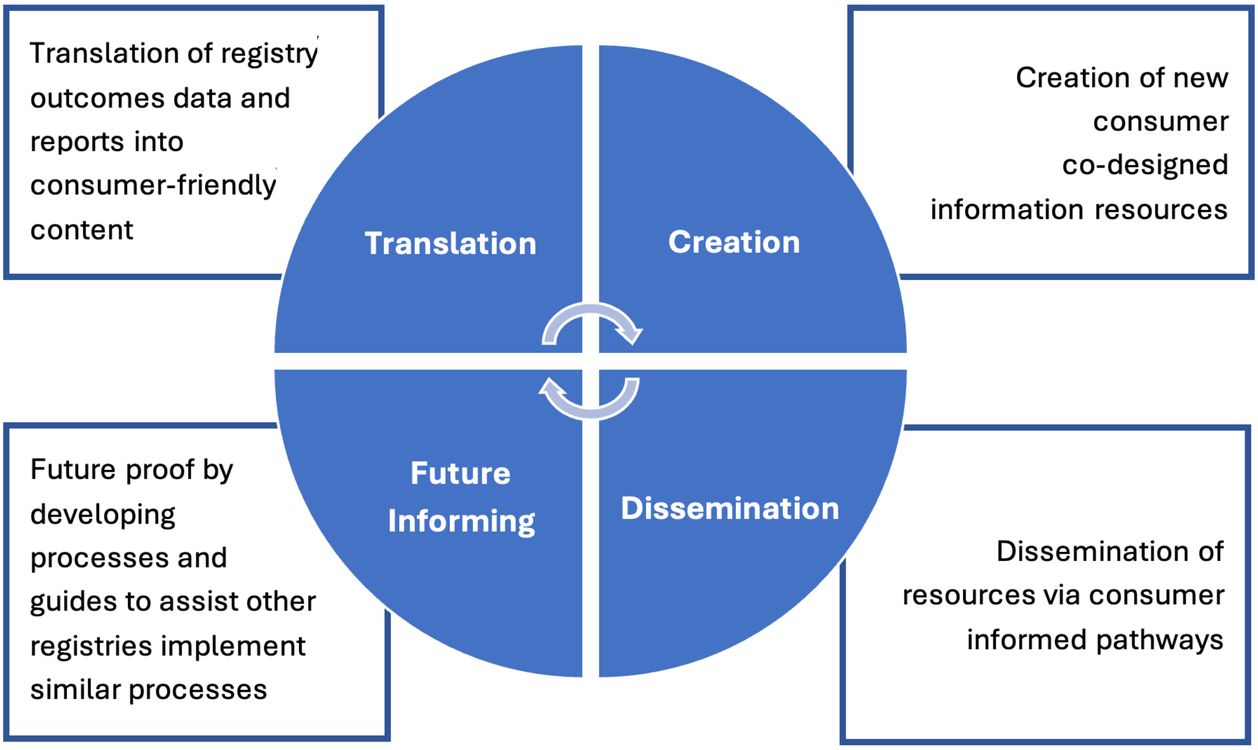
Create and disseminate easily understandable and reliable outcome information direct from registries, to empower consumers and their families to make informed decisions about their health.

Objectives

Using a collaborative consumer co-design approach, the CoFI project aimed to:

1. Translate registry outcome data and reports into consumer-appropriate formats
2. Create new (or enhance existing resources into) consumer co-designed resources to inform consumers and guide decision making
3. Disseminate resources via consumer informed pathways to increase accessibility
4. Futureproof processes and develop guides to assist other registries to improve their public communications

Figure 1. Project Objectives



Translation of registry outcomes data and reports into consumer-friendly content

Creation of new consumer co-designed information resources

Future proof by developing processes and guides to assist other registries implement similar processes

Dissemination of resources via consumer informed pathways

2. Background

The Clinical Quality Registry (CQR) sector is undergoing a significant transformation, driven by the need to improve the safety, effectiveness and appropriateness of care for the Australian community. While the reasons for this shift are varied, a central aim is to increase the impact of registries on health outcomes.

Currently, the rich information developed and held by registries is rarely used by consumers to support informed healthcare decisions. However, if these outputs were adapted with consumers in mind, they could have a greater reach and impact.

Both the National Clinical Quality Registry and Virtual Registry Strategy 2020–2030[2] (the Strategy) and the Framework[1] emphasise the importance of consumer engagement in the registry sector. Notably, the Framework encourages registries to present their outputs in ways that are accessible and meaningful to consumers.

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 community, to 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. For further information about the Centre, see SAHMRI Registry Centre.

One of the Centre's strategies to enhance the value of registry data is to support registry members in partnering effectively with consumers. The CoFI project 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 provide project advice and recommendations.

CoFI Project Management Group

The CoFI Project Management Group was a coalition of representatives from the participating registries and a consumer representative, formed to discuss specific implementation challenges and provide updates as they arose. The group consisted of:

- Strategic Director of the SAHMRI Registry Centre
- Senior Project Officer
- Senior representative from each of the three participating registries
- CoFI Consumer Group representative

3.1.2 Establish the Project Team

The Strategic Director of the SAHMRI Registry Centre contributed 0.1 FTE of their work to oversee the management of the project. In February 2024, a Senior Project Officer with experience engaging consumers in health research and communications commenced to work 0.3 FTE to deliver the project.

3.1.3 Project Plan Development

A project plan with contingencies was created to ensure adherence to the contracted objectives and key milestones. This was approved by the SAHMRI Registry Centre Executive Group.

3.2 Implementation of the CoFI Project

Key implementation activities were undertaken in parallel during the activation of the project.

3.2.1 SAHMRI Registry Centre Environmental Scan

Development of the Survey Tool

As part of a formative evaluation, the SAHMRI Registry Centre developed a survey to conduct an environmental scan of registry characteristics and reporting practices. An iterative process in the survey development was undertaken and guided by the Framework[1] the Strategy[2], and consultation with SAHMRI Registry Centre contacts and representatives from the Department Clinical Quality Registry Program.

Survey Administration and Sample Characteristics

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

Analysis of the Results

Survey responses were exported to Microsoft Excel and analysed. Analyses and interpretation of the results as well as the provision of recommendations was supported by the Framework, which was officially released following the development of the survey.

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 Establishment of the CoFI Consumer Group

An effective consumer group was considered a critical element to the success of this project.

Terms of Reference

A Terms of Reference (ToR) was developed (Appendix A) to outline the purpose of the group, the roles and responsibilities of members, the criteria for recruitment, operating procedures, and reimbursement policy. This document formed the basis of the recruitment process.

Recruitment of Consumers

Nine consumers were recruited for specific lived experience as outlined in Table 1.

The three general consumers were recruited to ensure that resources created would benefit those with no prior lived experience of the specific areas of health.

Table 1: Consumer representation on the CoFI Consumer Group

Position	# of Consumers	Method for recruitment
Consumers who have undergone a corneal transplant for keratoconus	2	ACGR recommended two consumers from the *ACGR Consumer Group*.
Consumers with experience with the Australian aged care sector	2	Presentation at a *ROSA Consumer & Community Advisory Committee* meeting.
Consumers with experience of heart-related health issues*	2	Recruitment through Health Translation SA's *Community Interest Register*.
General consumer with significant experience navigating health challenges – in any area.	3	Recruitment through Health Translation SA's *Community Interest Register*.

**The initial version of the ToR specified the inclusion of two consumers who had undergone a TAVI procedure. However, the Senior Project Officer was unable to identify suitable participants - likely due to the advanced age and health status of this group. As a result, the decision was made to recruit consumers with experience of heart-related health issues more broadly.*

Onboarding of Consumers

An introductory CoFI Consumer Group meeting was held in May 2024 to onboard each consumer to the project. At this meeting the ToR was discussed and approved. Consumers had the opportunity to ask questions, clarify their roles and responsibilities, and get to know other group members. All consumers remained on the group throughout the duration of the project.

3.2.3 Consumer Co-design Workshops

Registry Output Selection

In preparation for the consumer co-design workshops, the Senior Project Officer was provided with the registry outputs for translation from each registry. The outputs provided by each registry are outlined in table 2.

Table 2: Registry outputs for translation

Registry	Output for translation	Reason for selection
Australian Corneal Graft Registry (ACGR)	Four-page flyer on keratoconus. This included an explanation of the condition, treatment options, and statistics on the success of corneal graft transplants.	Previously developed at the request of the ACGR Consumer Group. Consumer feedback was the flyer was too technical and suitable for clinicians, not consumers.
Registry of Senior Australians (ROSA) Research Centre	Two academic publications on: • Risk of fractures upon entering aged care homes utilising an algorithm[3] • Comparison between older Australians in aged care homes and those at home accessing aged care services, and the rates of unplanned hospital visits[4]	To translate current findings by ROSA.
Transcatheter Aortic Valve Implantation (TAVI) Registry	Patient-Reported Outcomes Measures (PROM) Data showing pre-TAVI and 30 days post-TAVI procedure, for five quality of life factors.	To share PROM data with the community.

CoFI Consumer Group Co-Design Workshop one

The first co-design workshop was held in June 2024. This workshop covered the following:

1. **Communication presentation.** The Senior Project Officer presented on clear, accessible communication and demonstrated different methods for presenting consumer-friendly information, including academic paper lay summaries, factsheets, infographics, booklets, videos, podcasts and animations.
2. **Consumer sub-group formation.** Each consumer self-nominated to work on one of the registry outputs. Three subgroups were established with three consumers per group and included a mix of lived experience expertise and a general perspective.
3. **Clarification on registry outputs.** Each sub-group met with a registry spokesperson who explained the registry output in detail and answered questions.
4. **Identification of key messages.** The sub-groups were led through an exercise to collaboratively distil the key messages from the output.
5. **Selection of resource types.** The sub-groups utilised two templates to decide the type of resources to create, which were:
    - i) ACGR: A video and an information booklet. After discussing the video with the registry, it was decided that an animation would be produced instead as subject matter experts preferred not to be filmed.
    - ii) ROSA: Two academic paper lay summaries
    - iii) TAVI: An infographic and a video.

CoFI Consumer Group Co-Design Workshop two

The second co-design workshop was held in July 2024. This workshop covered the following:

1. **Prototype presentation.** The Senior Project Officer explained how to create a prototype utilising provided templates.
2. **Researching currently available consumer resources.** The sub-groups searched for health promotion materials that were currently available online to avoid duplication.
3. **Identification of information to include in prototypes.** The sub-groups utilised the templates to identify what should be included in the resources. The information included the text, colours, and images. For videos, who would be filmed, where the filming should occur and key talking points were included in the templates.

3.2.4 Consumer Resource Development

In developing the consumer-friendly resources, the Senior Project Officer worked with each sub-group and registry individually. The number of meetings, versions and communications varied considerably across areas, depending on the complexity of the outputs and degree of alignment between consumer and registry perspectives.

Key Activities Included:

Development of Prototypes

To develop the prototypes, the following steps occurred:

1. **Development of draft prototypes.** The Senior Project Officer drafted prototypes and storyboards based on the consumer-completed templates from the second co-design meeting.
2. **Consumer review.** The sub-groups provided their feedback on the draft prototypes and amendments were made.
3. **Registry review.** The registries reviewed and edited the draft prototypes. The registries were primarily concerned with ensuring the content accurately reflected the outputs.
4. **Iterative refinement until agreement.** The draft prototypes continued to be reviewed and edited until agreement on the prototype by consumers and registries was reached. The TAVI prototypes required minor edits until agreement was reached. The ACGR and ROSA prototypes required more versions to be produced.

In developing the prototype for the ROSA publication on risk of unplanned hospital visits[4], the consumers and registry spent significant time negotiating key messages for inclusion and exclusion. ROSA determined that their publication on star ratings in aged care homes would be more suited to translation. The process commenced for the new publication to be translated into a lay version.

Development of Resources

The prototypes were utilised to approach professionals (videographers, animators and designers) to discuss project deliverables and seek quotes.

Once professionals were engaged, the steps required to produce the resources varied between resource type. The steps involved are detailed in table 3.

Table 3: Steps involved in developing resources by type.

Handouts *infographics, lay summaries and booklets*	**Video**	**Animation**
1) **First draft** received from the designer based on the prototype. 2) **Review of the first draft** by the Senior Project Officer and edits sent back. 3) **Circulation of the second draft** with the consumers and registries for their feedback and amendments. 4) **Collated edits** provided to the designer. This process of review, collated edits, and new drafts provided continued until the consumers and registries approved the designed resources.	1) **Securing a date and location** for filming, looking at the videographer, clinician and consumers availability. 2) **Location approval.** Receiving approval from the hospital to film on location. 3) **Filming** on the day. 4) **Production of the video** by the videographer. 5) **Review** by consumers, clinician and registry. 6) **Minor changes** requested and made. 7) **Final approval** by all.	1) **Refinement and approval of the script** by consumers and clinicians to ensure the information is accurate and fits within the allocated time limit. 2) **Voiceover artist engagement** to record the script. 3) **Approval on the style** of the animation based on a sample of stills. 4) **Final storyboard approval** i.e. a still of each scene with the matched script. 5) **Animation produced.** 6) **Minor changes** requested and made. 7) **Final approval** by all.

Development of Accessible Versions

Once the resources had been approved, the Senior Project Officer worked with a consumer with vision impairment and the South Australian Council for Intellectual Disability to create additional resources.

1. **Low vision versions.** PDFs were created that were suitable for viewing for those with low vision (larger font, high contrast, large images) and were able to be read by a screen reader. A consumer with low vision provided guidance and tested and approved all low vision versions.
2. **Easy read guides.** The South Australian Council on Intellectual Disability[5] created easy-read guides based on the original content. These guides are for consumers with communication challenges, such as intellectual disability and people for whom English is not their first language.

These accessible versions were reviewed and approved by the registries. Some minor changes were required.

3.2.5 Dissemination of Resources

To maximise the likelihood of the resources reaching the target audience(s), a collaborative approach to identifying dissemination pathways occurred.

Stakeholder Mapping Workshop

At this workshop the Senior Project Officer led the CoFI Consumer Group through a stakeholder mapping exercise. This workshop commenced with a brief presentation and discussion around where the community might seek out health information. The group considered the characteristics of the target audiences and how this might impact how they access health information.

The subgroups undertook a mind mapping exercise to identify all potential stakeholders who interact with the target audiences in a health capacity.

The prompts provided to the group to assist in the identification process are listed in Table 4.

Table 4: Prompts for identifying stakeholders

Health and wellbeing	**Community groups**	**Government** *State / National*
Clinicians, nurses	Advocacy groups or individual advocates	Health Departments
General Practitioners	Not-for-profits, charities, disease specific organisations	Policy makers
Hospital or LHN Executives and professionals	Local councils and services i.e. libraries	
Industry professionals	Community health centres	
Pharmacies	Peer support groups	
Professional associations	Social media groups	
Allied Health		

The group was asked to consider how each of the stakeholders could share the information with the target audiences. Options suggested included websites, social media, in waiting rooms, newsletters, clinical consults and in meetings with GP practices.

Communication Strategy

The Senior Communication Officer used the information from the consumer mind mapping exercise to draft the communication strategy. This strategy included draft emails for disseminating the resources, a list of stakeholders, how and why each stakeholder was being approached, and tracking. A snapshot of this table is shown in Table 5.

Table 5: Snapshot of stakeholder approach table

Stakeholder	Contact method	Opportunities to share with patients	Date contacted	Response Y/N	Uptake Y/N
TAVI Coordinators	Email from TAVI Registry	In consults with patients, waiting rooms and patient packs			
TAVI / Cardiac Surgeons	From TAVI Coordinators	In consults with patients, in waiting rooms and patient packs			
GPs	Senior Project officer to meet with Adelaide PHN who will share with GPs	In visits to GP Practices			

The communications strategy was shared with the registries for their feedback. The registries were specifically asked the following questions:

a) Are there any stakeholders who should not be approached?

b) Have any stakeholders been missed who interact with the target audiences?

c) Do you have a relationship with the stakeholders and should make the initial approach?

Minimal changes were made to the stakeholder list. The strategy was shared with the consumers for their final approval, which was received with no changes.

Dissemination of Resources

The Senior Project Officer enacted the communications plan and tracked responses to the approaches.

3.2.6 User Guide Development

Throughout the project, the Senior Project Officer documented the processes detailed above and recorded lessons learnt to inform the content of a user guide for registries to follow when translating registry outputs into consumer-friendly resources. In an environment where resources are constrained and time available to registry teams is limited, it was felt that providing a tried-and-tested user guide would be an asset to registries intending to develop consumer friendly resources.

The guide provides a step-by-step process and includes the templates used in this pilot project, eliminating the need for registries to start from scratch.

This guide is available from the Department's website and the SAHMRI Registry Centre website.

3.2.7 Knowledge Sharing

To more broadly share the knowledge gained whilst undertaking this project, the planning and establishment phase of the project—through to the development of accessible versions—was documented in a case study manuscript to guide other registries in creating consumer-friendly resources from registry outputs and findings. As of June 2025, the manuscript had been submitted to a peer review journal and is awaiting publication.

3.2.8 Registry Feedback

At the final SAHMRI Registry Centre Executive Group and CoFI Project Management Team meetings, the Senior Project Officer shared the final resources with the groups.

Members of each group were asked their thoughts on the final resources and the co-design process. This was an informal group discussion, where members provided feedback and their perspectives on the project. A summary of registry feedback is presented in Appendix B.

3.2.9 Consumer Feedback

At the final CoFI Consumer Group meeting, the Senior Project Officer shared the final resources with the Consumer Group. The consumers were asked to reflect on the process of creating the resources and the wins and challenges from their perspectives.

Following the meeting, the consumers were invited to provide additional feedback in a short survey. A summary of consumer feedback is presented in Appendix B.

4. Findings and Recommendations

The following section summarises the project findings and provides recommendations aimed to support registries in the implementation of consumer co-design projects.

4.1 Feedback

Consumer involvement in health and medical research is becoming increasingly common, driven by its many benefits – such as better alignment with community needs and more effective translation of findings.

Reflecting this growing recognition, the Australian Framework for National Clinical Registries 2024 recommends that Clinical Quality Registries consider the priorities of consumers in all aspects of their function. This includes the way information is provided to the community, with a clear emphasis on making registry reports accessible and appropriate for consumer use.

This project showed that for consumer involvement to be effective, it must be genuine and purposeful—not a 'tick box' exercise. Consumers can quickly sense when their input is undervalued and may disengage as a result (Ng et al., 2025[6]).

In the CoFI project, consumers were given clear roles and real decision-making power. The co-design process demonstrated that registries can successfully develop a range of consumer resources—such as infographics, lay summaries, factsheets, information booklets, videos, and animations—from their findings and outputs. These resources were then shared with relevant consumer-facing stakeholders, who expressed willingness to distribute them to the communities they serve.

4.1.1 Consumer Views

The consumers were all aligned in the feedback they provided (Appendix B). They reported high satisfaction with the final resources and felt the materials would have been helpful during their own health journeys and believed they would support others facing similar challenges. Consumers noted that the resources helped fill important gaps in the information currently available to the public. They all found the project valuable and expressed interest in continuing to work with registries in the future, encouraging other registries to adopt a similar co-design process when developing consumer resources.

Recommendation 1: Registries are encouraged to adopt a consumer co-design process to translate relevant registry findings into consumer resources as part of their core business.

Sharing registry findings with the public in consumer-friendly formats and locations will assist patients and their families in navigating health and life challenges.

4.1.2 Registry Views

The Registry Centre Environmental Scan (Appendix C) indicated that 53% (n=9) of registries reported that they have additional outputs that would be beneficial to consumers if translated into lay terms. Despite this, 25% (n=2) of registries reported that translating findings was a low priority for them.

Feedback from two of the CoFI Project participating registries indicated that they felt the resources were highly valuable to consumers but not aligned with the primary purpose of their registries – supporting clinicians in practice, rather than serving the community directly (see Appendix B). They viewed their role as generating and presenting data as-is, leaving it to others to interpret or repurpose for broader use.

Evidence shows that more informed consumers contribute to improved patient outcomes through better healthcare engagement and decision making (Ng et al., 2025[6]). Therefore, as per the guidance in the Framework it is important that registries develop a stronger understanding of the value of consumer resources in achieving this goal.

As registries develop and align themselves with the Framework, informing consumers would be considered an expectation of the role of mature, high functioning CQRs.

Recommendation 2: Build sector-wide understanding of the value of consumer-friendly resources in improving patient outcomes to expand translation activity across the registry sector.

Given that 25% of registries reported placing a low priority on the development of accessible resources, without education on the broader societal benefits and a commitment to improving health outcomes, registries may be less inclined to engage in the co-design process. One way to inform the sector of the value of working with consumers could be through showcasing the positive health impacts of co-design projects—shared by larger registries and consumers—at sector-wide conferences.

Registries further reported that they do not have the budget, skills or time to create consumer resources in the absence of the dedicated time and funding provided to the Senior Project Officer. Even with the external resource provided through this project, registry feedback (Appendix B) indicated that their contribution of time was significant and a barrier to work of this type.

This is in line with responses received from the SAHMRI Registry Centre Environmental Scan (Appendix C). Respondents were asked to rank the factors that prevented them from translating registry outputs into consumer resources. 88% (n=7) of respondents indicated that insufficient staffing resources was their top reason, with the second most common response being lack of financial resources.

To support registries in co-designing consumer resources, external funding such as grants and project funding, in addition to core funding, should be considered to support co-design activities.

Recommendation 3: Registries be appropriately funded and resourced to embed the co-design and translation of consumer-friendly resources into core business.

To enable sustained engagement in co-design, registries require adequate funding, staffing, and support - without which the creation of meaningful consumer resources is unlikely to occur.

4.2 Development of Consumer Resources

As a pilot project, initial ideas and approaches were trialled - some were more successful than others, leading to the development and testing of new strategies. This section outlines where the project deviated from original expectations, the challenges encountered, lessons learned, and the adaptations made in response. These insights have been built into the User Guide to strengthen the design and delivery of future projects.

4.2.1 Selecting Registry Findings and Outputs to Translate

The project found that not all registry outputs are equally valued by consumers. Some offer clear insights to support health decisions, while others are highly technical or theoretical. In this project, consumers preferred practical, decision-supporting resources, while registries tended to prioritise clinically significant findings.

For example, during development of the ACGR resources, consumers found some of the technical content in the ACGR output to be too complex and unnecessary for a consumer-friendly resource. They viewed it as information intended for clinicians and chose to remove it from the final design.

The SAHMRI Registry Centre environmental scan indicated that only 40% (n=8) of member registries have consumers collaborating on interpreting registry results (Appendix C). However, this question did not delve into whether the interpretation leads to consumer-friendly ways of displaying the resource or simply a co-interpretation activity.

Each registry independently selected the findings and outputs to translate, without consumer input. Involving consumers in this process from the outset would likely have prevented duplication and ensured the final resources were better aligned with community needs. Guidance to involving consumers in the selection of findings for translation is recommended.

4.2.2 Terms of Reference

Analysis of the SAHMRI Registry Centre environmental scan found that of the 15 (75%) registries who do not have a consumer advisory group, five indicated they would like assistance to establish one (Appendix C). The development of guidance in this area is recommended.

We found that a well-considered Terms of Reference (ToR) was key to successful recruitment and setting clear expectations (Appendix A). It outlined the project's purpose, ideal consumer profiles, and clearly defined roles. Initially, the project aimed to recruit two consumers with direct experience of each condition, including the TAVI procedure. Despite extensive efforts, the Senior Project Officer was unable to recruit participants with direct TAVI experience, likely due to the advanced age and health status of this group. Two consumers with broader cardiac experience were engaged instead.

Having contingency plans in place from the outset—for both consumer profiles and recruitment channels—would have allowed the team to adapt more quickly and avoid delays.

4.2.3 Resource Selection Parameters

The project found that the time and cost required varied significantly across formats - printed materials are generally faster and cheaper to produce, while videos and animations require longer timelines and higher budgets. For example, a 5-minute video cost around $3,000 and took 5 weeks to produce, and a 2-minute animation cost around $17,000 and took 10 weeks to produce. By contrast, a lay summary of an academic paper cost around $500 and took 2 weeks to produce.

Discussing budget, timelines, and other limitations early helps to manage expectations and focus co-design on viable options. In one case, a group developed a video storyboard, only to find no experts were available to be filmed. The group pivoted to an animation, which worked well but was more expensive and delayed delivery by three months. Without the budget for this change, the design process would have needed to restart.

Throughout the project it became clear that registries must at the outset outline any constraints in time, cost, availabilities or resourcing that could affect the final product before guiding consumers to choose a resource type (e.g. lay summary, factsheet, booklet, video, animation). Guidance on this process is recommended.

4.2.4 Accessibility

The pilot found that when designing consumer resources for broad use, it's important to consider how different people access and engage with information. Simplifying content and design for accessibility - such as for those with communication challenges or those with low vision - can make resources less engaging for others without these challenges.

In this project, the focus was on creating engaging resources for broad audiences. Initial attempts to adapt the main resources for accessibility reduced their visual appeal and engagement. In response, separate versions were created for people with low vision or specific communication needs to ensure they could access the information provided. This approach extended the reach and usability of the resources without compromising engagement for the broader community and is recommended as low-cost approach to providing accessible resources.

4.2.5 Dissemination

As part of the communications strategy, registries and consumers identified contacts within target organisations. When a known contact was available, registry staff made the first approach or provided a direct email address. If no contact was known, the Senior Project Officer sent the resource to a generic inbox.

Results of this process show the value of personalised outreach:

- Registry staff making the initial contact achieved a 100% response rate with confirmed agreement to share the resource.
- The Senior Project Officer emailing a known registry-provided contact also achieved a 100% response rate with confirmed agreement to share the resource.
- When the Senior Project Officer emailed a generic inbox, the response rate dropped to 11% with confirmed agreement to share the resource.

This highlights the importance of leveraging existing relationships to maximise engagement and resource uptake.

4.2.6 Maintaining currency

One of the key challenges in creating resources from registry data is that the data continually changes, which can quickly render resources outdated.

There are various considerations around the currency of resources. Data is inevitably ‘moment in time’ relative to the research activity being undertaken. Approaches could include:

- creating simpler formats such as infographics, factsheets, and booklets that can be easily and affordably updated
- clearly stating the data's publication date and noting that it is subject to change
- presenting consumer resources alongside the corresponding registry outputs to reinforce the link to current findings (this is particularly important for academic papers).

To ensure consistency between original academic papers and subsequent translations, it is recommended they be published in parallel to facilitate consumer access to plain language content with accurate context.

Recommendation 4: Registries adopt the ‘A registry guide to co-designing consumer friendly resources’ to support the translation of registry outputs.

This practical resource will equip teams to avoid common challenges, build consumer resources efficiently, streamline processes and foster meaningful collaboration between registries and consumers.

4.3 Impact of Resources

Assessing the impact of the consumer resources was beyond the scope of this pilot project. Aside from positive feedback from participating consumers who felt the resources would be beneficial, and some encouraging responses from stakeholders involved in dissemination, no formal assessment of reach or impact has been undertaken.

A follow-up project focused on evaluating the consumer resources’ reach, user engagement, influence on consumer understanding and decision-making, and any measurable effects on health outcomes would provide valuable insights into the impact of translating registry resources into consumer-friendly resources.

Recommendation 5: That a comprehensive evaluation of the impact and usefulness of consumer resources developed from registry data be conducted.

Such evaluation is important to demonstrate effectiveness to the registry sector, justify ongoing investment, and guide improvements that maximise benefits for consumers and the broader community. It could also be broadened to include consumer resources developed by other registries beyond the CoFI project. Note that undertaking this evaluation would require additional funding.

5. Discussion

The CoFI project demonstrated that registries can successfully partner with consumers to co-design engaging, relevant, and accessible resources that translate complex registry outputs into formats that better support patient understanding and decision-making. All participating consumers (100%) reported high satisfaction with the final products and believed the resources would have been valuable during their own health journeys - particularly at key decision points such as diagnosis.

This was echoed by two participating registries, which acknowledged the usefulness of the created resources for consumer education. However, the project also highlighted a significant gap: without dedicated project funding and staffing, registries lack the capacity to carry out consumer co-design activities.

Translation projects are resource-intensive and have not traditionally been considered core to the work of registries. However, the Framework clearly signals an expectation that consumers should be involved in translating findings.

Findings from the SAHMRI Registry Centre Environmental Scan further reinforced this:

- 53% (n=9) of registries indicated they had outputs that would benefit consumers if translated.
- 88% (n=7) identified insufficient staffing as the main barrier to translation work.
- 25% (n=2) stated that consumer translation was currently a low priority.

The project also showed that misalignment between registries and consumers on what findings to translate and what formats to use can lead to delays or misdirected efforts. Involving consumers early in the selection of outputs and clearly discussing limitations around budget, time, and resourcing significantly improved the quality and relevance of the end products.

Finally, the project identified the importance of planned dissemination and maintaining currency of resources. Personalised stakeholder outreach greatly increased uptake, and creating flexible, easy-to-update formats supported sustainability. These practical learnings have been compiled into a User Guide, now available to support other registries in future co-design projects.

6. Conclusion

The CoFI project confirmed that consumers see real value in translating registry outputs into consumer-friendly formats. When involved meaningfully, they can play a critical role in ensuring resources are useful, accessible and impactful.

While the potential to improve health outcomes through consumer-informed resources is clear, realising this impact across the registry sector will require targeted education to build sector-wide understanding of the benefits of co-design, as well as practical support through funding, staffing, and capability-building.

This report outlines the key findings and provides practical, actionable recommendations to support registries to embed co-design into core business. With the availability of the User Guide, registries can follow clear, practical steps when translating registry outputs and findings into consumer-friendly resources.

Importantly, this report articulates the health, social and economic benefits of registries partnering with consumers to translate and share health knowledge. These include increased consumer confidence in diagnoses and treatments, more informed consumer engagement in their healthcare, maximising the benefit value of registries by broadening the target audience, and crucially, better application of evidence-based data to support individualised treatments, resulting in improved outcomes and reduced burden on the health system.

7. Appendices

Appendix A – CoFI Consumer Group Terms of Reference

Vision

Create and disseminate easily understandable and reliable resources direct from registries, to empower consumers and their families to make informed decisions about their health.

Consumer Friendly Information (CoFI) Project

Using a collaborative consumer co-design approach across three mature national Clinical Quality Registries (Registry of Senior Australians (ROSA), Australian Corneal Graft Registry (ACGR) and Transcatheter Aortic Valve Implantation Registry (TAVI)), the COFI project will:

1. Translate registry outcome data and reports into consumer appropriate formats
2. Create consumer co-designed resources (new or enhanced), to inform consumers and guide decision making
3. Disseminate resources via consumer informed pathways to increase accessibility
4. Futureproof processes and develop guides to assist other registries to implement similar processes.

Purpose and Role of the CoFI Consumer Group

The CoFI Consumer Group will work with the Senior Project Officer at the SAHMRI Registry Centre to create and disseminate a series of consumer-friendly resources, from registry outcome data and reports, for the purpose of empowering consumers to make informed decisions about their health.

Through monthly workshops, this group will:

- Define the purpose and objectives for each resource that is to be developed, including the format of resource (i.e. fact sheet, video, podcast)
- Co-design the prototype process
- Test prototypes and provide feedback, ensuring content is easily understood, produced in user-friendly layouts, and follows Web Content Accessibility Guidelines. This process will include multiple iterations
- Identify suitable dissemination pathways, in collaboration with broader stakeholders (i.e. clinicians, hospital healthcare workers)

Membership

The CoFI Consumer Group will be chaired by the Senior Project Officer, SAHMRI Registry Centre, and will consist of 9 members.

Table 6: CoFI Consumer Group membership

Position	**# of Consumers**	**Method for recruitment**
Consumers who have undergone a corneal transplant for keratoconus	2	ACGR recommended two consumers from the *ACGR Consumer Group*.
Consumers with experience with the Australian aged care sector	2	Presentation at a *ROSA Consumer & Community Advisory Committee* meeting.
Consumers with experience of heart-related health issues	2	Recruitment through Health Translation SA's *Community Interest Register*.
General consumer with significant experience navigating health challenges – in any area.	3	Recruitment through Health Translation SA's *Community Interest Register*.

Experience, Knowledge and Skills

Members of the CoFI Consumer Group will have:

Essential:

- Personal experience in consuming health information
- Great communication skills
- Ability to work collaboratively and as part of a team
- An interest in developing and reviewing resources to empower other members of the community to improve their health

Desirable:

- Understanding of Web Content Accessibility Guidelines or experience in the development of resources for individuals with a disability or from CALD communities

Term

Members are appointed for 14 months with the opportunity to join the SAHMRI Registry Centre Consumer Group to be established at the completion of this project. 1-3 hour monthly meetings will be held in-person at SAHMRI on a Thursday afternoon – time and dates TBC.

Member Responsibilities

The Senior Project Officer, SAHMRI Registries Centre is responsible for:

- Providing information, training and development opportunities to members relevant to their role on the Advisory Group.
- Providing the necessary resources needed to undertake agreed tasks and to participate in meetings.

- The secretariat support to the Consumer Group.
- Provide regular updates to the CoFI group members

CoFI Consumer Group members are responsible for:

- Sharing their knowledge, skills and experience to inform the project.
- Attending and actively participating in CoFI Consumer Group meetings and responding to reasonable and agreed out-of-session requests for advice.
- Actively participating in the development of and review of consumer friendly resources.
- Identifying and reporting an interest that is in potential or actual conflict with their involvement in the CoFI project.
- Notifying the Senior Project Officer as soon as practical, if any matter arises which may be deemed to affect the progress of the CoFI project or their ability to remain on the Consumer Group

Operating Procedures

Quorum

Quorum is considered at least half plus one of the CoFI Consumer Group membership.

Decision-making

The role of the CoFI Consumer Group is advisory, and decision-making is via consensus with divergent views and rationales noted in the minutes.

Sitting Fees

Consumer members are eligible for sitting fees and reimbursement for out of pocket expenses in-line with the SAHMRI Consumer and Community Engagement Policy for Reimbursement and/or Sitting Fees of Advisory Groups. Please note, the reimbursement rate will be $50/hour.

Meeting schedule

The CoFI Consumer Group will meet monthly, for between 1-3 hours. There may also be occasions when members are invited to attend events, or training and development opportunities, outside of the regular meeting schedule.

Meeting venue

Meetings will be held at SAHMRI, unless otherwise indicated.

Meeting papers

Agenda papers will be circulated at least a week prior to the CoFI Consumer Group meetings.

Minutes or meeting notes will be sent within a fortnight of each meeting and confirmed at the following meeting.

Other Terms and Conditions

Disclosure of members' personal information

The Privacy Act allows disclosure of personal information in a few circumstances, including where the individual has been made aware that information of that kind is usually disclosed, or the person has consented to the disclosure.

Members are advised that their names, official positions outside the CoFI project, relevant expertise and biographical details may be included on project documentation and reporting, including online publications.

Under these guidelines, it is construed that members of the CoFI Consumer Group have given implied consent to their names as members of this Group being publicly disclosed, unless otherwise indicated.

Conflict of Interest

A conflict of interest arises when a member has a direct or indirect interest which influences, or may appear to influence, the undertaking of functions relating to the above terms of reference in a fair and independent manner.

A conflict of interest may include any of the following, or a combination of them:

- Actual - when an interest is known to exist
- Potential - when the interest is believed to be under consideration or discussion

Members are requested to disclose to the Senior Project Officer, SAHMRI Registry Centre any personal, financial or other interest which may represent an actual or potential conflict of interest at the start of their participation on the CoFI Consumer Group or alternatively at a respective meeting if an issue arises during their involvement. The responsibility to identify and report an interest that is in potential or actual conflict with their involvement, or has the appearance of such a conflict, always rests with the member.

Confidentiality

It is the responsibility of CoFI Consumer Group members and the Senior Project Officer, SAHMRI Registry Centre, not to disclose to any person any confidential information (including confidential commercial information), to which they become privy because of their involvement with the CoFI project.

This does not prohibit disclosure of information in the undertaking of functions relating to the above terms of reference.

Intellectual Property

Members warrant that anything done during this project does not infringe the Intellectual Property rights of any person.

Members’ contribution to the outcomes produced by the CoFI project will be appropriately acknowledged throughout the course of their involvement on the CoFI Consumer Group.

Appendix B - CoFI Project Feedback

Registry Feedback

The participating registries were asked to share their feedback informally during a SAHMRI Registry Centre Executive Meeting and a CoFI Project Management Team meeting. This is summarised below.

Time and Budget Constraints

Registries noted that developing consumer-friendly resources required a significant time investment from their staff - even with the support of the Senior Project Officer leading the process. A common concern was that without dedicated additional project management with the right skill set, they would not have the time, skills or budget to produce such resources independently.

Registry Scope and Purpose

Two registries noted that while they recognised the value of consumer-friendly resources for the community, developing such materials falls outside the core remit and purpose of their work – being to support clinicians and not the community. They viewed their role as generating and presenting data as-is, leaving it to others to interpret or repurpose for broader use. They expressed concern that dedicating time and resources to resource development diverts attention from their primary functions and offers no direct benefit to the registry itself.

Resource Content

One registry expressed concern that the translated resources included information beyond the original registry outputs. They felt that this additional content could be accessed through other sources and did not see value in including it. This view contrasted with the consumer perspective, creating some tension between the registry’s preference for strict alignment with its outputs and the consumers’ desire to provide broader, more helpful context.

Consumer Feedback

Consumers were asked to share their feedback on the project via a survey and informally in the final CoFI Consumer Group meeting. The feedback is summarised as follows.

Importance of Consumer Involvement in Registries

All consumers found the project valuable and expressed an interest in continuing to work with registries into the future. A common concern was that registries are not considering what is important to consumers and involving them would benefit the public.

Resource Providing Clarity

All consumers expressed high satisfaction with the final resources developed. They felt the materials would have been valuable in helping them navigate their own health experiences. In particular, the keratoconus resources were highlighted as something that would have been especially helpful to the two consumers during their diagnoses, providing clarity and support at a time when they needed it most.

SAHMRI Registry Centre Consumer Group

There is potential to establish a SAHMRI Registry Centre Consumer Group, which could serve as a shared resource for registries. Six out of nine consumers indicated their interest in joining the group.

Appendix C - SAHMRI Registry Centre Environmental Scan – Consumer Engagement

The SAHMRI Registry Centre environmental scan indicated that only 40% (n=8) of member registries have consumers collaborating on interpreting registry results. Data extracted from the SAHMRI Registry Centre Environmental Scan (Table 7) shows responses from 20 registries on their current consumer activities.

Table 7: Health consumer or community involvement in registries

Consumer Engagement	Results (N, %)
Health consumers or community members in at least one area of the registry	15, 75%
Co-designing the information being collated	9, 45%
Registry set-up	8, 40%
Collaborating on interpreting results	8, 40%
Established a separate Consumer Advisory Group	5, 25%
Governance committee representation	4, 20%

Translation of Outputs

More than half (53%, n=9) of the SAHMRI Registry Centre members indicate they have additional outputs that would be beneficial to consumers but require translation into lay terms. Table 2 shows responses from eight registries on the factors which prevent the registry from translating registry outputs.

Table 8 Translation of registry outputs for consumers and factors which prevent translation

Translation of Outputs	Results (N =17)
Have additional outputs that would be beneficial to consumers but require the translation into lay terms	9, 53%
Factors that prevent the translation of registry outputs for consumers (N=8)*	
Insufficient staffing resources	7, 88%
Low priority	2, 25%
Complexity of the information	2, 25%
Other - lack of financial resources for breadth of translations required	2, 25%
Lack of affiliation with consumers	1, 13%
Lengthy approval process for review of documents	1, 13%

**Registries who responded ‘no’ (n-8) were asked to provide factors which prevent the translation of outputs for consumers.*

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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.

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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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