

# BMJ Open Quality 'The way that we are collecting and using data has evolved' evaluating the Australian National Stroke Audit programme to inform strategic direction

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## ABSTRACT

**Background** The National Stroke Audit has been used to audit and provide feedback to health professionals and stroke care services in Australia since 2007. The Australian Stroke Clinical Registry was piloted in 2009 and numbers of hospitals participating in the registry are increasing. Considering the changing data landscape in Australia, we designed this study to evaluate the stroke audit and to inform strategic direction.

**Methods** We conducted a rapid review of published literature to map features of successful data programmes, followed by a mixed-methods study, comprising national surveys and interviews with clinicians and administrators about the stroke audit. We analysed quantitative data descriptively and analysed open-ended survey responses and interview data using qualitative content analysis. We integrated data from the two sources.

**Results** We identified 47 Australian data programs, successful programs were usually funded by government sources or professional associations and typically provided twice yearly or yearly reports.

106 survey participants, 14 clinician and 5 health administrator interview participants were included in the evaluation. The Stroke Audit was consistently perceived as useful for benchmarking, but there were mixed views about its value for local quality improvement. Time to enter data was the most frequently reported barrier to participation (88% of survey participants), due to the large number of datapoints and features of the audit software. Opportunities to improve the Stroke Audit included refining Audit questions, developing ways to automatically export data from electronic medical records and capturing accurate data for patients who transferred between hospitals.

**Conclusion** While the Stroke Audit was not perceived by all users to be beneficial for traditional quality improvement purposes, the ability to benchmark national stroke services and use these data in advocacy activities was a consistently reported benefit. Modifications were suggested to improve usability and usefulness for participating sites.

## INTRODUCTION

Audit and feedback is commonly used to improve the quality of healthcare, professional practice and healthcare outcomes.<sup>1 2</sup> Audit and feedback consists

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Audit and feedback are commonly used to monitor and improve quality of care. The Australian National Stroke Audit occurs biannually and provides a snapshot of quality of care of Australian stroke services. Given only 40 cases/site are audited every 2 years, it was important to evaluate the benefits of Audit participation.

## WHAT THIS STUDY ADDS

⇒ Participation in the Audit was valuable to new stroke services and sites with no previous Audit involvement. Sites with long-term participation in the Audit reported equivocal benefit for local quality improvement. Perceived benefits of participating in the audit included availability of data for national advocacy activities and the opportunity to educate clinicians about the stroke guidelines.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The Audit will continue to provide access to national data for advocacy activities in Australia. Adjustments to Audit reports will occur to allow more sophisticated benchmarking of 'like' services. Research and development activities are underway to investigate systems to automatically export data from electronic medical records to the Audit.

of measuring performance of individuals, healthcare teams or services against professional standards or evidence-based recommendations, and then providing a summary to those audited.<sup>1</sup> In the Cochrane review (140 randomised trials), audit and feedback led to a median 4.3% absolute improvement in compliance with recommended practice, but the effect varied substantially between trials.<sup>1</sup>

In Australia, Stroke Foundation is a registered charity, which drives quality improvement by developing and maintaining clinical guidelines and coordinating national audits.<sup>3 4</sup> The National Stroke Audit (hereafter referred to as the Audit) commenced



in 2007 and is conducted annually, alternating between acute and rehabilitation care. The Audit comprises an organisational resource survey, and a retrospective medical record audit of 40 consecutive patient admissions at each participating site to monitor adherence to guideline recommendations. Participation is voluntary and participation rates are high; 89% of acute admissions for stroke<sup>5,6</sup> and 92% of inpatient rehabilitation admissions for stroke<sup>7</sup> are to hospitals that participate in the Audit. Sites provide in-kind staff time to collect data, and coordination, data analysis and reporting are managed by Stroke Foundation.

The data landscape in Australia has evolved since the Audit was initiated. The Australian Stroke Clinical Registry (AuSCR) was piloted in 2009 to collect data on core processes of acute stroke care and patient reported outcome measures in all consecutive admissions of stroke or transient ischaemic attack.<sup>8</sup> The AuSCR provides an additional mechanism for delivering audit and feedback to participating sites, although with fewer datapoints included than the Audit. The number of acute hospitals participating in the AuSCR is steadily increasing, although it has yet to achieve national coverage.<sup>8</sup> Concurrently, more hospitals have transitioned to electronic medical records<sup>9,10</sup> and maintain local stroke data systems.

Considering the changing context regarding stroke data programmes in Australia, the aim of this study was to inform strategic direction and opportunities to maximise the impact of the National Stroke Audit programme by:

1. Identifying characteristics of successful data programmes for diseases other than stroke in Australia.
2. Understanding the views of clinical and administrative stakeholders about the Audit.
3. Understanding factors influencing site involvement.
4. Identifying opportunities to improve the Audit.

## METHODS

### Rapid review

To identify national clinical data programmes, we searched grey literature (Google and Google scholar) using combinations of the terms audit OR registry AND Australia. We restricted our search to publications within the last 10 years and programmes which communicated primarily in English. The search was not intended to be exhaustive but to focus on the largest and most established data programmes. One person conducted the search and a second person searched for additional relevant information that may have been missed. We included information sourced from websites, reports, policy documents and scientific papers in academic journals. We included data programmes (audits or registries), which were large in scale (more than one site).

One person extracted data including funding, governance, setting, stakeholders, outputs, longevity of programme, participants, clinical condition into a table (where these data were available). A second person checked the accuracy of data extraction in 10% of

entries. We identified data programmes, which appeared to be most successful based on our nominated criteria of longevity (existing for 3 or more years), size (five or more sites) and provision of feedback to sites.

### Survey

We used mixed methods (surveys and interviews) to seek perspectives of clinicians and state-based administrators involved in stroke care.

We created a survey comprising demographic information, closed-ended questions about participation in and attitudes to the Audit, and open-ended questions about changes to the Audit (see online supplemental appendix 1). The survey was piloted in Qualtrics by the research team and edited prior to distribution.

The link to the online survey was emailed to contact people from hospitals that had previously participated in the National Stroke Audit (295 potential participants from 169 hospitals on the Stroke Foundation National Stroke Audit database), on 25 October 2021. Two reminders were sent at weekly intervals. Respondents were invited to indicate their interest in participating in follow-up interviews.

### Interviews

We developed two interview guides: one for clinicians and another for state-based administrators involved in stroke care. The interview guide for clinicians was piloted and no adaptations were required.

We emailed interested clinician survey respondents and Stroke Foundation emailed state-based administrators in three states, inviting them to participate in interviews. We interviewed clinicians and administrators separately. When possible, group interviews were organised; individual interviews were organised when only one participant nominated for a proposed time, or to suit participants' availability. Repeat interviews were not conducted and field notes were not made.

EL, a physiotherapist and researcher, facilitated all interviews via Microsoft Teams. She presented the aims of the research to participants and clarified the research team's independence from Stroke Foundation. Automatic transcripts were reviewed for accuracy and were not returned to participants. Data from preceding interviews were sometimes presented for discussion with subsequent participants to determine consistency in participants' views. Data saturation was reached with no new themes identified within the data from the last three clinician interviews.

### Analysis

We analysed quantitative survey results descriptively using SPSS version 27. We dichotomised attitudes to the Audit into positive (strongly agree/somewhat agree with listed statements) and not positive (strongly disagree/somewhat disagree/neither agree nor disagree).

EL and TL conducted qualitative content analysis<sup>11</sup> on open-ended survey responses and interview data.

Data from each transcript pertinent to three topics of interest (views about the Audit; factors influencing participation; strategies to improve Audit) were highlighted and grouped using tables in Microsoft Word. Themes pertaining to each area of interest were inductively identified and illustrative quotes are presented.

We compared data from both sources and presented the integrated findings according to our study aims. We have reported numbers of responses when presenting survey data, and an overview (eg, numerous, some, rarely) of how often interview participants discussed themes. Interview participants were sent a summary of results but did not provide feedback on the findings.

### Patient and public involvement

People with stroke and carers provide input into the Stroke Audit report and executive summary. People living with stroke were not directly involved with the design or analysis of this study which was explicitly designed to evaluate the usefulness of the audit for clinical services.

## RESULTS

### Rapid review

We identified 47 Australian data programmes, comprising 22 audits and 25 registries. Details of these programmes are presented in online supplemental appendix 2. Both audits and registries included state-based and national programmes and a range of clinical conditions. We identified six audits<sup>12-17</sup> and six registries<sup>18-23</sup> which met our predetermined criteria of success (collected data over 3 years or more, involved five or more sites and provided feedback or access to data to participating sites). These successful programmes involve most or all applicable sites in Australia, and many had obtained long-term funding from government sources (eg, Department of Health) or from the relevant professional association. Participation in three audit programmes is mandatory for the relevant health professionals (surgeons, breast cancer surgeons, vascular surgeons).<sup>12-14</sup> Most programmes produce twice yearly or yearly reports and offer information to benchmarks sites' performances.

### Audit evaluation

There were 106 survey responses included. Response rates were 36% (106/295) for individuals and 52% (88/169) for organisations. All states and territories were represented at similar proportions as in the Audit. About two-thirds of organisations treated  $\geq 100$  stroke patients annually. Most respondents were nurses with  $\geq 11$  years of experience (table 1), reflecting the role that nurses commonly play in overseeing site participation in the Audits.

Nineteen people (14 clinicians, 5 administrators) from 5 states/territories participated in interviews. Four group (2-4 participants) and three individual interviews were conducted with clinicians (see table 2 for demographic details). One group (three participants from one state) and two individual interviews were conducted

**Table 1** Demographics of respondents and the participating organisations, and for all National Stroke Audit participants

Variable	Categories	n (106)	%	% in national audit
State/territory	ACT	1	0.9	0.9
	New South Wales	34	32.1	32.9
	Northern Territory	3	2.8	1.4
	Queensland	17	16.0	20.7
	South Australia	10	9.4	6.1
	Tasmania	4	3.8	2.8
	Victoria	24	22.6	26.3
	Western Australia	13	12.3	8.9
Funding	Public	93	87.7	92.5
	Private	7	6.6	7.5
	Mixed	6	5.7	
Location	Metropolitan	59	56.2	75.6
	Regional	43	41.0	24.4
	Other	3	2.9	
Unit	Stroke acute care only	28	26.7	
	Acute and rehabilitation	39	37.1	
	Rehabilitation only	32	30.5	
	Other	6	5.7	
No of patients per year	Less than 100	34	32.4	
	100 or more	71	67.6	
Profession	Medicine	16	15.2	
	Nurse	60	57.1	
	Physiotherapist	6	5.7	
	Occupational therapist	12	11.4	
	Speech pathologist	2	1.9	
	Administration/clinical	1	1.0	
Years' experience	Other	8	7.6	
	0-1	1	1.0	
	2-5	12	11.4	
	6-10	31	29.5	
	11 or more	61	58.1	

ACT, Australian Capital Territory.

with administrators from three states. Interviews lasted between 30 and 60 min.

### Views about the Audit

The majority of survey respondents (n=58, 59%) participated in both acute and rehabilitation audits. 19% participated in the acute audit only, and 17% in the rehabilitation audit only. Just over 40% of respondents participated in the AuSCR, and one-third reported using local data

**Table 2** Clinician interview participant demographics

Clinician interview participant demographics	N=14 (%)
Female sex	13 (93)
State	
New South Wales	6 (43)
Victoria	3 (21)
South Australia	2 (14)
Queensland	2 (14)
Northern Territory	1 (7)
Stroke care provision	
Acute only	8 (57)
Rehabilitation only	2 (14)
Acute and rehabilitation	4 (29)
Years' experience working with stroke	
2–5	1 (7)
6–10	5 (36)
11+	8 (57)
Professional role	
Nurse	6 (43)
Stroke coordinator	4 (29)
Physiotherapist	2 (14)
Neurologist	1 (7)
General physician	1 (7)

programmes. Interview participants suggested that the lack of alternative data programmes relevant to rehabilitation service delivery strengthened the value of the rehabilitation audit.

We are more interested in the rehab [Audit] rather than the acute. And that's probably because AuSCR doesn't give us much in the rehab space [Clinician\_1]

Virtually all survey respondents (n=96, 98%) participated in the Audit to monitor local quality improvement. The next most frequent response was benchmarking against peer hospitals (n=83, 85%). These findings were validated at interview, with all administrators reporting the Audit provided access to national data and the ability to benchmark against other sites and states. However, administrators had conflicting views regarding usefulness of Audit data for improving stroke care; administrators from two states reported that the small numbers audited and the delay between care provision and receiving feedback limited the Audit's usefulness, whereas a third state reported using Audit data to set state priorities and evaluate changes.

It's been really useful to review our priorities...to say...these are all the things we're trying to achieve, but what do we need to focus on first? And how do we need to prioritize that and then using that as a benchmark? So then...we use this as a mechanism in

which to measure and evaluate the changes that we do try to put in place. [Administrator\_1]

Most clinician interviewees reported no longer using Audit data to initiate or monitor quality improvement projects. One exception was a respondent from a site without a dedicated stroke unit who reported using Audit data to advocate for improved clinical care provision.

Having that hard data to feedback to colleagues, managers, the hospital has been incredibly helpful. I feel like I'm doing the battle that the...bigger hospitals had ten years ago, bringing thrombolysis in and I had a lot of resistance to that within the hospital, so... instead of me just being this, "Hey yeah, let's do it", it's me coming along and saying "We've been part of this nation-wide thing, this is where we sit"...It's also been a way to get...allied health and some nursing staff on board about some of the data we should be collecting and what should be documented and trying to improve our clinical pathways [Clinician\_2]

Most survey respondents indicated positive attitudes to the Audit with high ( $\geq 80\%$ ) levels of agreement with the nominated statements (table 3). Excluding the one negatively worded statement, the item with the lowest level of agreement was about Audit data accurately reflecting clinical practice (66% agreement).

Interview participants frequently described concerns that data were only collected about processes of care received within each hospital, which did not reflect care received by patients transferred between acute and regional hospitals or retrieved via the stroke ambulance.

We are an ECR [endovascular clot retrieval] centre, so we transfer a lot of patients in for ECR, which the Audit doesn't really reflect...The patients are being discharged through us to another...hospital...So then it shows that we're doing poorly in secondary prevention which is not actually true because...they're actually being transferred elsewhere and they'll get all of that work up...I think the data doesn't really reflect what's happening to our patients [Clinician\_3]

Further, participants reported concerns due to the small numbers of cases reviewed.

I always...flag for people to be cautious with the data that's presented, for example, our thrombolysis rates. So it's only 40 patients, when we did our audit for 2021, there was only one patient in those 40 that was thrombolysed. And so that's 3%. And that's not reflective of our overall 12-month lysis rate [Clinician\_4].

Interview participants also suggested that the Audit was not sensitive enough to capture when care was tailored to an individual's needs, because the questions did not reflect when care was not indicated.

You don't actually know what the reason is that we're not mobilizing people. It might be a haemorrhagic

**Table 3** Attitudes towards the Audit (agreement with statements in survey)

Statement in survey	Agree/strongly agree	
	n=96	%
Participating in the Audit provides useful information to monitor the quality of stroke care	84	86.6
Participating in the Audit helps improve the quality of stroke care at my hospital	77	79.4
The Audit data accurately reflect clinical practice	64	66.0
The Audit is time consuming for staff	82	84.5
The burden of participating in the Audit exceeds the benefits gained*	41	42.3
Results from the Audit are easy to understand	76	78.4
Audit results allow comparisons between my hospital and other hospitals	80	82.5
I trust the way the Stroke Foundation carries out and reports on the Audit	85	87.6
I am aware of the target benchmarks for key performance indicators	86	88.7
At my site, issues identified in the Audit are targeted for improvement	81	83.5
It is important that my hospital participates in the Audit	83	85.6
The National Stroke Audit programme should continue to be used	82	84.5

\*Negative statement: 'Neither agree nor disagree' included with 'strongly agree' and 'agree' in data presented in table.

stroke and blood pressure consistently above 170 [Clinician\_6]

### Factors influencing site involvement in the Audit Barriers

In the survey, the most frequently reported barrier to participation was time to collect and enter data (n=84, 88%), followed by inconsistency of data entered by different staff/different sites (n=41, 43%) (table 4). In interviews, the time burden was raised frequently. Participants also spoke about the additional time required to answer repetitive or inapplicable questions due to lack of skip logic within the Audit tool.

One of the things I do find frustrating is if you say that the patient is not on any anticoagulants, and still have to go through and say “no” to everything [Clinician\_4]

Most clinician interview participants discussed strategies such as providing training or referring colleagues to the data dictionary to ensure data were entered consistently. However, some respondents reported difficulties extracting data due to problems with unclear, or discipline-specific jargon.

I tried to assist with the rehab Audit once. And some of the questions I had to Google...I had no idea [Clinician\_6]

Further barriers were raised in interview that had not been noted in the survey. The delay between care provision and receiving the Audit report was a major problem for some. Many respondents kept local datasets or participated in the AuSCR or state-based initiatives, which included more patients and enabled more timely reporting, although with a reduced amount of data for each patient audited.

Numerous clinicians also reported that the Audit collected data that they did not feel were useful; other processes of care were not considered by some participants to be appropriate to deliver during the acute hospital stay.

Things like carer training...It's rehab, why is it in the acute Audit not in the rehab Audit? [Clinician\_9]

### Incentives

Incentives were more commonly reported than barriers in the survey. These included benchmarking with other services (n=80, 83%), and monitoring and improving patient care (n=76, 79%).

In contrast to the survey results, interview participants rarely reported that being involved in the Audit highlighted improvements in care. Nonetheless, most intended to continue participating in the Audit, because this was viewed as ‘doing the right thing’.

It wouldn't be good for our reputation if we pulled out [Clinician\_5]

Additional incentives were raised in interviews. Participating in the Audit was seen to improve awareness of guidelines, care delivery and documentation, and when more than one person was involved in entering audit data, this provided opportunities to enhance teamwork.

We have many rotating staff coming through and...it's a great way for staff to have a better understanding... around benchmarking around the guidelines and the KPIs that we're trying to achieve for stroke clients... it's also a useful reminder to get more staff on board to know what the stroke guidelines are and what we should be aiming for as a team [Clinician\_10]

**Table 4** Barriers and enablers to ongoing participation in the National Stroke Audit

Barrier	n=96	%
Time taken to collect and enter data	84	87.5
Inconsistency of entering data (between staff members or sites)	41	42.7
Lack of local system for ensuring data is used in quality improvement	25	26.0
Delay between patient care and getting report	24	25.0
Lack of incentives to participate	18	18.8
Too long between audit cycles (2 years)	15	15.6
The data analysis does not provide meaningful or useful data	13	13.5
Not mandated	11	11.5
Lack of recognition of good performance	10	10.4
Problems with technology	8	8.3
Lack of trust in how the data is used	1	1.0
Other (free text)	22	22.9
Staffing issues with carrying out audits and data entry	9	9.4
Audit not reflective of health service practices	6	6.3
Wording of questions: not nuanced enough or too much jargon	3	3.1
Other	4	4.2
Incentives/benefits		
Allows benchmarking with other/similar services	80	83.3
Allows monitoring and improvement in patient care	76	79.2
Identifies issues for quality improvement activities	75	78.1
Analysis and reports provided free	67	69.8
Support in quality improvement activities	65	67.7
Can be used in hospital accreditation	41	42.7
Only need to enter data every 2 years	18	18.8
New national and international awards recognising achievement	16	16.7
No benefits	1	1.0
Other (free text)	4	4.2

### Identifying opportunities to strategically improve the Audit

The most common free-text survey response about how the Audit should be refined (n=29) was to change the questions (table 5). Interview participants suggested reviewing terminology to improve clarity and to remove questions that were not included in reports or were not relevant for all patients. Additional questions were suggested that could guide clinical practice.

Rather than ask me what their motor deficits, speech are, say “Have they had a NIHSS score in ED”...That’s a helpful piece of data....The stuff that we actually need to try and improve clinically [Clinician\_12]

The next most suggested improvements in the survey were to improve the Audit tool/software (n=15) and to enable data collection across hospital transitions (n=8). Almost all interview participants spoke about the need to improve ease of Audit data entry. Sites with electronic medical records and administrators spoke about the possibility of exporting routinely collected data to populate the Audit.

What you don't want is someone have to go through and click, click, click, for each patient. Ideally it's some way that we can send data...to the Audit in...data points that we are already collecting [Administrator\_4]

Changing the frequency of the Audit was suggested in surveys (n=5) and at interview. Interview participants who took part in the rehabilitation Audit and those who were new to the acute Audit recommended that the frequency remained biannually.

I wouldn't wanna do it more frequently than bi-yearly because it just doesn't give you enough time to actually implement and see significant change [Clinician\_14]

Others felt that the Audit should be conducted more frequently, with the potential to collect more data on fewer areas of focus, or to use the Audit within local projects.

I would love to see the audit cycle more frequently and I would like to see...“Let’s focus on continence,

**Table 5** Suggestions in interviews (number of survey free-text responses) to improve Audit programme

	Reduce time requirements*†
	Allow export of already collected data*†
	Build in skip/branch logic so removes/adds questions based on previous responses*
	Allow for flexibility
	▶ To collect data on focus areas, with more frequent focused audit cycles*, coordinated with support from Stroke Foundation to improve clinical care in these focus areas
	▶ To have extra optional variables/ability to conduct out-of-cycle audits so it can be used for local research/quality improvement projects
Audit tool (n=15)	Build functionality to allow business reporting at participating sites
Audit questions (n=29)	Remove questions that are not included in report*†
	Ensure all questions can guide better clinical practice, or be used for advocacy*†
	Allow capture of data about contraindications to recommended treatments*
	Clarify wording in questions so auditors do not need to interpret whether processes of care were delivered
	Ensure other initiatives for example, stroke unit certification questionnaire use questions that align with questions on Audit
Track interhospital transfers (n=3)	Allow capture of data about care processes for patients transferred to comprehensive sites from regional site/stroke ambulance*†
	Collect waiting time to return to referring hospital*†
Track acute-rehabilitation stays (n=5)	Allow capture of data for processes of care delivered before (for rehabilitation audit) or after (for acute audit) audited period
	OR have separate audit for comprehensive sites
Timing of audit (n=2)	Change date so not emphasising care in December* (key staff often on leave)
	Change date so data closer to reporting period
Frequency and scope of audit (n=5)	More than 40 cases*†
	More frequent*
	Allow 1 or 2 years' worth of data
	Allow entry of data throughout year when entering data for AuSCR (for people using paper-based records, to avoid having to re-order medical records)
	Collect core dataset continuously
Audit report (n=4)	Improve timeliness of data included in report*† (ideally real-time/living)
	Benchmarking like-for-like hospitals nationally*
	Include access to rehabilitation in acute audit report
	Include cost effectiveness of care in different states (if possible)
	Include numerator and denominator for calculations
	Deliver report at beginning of financial year
Communication about audit programme	Include rationale for audit questions*†
	Let auditing/clinical teams know why data that isn't useful for clinicians is being collected*†

\*Raised in two or more interviews/focus groups.  
 †Raised by clinicians and administrators.  
 AuSCR, Australian Stroke Clinical Registry.

let's focus on discharge care planning" and drill down further with the questioning and the type of reports and the type of professional development and support that comes out of the Stroke Foundation to sit alongside that [Clinician\_5]

I think there needs to be...a core spine of things which are continually collected across all sites...and then a wider choice of things that that can be done... as a spotlight...If there was...a new...treatment...we

could use [the Audit] to spotlight to see where the practice was translating [Clinician\_13]

## DISCUSSION

With a growing prevalence of data programmes in acute stroke, the benefit of the Audit over the continuous minimum data collected via the AuSCR or locally held databases was not universally recognised. Nonetheless, most participants were in support of the Audit continuing.



Strengths of the Audit were its national coverage and Stroke Foundation's track record of using audit data to advocate for improved stroke services.

Unlike other well-established data programmes in Australia we identified, the National Stroke Audit is not supported by government or health departments, but by a charity. Participation in the Stroke Audit is voluntary, as for many (but not all) other Australian data programmes. The tradition of participating in the Audit was important at some sites, but the programme's longevity brings specific challenges. Externally coordinated audits tend to be effective early in their implementation, but impact decreases over time.<sup>24</sup> This was evident in our study, with sites new to the Audit reporting clear benefits of participation, whereas sites with more Audit experience reported that participation did not provide new information. To enhance the Audit's usefulness, it must be refined to provide benefits to Audit users, beyond them altruistically contributing data for national advocacy purposes.

Currency of data and frequency of audit cycles were important to study participants, both of which are indicators of audit quality.<sup>1 25-27</sup> Respondents in our study frequently expressed reservations about collecting data on only 40 patients/site every 2 years. Looking further afield, most international stroke data programmes are registers or registries which continuously collect minimum datasets<sup>28</sup>; we identified only three ongoing international stroke audit programmes (Sentinel Stroke National Audit Programme, SSNAP (England, Wales and Northern Ireland),<sup>29</sup> Scottish Stroke Care Audit,<sup>30</sup> Irish National Audit of Stroke.<sup>31</sup> While these audit programmes are designed to collect data on 90%–100% of hospital admissions with stroke, feedback is still only published yearly (Scottish and Irish audits)<sup>30 31</sup> or quarterly (SSNAP),<sup>29</sup> similar to the Australian data programmes identified in the rapid review. Balancing the need for comprehensive, up-to-date data and regular feedback cycles with reducing the data entry requirements is not straightforward. Including data from every patient with stroke in the National Stroke Audit in its current version would increase the time burden, which was already a major barrier to participation. One solution would be to partner with health and research teams in Australia that are striving to integrate health data across different sectors.<sup>32</sup> The development of automated data extraction to facilitate inclusion of more patients and provide more frequent feedback of results without additional data collection burden would be of value for Audit effectiveness as well as usefulness and sustainability. Consequently, Stroke Foundation and the AuSCR team are currently investigating rebuilding the Audit tool with a specific focus on improved technologies to allow the automatic transfer of data from electronic medical records or existing databases (K. Hill, Stroke Foundation, personal communication 8 December 2022).

Limitations of the study include the select sample of clinicians who consented to participate; it is likely that people who felt most strongly about the Audit would

volunteer to provide feedback. Strengths of this study include that survey respondents had similar proportionate state representation to general Audit respondents, and the geographical and professional diversity of the interview participants. The authorship team brought both content expertise and objectivity to the evaluation, with the team comprising three members EL, KL and TL who were closely familiar with the Audit, and one member TS with extensive health services research expertise and no previous work in stroke. All authors were university employees independent of the Stroke Foundation.

## CONCLUSIONS

There was strong support for the Audit to continue, with widespread appreciation of the value of the Audit for national benchmarking and advocacy activities, but inconsistent reports on its usefulness for facilitating local quality improvements. Other benefits from Audit participation included staff education and awareness of guidelines. Suggested modifications include developing systems to facilitate automatic data entry and timely feedback, and collecting data that accurately reflect care provision when patients transition between different services. Other value-added propositions include having the flexibility to use Audit infrastructure to conduct local audits on focused areas with the ability to add locally relevant datapoints.

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**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Ethics approval** This study received approval from Flinders University Human Ethics Low Risk Panel (Project no 4840). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available on reasonable request. The datasets used and/or analysed during this study will be available from the corresponding author on reasonable request after the publication of results.

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## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			P6
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	P6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	P6, P20
Occupation	3	What was their occupation at the time of the study?	Not presented
Gender	4	Was the researcher male or female?	P6
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			P6
Relationship established	6	Was a relationship established prior to study commencement?	P6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	P6
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	P6, P19
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	P7
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	P6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	P6
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	P7-8
<i>Setting</i>			P6, 7-8
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	P6
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	P6
<i>Data collection</i>			tables 1,2 P7,8
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	P6
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	P6
Duration	21	What was the duration of the interviews or focus group?	P6-7
Data saturation	22	Was data saturation discussed?	P6
Transcripts returned	23	Were transcripts returned to participants for comment and/or	P8
			P8
			P7

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			P7
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	No
Description of the coding tree	25	Did authors provide a description of the coding tree?	P7
Derivation of themes	26	Were themes identified in advance or derived from the data?	P7
Software	27	What software, if applicable, was used to manage the data?	P7
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			P8-16
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	P8-16
Data and findings consistent	30	Was there consistency between the data presented and the findings?	P8-16
Clarity of major themes	31	Were major themes clearly presented in the findings?	P8-16
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

## Data programs in conditions other than stroke being conducted in Australia

Data Program	Funding	Governance	Setting (acute/ non-acute)	Stakeholder Engagements	Selected Outputs	Longevity of Program	No. of Ps	Clinical Condition	Auditing Provider	Frequency of Audit	No. of Data Points	Feedback Provision Method	Incentives/ Disincentives	Key Reference/s
<b>AUDITS</b>														
<b>Australian and New Zealand Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI)</b>	Royal Australasian College of Surgeons (RACS); Australian and New Zealand College of Anaesthetists (ANZCA); General Surgeons Australia (GSA); New Zealand Association of General Surgeons (NZAGS); Australian Society of Anaesthetists (ASA); New Zealand Society of Anaesthetists (NZSA)	RACS Morbidity Audits Department is responsible for day-to-day operations. Working Party with representation from all participating colleges and societies. Steering Committee to be formed.	Acute	Royal Australasian College of Surgeons and the Australian and New Zealand College of Anaesthetists	Royal Australasians College of Surgeons. (2020). <i>Australian and New Zealand Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI): First ANZELA-QI program summary report 1 June 2018 to 30 June 2020.</i>	The ANZELA-QI was established in 2017	24 hospitals participated in 2020 2,886 patients (2020)	Acute abdomen, (data from those receiving emergency laparotomies)				Provides regular feedback to each participating site, including evidence-based indicators of care for easy comparison		<a href="https://www.surgeons.org/research-audit/morbidity-audits/morbidity-audits-managed-by-racs/anz-emergency-laparotomy-audit-quality-improvement">https://www.surgeons.org/research-audit/morbidity-audits/morbidity-audits-managed-by-racs/anz-emergency-laparotomy-audit-quality-improvement</a>
<b>Australian Appendicectomy Mortality Audit</b>	Australian Government Research Training Program Scholarship			Utilised databases from the ANZASM, CHASM, and Australian Institute of Health and Welfare (AIHW)	Young, E., Stewart, S., McCulloch, G. A. J., & Maddern, G. J. (2019). Appendicectomy mortality: an Australian national audit. <i>ANZ Journal of Surgery</i> , 89(11), 1441-1445.	Audit has ended	82 cases	Death associated with appendicectomy procedure	Royal Australasian College of Surgeons	Occurred once in 2019			N/A	Young, E., Stewart, S., McCulloch, G. A. J., & Maddern, G. J. (2019). Appendicectomy mortality: an Australian national audit. <i>ANZ Journal of Surgery</i> , 89(11), 1441-1445.
<b>Australian Capital Territory Audit of Surgical Mortality (ACTASM)</b>	ACT Health	ACTASM Management Committee meets quarterly and oversees the project		Royal Australasian College of Surgeons (ACT regional office) and the ACT Annual Scientific Meeting program	Royal Australasian College of Surgeons. (2016). <i>Australian Capital Territory Audit of Surgical Mortality (ACTASM) REPORT 2016</i> . Deakin, ACT.	ACTASM forms the ACT component of the ANZASM	100% participation from public and private hospitals. 97% from surgeons (mandatory), and 47% from gynaecologists (voluntary) as of 2016  76 cases reported in 2016	Deaths associated with surgical care	Royal Australasian College of Surgeons	Annually		Participating surgeons receive written feedback from assessors on their cases. Reports and Case Note Review Booklets are provided to hospitals annually. Feedback seminars are held in regional ACT areas.	Participation by surgeons is mandatory as part of the RACS Continuing Professional Development Program. Participation by gynaecologists is voluntary.	<a href="https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/actasm">https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/actasm</a>
<b>Australian National Diabetes Audit (ANDA)</b>	Commonwealth Department of Health	ANDA Scientific Advisory Committee (including representatives from key stakeholder organisations), provides overall guidance to the audit and ensures objectives are met.	Non-acute	Royal Australasian College of Surgeons, Monash University, National Association of Diabetes Centres	Australian National Diabetes Audit. (2020). <i>Australian Quality Clinical Audit 2019 Annual Report</i> . Melbourne, VIC: Australian Department of Health.	Data collection has occurred regularly (each audit occurring within 3 years of the last) since 1998. In 2019, NADC commenced a longitudinal register to follow up with participants, aiming to develop a Clinical Quality Registry.	80 disability centres from across all Australian states and territories participated in 2019  6,436 participants in 2019	Diabetes	National Association of Diabetes Centres (NADC)	Occurs annually: the ANDA-AQSM (Australian Quality Self-Management Audit) and ANDA-AQCA (Australian Quality Clinical Audit) are conducted on alternate years		Site-specific reports were provided to each participating centre.	Participation is voluntary	<a href="https://nadc.net.au/anda/">https://nadc.net.au/anda/</a>

<b>Australian National Diabetes Information Audit &amp; Benchmarking</b>	Australian Government Department of Health and Ageing	Project was developed by the National Association of Diabetes Centres, an organization jointly established by the Australian Diabetes Society and the Australian Diabetes Educators Association	Non-acute	National Association of Diabetes Centres and Australian Institute of Health and Welfare	Lee, A. S., Colagiuri, S., & Flack, J. (2018). Successful implementation of diabetes audits in Australia: The Australian National Diabetes Information Audit and Benchmarking (ANDIAB) initiative. <i>Diabetic Medicine</i> , 35(7), 929-936. <a href="https://doi.org/doi:10.1111/dme.13635">https://doi.org/doi:10.1111/dme.13635</a>	The audit ceased in 2011 after 13 years of data collection	42 sites (39 diabetes centres and 3 private practices) participated in 2011 4,629 patients were recorded in 2011 The entire audit (1998-2011) reported 38,155 total clinical encounters	Diabetes	National Association of Diabetes Centres	Data collection occurred annually between 1998 and 2000, and then biennially until 2011	Participating sites and doctors received pooled data analysis reports which enabled comparison and benchmarking	Participation was voluntary	Lee, A. S., Colagiuri, S., & Flack, J. (2018). Successful implementation of diabetes audits in Australia: The Australian National Diabetes Information Audit and Benchmarking (ANDIAB) initiative. <i>Diabetic Medicine</i> , 35(7), 929-936. <a href="https://doi.org/doi:10.1111/dme.13635">https://doi.org/doi:10.1111/dme.13635</a>
<b>Audit of children and adolescents in the Australasian Diabetes Data Network (ADDN)</b>			Non-acute		Phelan, H., et al. (2017). The Australasian diabetes data network: First national audit of children and adolescents with type 1 diabetes. <i>Medical Journal of Australia</i> , 206(3), 121-125.	Audit has ended, however ADDN registry is still collecting data	5 diabetes centres across Australia 3,279 participants in the ADDN in 2015	Children with diabetes	Australasian Diabetes Data Network (ADDN)	Occurred once in 2016			Phelan, H., et al. (2017). The Australasian diabetes data network: First national audit of children and adolescents with type 1 diabetes. <i>Medical Journal of Australia</i> , 206(3), 121-125.
<b>Audit of Surgical Mortality from Oral Squamous Cell Carcinoma (OSCC) Resection</b>	Australian Government Research Training Program Scholarship			Utilised ANZASM database	Ong, Y. L. R., Sambrook, P., & Maddern, G. (2021). Oral squamous cell carcinoma resection and neck dissection mortality: a 10-year national audit study. <i>ANZ Journal of Surgery</i> , 91(1-2), 145-151.	Audit has ended	25 cases	Deaths associated with OSCC resection	Royal Australasian College of Surgeons	Occurred once in 2020		N/A	Ong, Y. L. R., Sambrook, P., & Maddern, G. (2021). Oral squamous cell carcinoma resection and neck dissection mortality: a 10-year national audit study. <i>ANZ Journal of Surgery</i> , 91(1-2), 145-151.
<b>Australian Vascular Surgical Audit (AVA)</b>	Members of the Australian and New Zealand Society of Vascular Surgery (ANZSVS)	Audit Monitoring Committee oversees auditing process	Acute		Australian and New Zealand Society for Vascular Surgery. (2021). <i>Australasian Vascular Audit Public report – 2018-2020</i> .	Data collection has occurred annually since 2008	233 hospitals/clinics participated between 2018-2020 129,569 operations between 2018-2020 (115,570 from Australia)	Vascular surgery	ANZSVS	Occurs annually	Members of the ANZSVS are provided access to reports, and can access their own outcomes compared to a peer group	Participation is compulsory for members of the ANZSVS	<a href="https://www.anzsvs.org.au/audit/">https://www.anzsvs.org.au/audit/</a>

<b>Binational Colorectal Cancer Audit (BCCA)</b>	Colorectal Society of Australia and New Zealand (CSSANZ)	Steering Committee (clinicians, funders, consumers and other specialists) responsible for overseeing and regularly reviewing BCCA. Operations Committee responsible for day-to-day operations. Research Committee responsible for evaluating research.		Monash University	Produces annual reports Dagher, H. et al. (2021). <i>The 2020 Data Binational Colorectal Cancer Audit Report</i> . Hawthorn, Victoria.	Data collection has occurred since 2007	>170 hospitals across Australia and New Zealand 43,002 patients (2020)	Bowel cancer		Annually		Annual reports are accessible by participating hospitals	Participation is voluntary	<a href="https://www.bowelcanceraudit.com/">https://www.bowelcanceraudit.com/</a>
<b>BreastSurgANZ Quality Audit (BQA)</b>	Breast Surgeons of Australia and New Zealand (BreastSurgANZ)	BQA Committee provides direction, oversight and clinical advice Royal Australasian College of Surgeons (RACS) are responsible for day-to-day operations	Acute	Breast Surgeons of Australia and New Zealand	Produces annual reports. Royal Australasian College of Surgeons. (2018). <i>BreastSurgANZ Quality Audit: Annual Report 2018</i> . Adelaide, Australia.	Data collection has continued since its pilot study in 1998	247 hospitals across Australia and New Zealand 353 surgeons, 18,850 episodes recorded in 2018	Breast cancer	Royal Australasian College of Surgeons (RACS)	Annually		Annual reports. Access to data	Participation is mandatory for all members of BreastSurgANZ (surgeons treating breast cancer)	Royal Australasian College of Surgeons. (2018). <i>BreastSurgANZ Quality Audit: Annual Report 2018</i> . Adelaide, Australia.
<b>Collaborative Hospitals Audit of Surgical Mortality (CHASM)</b>	NSW Department of Health	Managed by Royal Australasian College of Surgeons (RACS) and overseen by CHASM committee of surgical peers who report to the Minister for Health through the Clinical Excellence Commission of NSW			Clinical Excellence Commission. (2020). <i>CHASM Casebook 2018: Clinical Lessons and Data from the New South Wales Collaborating Hospitals' Audit of Surgical Mortality Program</i> . Sydney, Australia.	CHASM forms the NSW component of the Australian and New Zealand Audit of Surgical Mortality (ANZASM)	15 local health districts, 2 specialty health networks, and 12 private hospitals participated in 2018. >1,900 surgeons registered as participants (2018)	Deaths associated with surgical care	Royal Australasian College of Surgeons (RACS)	Annually		Numerous annual reports and casebooks (looking at cases and quality of care at an individual, local health district, and national level) are provided to participating surgeons. Surgeons also receive a confidential report on each audited death they are involved in.	Participation by surgeons is mandatory as part of the RACS Continuing Professional Development Program	<a href="https://www.ec.health.nsw.gov.au/Review-incidents/mortality-review-authorised-committees/chasm">https://www.ec.health.nsw.gov.au/Review-incidents/mortality-review-authorised-committees/chasm</a>
<b>Genetic Heart Disease national clinical audit</b>	National Health and Medical Research Council (NHMRC) grant, and the Australian Government' medical Research Future Fund (MRFF)	Data hosted by Murdoch Children's Research Institute (MCRI) as part of the Australian Genomics project.	Non-acute	Murdoch Children's Research Institute (MCRI)	Austin, R., et al. (2021). Investigation of current models of care for genetic heart disease in Australia: a national clinical audit. <i>International Journal of Cardiology</i> , 330(1), 128-134.	The prospective audit has ended	11 public tertiary hospitals participated across five Australian states 536 cases recorded	Genetic Heart Disease	Australian Genomics	Occurred once in 2018				Austin, R., et al. (2021). Investigation of current models of care for genetic heart disease in Australia: a national clinical audit. <i>International Journal of Cardiology</i> , 330(1), 128-134.
<b>Inflammatory Bowel Disease Audit</b>	Crohn's & Colitis, Australian Government Department of Health, and unrestricted educational grants from Janssen and Ferring Pharmaceuticals	Audit is run as part of CCA's IBD Quality of Care Program, which is overseen by an inter-organisational steering committee. Data analysis conducted by Monash University.	Acute	Royal College of Physicians UK, Translational Public Health and Evaluation Division, Stroke and Ageing Research Group, School of Clinical Sciences at Monash Health, Monash University	Crohn's & Colitis Australia. (2016). <i>Final report of the first audit of the organisation and provision of IBD services in Australia 2016: Inflammatory Bowel Disease Quality of Care Program</i> . Camberwell, VIC.	Occurred once (2015-16), with recommendation for further funding to repeat the audit.	71 hospitals from across all Australian states and the ACT 1,440 hospital admissions	Inflammatory Bowel Disease	Crohn's & Colitis	Occurred once between 2015-16.		Site-specific reports were provided to each participating hospital to inform quality improvement in their context.	Participation was voluntary and by invitation.	<a href="https://www.crohnsandcolitis.com.au/ibdqc/ibd-audit-report/">https://www.crohnsandcolitis.com.au/ibdqc/ibd-audit-report/</a>

<b>National Standard Medication Chart (NSMC) audit</b>	Australian Commission on Safety and Quality in Health Care		Both acute and non-acute	The Health Services Medication Expert Advisory Group (HSMEAG)	Australian Commission on Safety and Quality in Health Care. (2021). <i>National Standard Medication Chart: National audit technical report 2020</i> . Sydney, Australia: ACSQHC.	Audit began in 2018	377 hospitals participated in 2020 10,359 individual patient charts recorded in 2020	Use of medication charts	Australian Commission on Safety and Quality in Health Care	Has occurred twice: 2018, 2020.		Site coordinators are given patient audit reports, containing results at group and individual hospital levels	Participation is voluntary and by invitation	
<b>The Perth Emergency Laparotomy Audit</b>			Acute		Broughton, K. J., Aldridge, O., Pradhan, S., & Aitken, R. J. (2017). The Perth Emergency Laparotomy Audit. <i>ANZ Journal of Surgery</i> , 87(11), 893-897.	The prospective audit has ended, but was part of the process of presenting the need for an Australian-wide audit for emergency laparotomy, now seen in the ANZELA audit	10 hospitals and 198 patients across Western Australia	Emergency laparotomies	Royal Australasian College of Surgeons	Occurred in one 12-week period in 2016				Broughton, K. J., Aldridge, O., Pradhan, S., & Aitken, R. J. (2017). The Perth Emergency Laparotomy Audit. <i>ANZ Journal of Surgery</i> , 87(11), 893-897.
<b>Queensland Audit of Surgical Mortality (QASM)</b>	Queensland Department of Health	Managed by the Research, Audit and Academic Surgery (RAAS) of Royal Australasian College of Surgeons (RACS) through ANZASM and QASM Steering Committees			Royal Australasian College of Surgeons. <i>Queensland Audit of Surgical Mortality: Report 2007-2016</i> .	QASM has been collecting data since 2007 and forms the QLD component of the ANZASM	100% participation from both public and private hospitals in Queensland as of 2016 7,613 cases reported from 2007-2016	Deaths associated with surgical care	Royal Australasian College of Surgeons (RACS)	Annually		Participating surgeons receive direct feedback during the audit. Hospitals receive aggregated data and an overview of lessons learned through de-identified cases.	Participation by surgeons is mandatory as part of the RACS Continuing Professional Development Program	<a href="https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/qasm">https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/qasm</a>
<b>SNAPSHOT ACS Audit</b>	National organisations provided funding and state governments and health networks provided resources	Project was managed by a steering committee comprised of key stakeholders	Acute	Royal Australasian College of Surgeons, The Cardiac Society of Australia and New Zealand, the Heart Foundation of Australia, the Australian Commission on Safety and Quality in Health Care, the George Institute for Global Health, and health networks or state governments in New South Wales, Queensland, Victoria, South Australia and Western Australia	Chew, D P., et al. (2013). Acute coronary syndrome care across Australia and New Zealand: the SNAPSHOT ACS study. <i>Medical Journal of Australia</i> , 199(3), 185-191.	The prospective audit has ended	286 Australian and New Zealand hospitals participated in the entire audit process 4,398 patients with suspected or confirmed ACS	Acute Coronary Syndrome (ACS)	A binational academic network of clinicians and researchers conducted the audit	Occurred once as a prospective audit in 2012		At the end of the audit, results were provided to each participating site with benchmarks against their state/territory	Participation by hospitals was voluntary and by invitation. Individual patient participation was through opt-out consent	Chew, D P., et al. (2013). Acute coronary syndrome care across Australia and New Zealand: the SNAPSHOT ACS study. <i>Medical Journal of Australia</i> , 199(3), 185-191.
<b>South Australian Audit of Surgical Mortality (SAASM)</b>	SA Health	Managed by Royal Australasian College of Surgeons (RACS). SAASM Management Committee meets biennially and oversees the project		Royal Australasian College of Surgeons, The Australian and New Zealand College of Anaesthetists (ANZCA), the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), the South Australian Anaesthetic Mortality Committee (SAAMC), the Royal Australian and New Zealand College of ophthalmologists (RANZCO), the Royal	Royal Australasian College of Surgeons. (2020). <i>South Australian Audit of Surgical Mortality Annual Report 30 November 2020</i> . Kent Town, SA.	SAASM forms the SA component of the ANZASM	100% participation from public and private hospitals, and 96.1% from RACS surgeons as of 2020 2,943 cases reported from 2015-2019	Deaths associated with surgical care	Royal Australasian College of Surgeons (RACS)	Annually		Participating surgeons receive individual feedback, whilst participating hospitals receive aggregate data	Participation by surgeons is mandatory as part of the RACS Continuing Professional Development Program	<a href="https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/saasm">https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/saasm</a>

				Australasian College of Dental Surgeons (RACDS), and the Australian Orthopaedic Association (AOA)										
<b>Tasmanian Audit of Surgical Mortality (TASM)</b>	Tasmanian Department of Health	Managed by the Research, Audit and Academic Surgery (RAAS) of Royal Australasian College of Surgeons (RACS) through TASM Management Committee to oversee the project		Royal Australasian College of Surgeons, the Research, Audit and Academic Surgery (RAAS) and other state audits of surgical mortality	Royal Australasian College of Surgeons. <i>Tasmanian Audit of Surgical Mortality: Annual Report 2019</i> . Hobart, TAS.	TASM has been collecting data since 2004 and has had 100% participation from hospitals since 2012. TASM forms the TAS component of the Australian and New Zealand Audit of Surgical Mortality (ANZASM)	100% participation from all hospitals providing surgical services (4 public and 9 private hospitals) as of 2019  109 surgeons participated in 2019	Deaths associated with surgical care	Royal Australasian College of Surgeons (RACS)	Annually		Feedback in individual and group formats is provided to all participants	Participation by surgeons is mandatory as part of the RACS Continuing Professional Development Program	<a href="https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/tasm">https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/tasm</a>
<b>Western Australian Audit of Surgical Mortality (WAASM)</b>	Western Australian Department of Health	Managed by the Research, Audit and Academic Surgery (RAAS) of Royal Australasian College of Surgeons (RACS). WAASM Management Committee oversees the project.		Royal Australasian College of Surgeons, Patient Safety Surveillance Unit, Clinical Excellence Division, Western Australian Department of Health, and the Australian and New Zealand Audit of Surgical Mortality (ANZASM)	Royal Australasian College of Surgeons. (2021). <i>2021 Report: The Western Australian Audit of Surgical Mortality (WAASM)</i> .	WAASM has been collecting data since 2001 and forms the WA component of the ANZASM	2,209 cases reported from 2016-2020  100% participation from hospitals and surgeons as of 2020	Deaths associated with surgical care	Royal Australasian College of Surgeons (RACS)	Annually		Participating surgeons receive both feedback for individual cases, and a Case Note Review Booklet containing a selection of de-identified cases. Individual hospital reports are sent annually to participating hospitals.	Participation by surgeons is mandatory as part of the RACS Continuing Professional Development Program	<a href="https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/waasm">https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/waasm</a>
<b>The Australian and New Zealand Audit of Surgical Mortality (ANZASM)</b>	Each state/ territory receives funding from their respective department of health	Managed by the Research, Audit and Academic Surgery Division of Royal Australasian College of Surgeons (RACS)		Royal Australasian College of Surgeons and each state audit of surgical mortality	Produces annual reports and case note review booklets.  Royal Australasian College of Surgeons. (2016). <i>Australian and New Zealand Audit of Surgical Mortality: National Report 2016</i> . Adelaide, Australia.	Data collection has occurred since 2001, and participation as part of RACS Professional Development has been mandated since 2010	4,926 surgeons and 41,998 notifications of death associated with surgical care (2016)  Participation from 100% of public hospitals and 92% of private hospitals	Death under the care of a surgeon	Royal Australasian College of Surgeons (RACS)	Annually		Provides commentary directly to the treating surgeon, as well as National Case Note Review Booklet, which highlights lessons learned from de-identified cases	Participation by surgeons is mandatory as part of the RACS Continuing Professional Development Program	<a href="https://www.surgeons.org/research-audit/surgical-mortality-audits">https://www.surgeons.org/research-audit/surgical-mortality-audits</a>  Royal Australasian College of Surgeons. (2016). <i>Australian and New Zealand Audit of Surgical Mortality: National Report 2016</i> . Adelaide, Australia, 1-82.
<b>Victorian Audit of Surgical Mortality (VASM)</b>	Victorian Department of Health, and Human Services' Safer Care Victoria branch	Managed by Royal Australasian College of Surgeons (RACS) under a VASM Management Committee, which meets bimonthly to oversee audit		Royal Australasian College of Surgeons, the Victorian Government's Department of Health, and Safer Care Victoria	Royal Australasian College of Surgeons. <i>Victorian Audit of Surgical Mortality (VASM): 2019 Annual report</i> . Melbourne, VIC.	VASM has collected data since 2001 and forms the Victorian component of the Australian and New Zealand Audit of Surgical Mortality (ANZASM)	1,767 direct notifications of death associated with surgical care  93.2% return of required forms from participating surgeons across Victoria	Deaths associated with surgical care	Royal Australasian College of Surgeons (RACS)	Annually		Feedback is provided to participating surgeons and hospitals through educational events, hospital forums, committee meetings, feedback letters to individual surgeons, hospital governance reports, scientific papers and newsletters	Participation by surgeons is mandatory as part of the RACS Continuing Professional Development Program	<a href="https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/vasm">https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/vasm</a>

REGISTRIES													
<b>Australasian Diabetes Data Network (ADDN)</b>	Australian Research Council and the Australian Government Department of Health and Ageing	ADDN2 Steering Committee provides leadership to the registry	Non-acute	The Australasian Paediatric Endocrine Group, the Australian Diabetes Society, the JDRF Australia Clinical Research Network and the University of Melbourne	Clapin, H., et al. (2016). Australasian Diabetes Data Network: Building a Collaborative Resource. <i>Journal of Diabetes Science and Technology</i> , 10(5), 1015-1026.	Data collection for phase 1 (ADDN1) began in 2012 and concluded in 2015. Data collection for phase 2 (ADDN2) commenced in 2016	25 participating centres across Australia and New Zealand  21,531 participants	Diabetes	-	-			<a href="https://www.addn.org.au/">https://www.addn.org.au/</a>
<b>Australasian Oncofertility Registry (AOFR)</b>	Funding provided by Salesforce, The Kids Cancer Centre Sydney Children's Hospital, CanTeen Australia, Merck Serono, Sir Asher Joel Foundation, Fertility Society of Australia, and the Victorian Cancer Agency	The FUTuRE Fertility Research Group responsible for day-to-day operations Steering Committee oversees the governance of the AOFR FUTuRE Fertility Consumer Group involved in study development Governance structure reviewed on annual basis	Non-acute		Anazodo, A. C. et al. (2016). A Study Protocol for the Australasian Oncofertility Registry: Monitoring Referral Patterns and the Uptake, Quality, and Complications of Fertility Preservation Strategies in Australia and New Zealand. <i>Journal of Adolescent and Young Adult Oncology</i> , 5(3), 215-225.			Reproductive function of cancer survivors	-	-			<a href="http://www.futurefertility.com.au/registry/">http://www.futurefertility.com.au/registry/</a>
<b>Australian Rehabilitation Outcomes Centre (AROC)</b>	Funded from seven founding members (Australian Gov DoH, DVA, NSW Health, Vic DoH, AHIA, NRMA, TAC). Funded by subscription and user pays model. Members pay an annual subscription fee.	Management Advisory Group oversees. AROC is supported by the Australasian Faculty of Rehabilitation Medicine. AFRM appointed AHSRI at the University of Wollongong to manage AROC day to day management.	Non-Acute	Supported by the Australasian Faculty of Rehabilitation Medicine. Extensive list of members available on website	Reports available on website: <a href="http://uow.edu.au/ahsri/aroc">uow.edu.au/ahsri/aroc</a>  Australian Rehabilitation Outcomes Centre (AROC) 2018 Measuring the rehabilitation client's experience: the Australian Modified client centred rehabilitation questionnaire (AM-CCRG) <i>Journal of the Australasian Rehabilitation Nurses Association</i> , 21:1, 29-30	Commenced in 2002	Over 300 sites participating across Australia and New Zealand	Rehabilitation on participants			Reports twice per year to submitting hospitals, payers and other interested stakeholders	National benchmarking across private and public. Reports for stakeholders, ongoing education, training and certification in use of the FIM	<a href="https://www.uow.edu.au/ahsri/aroc">https://www.uow.edu.au/ahsri/aroc</a>
<b>Australasian Severe Asthma Registry (ASAR)</b>	AstraZeneca, gsk, Novartis, and Sanofi	Governance provided by Thoracic Society of Australia and New Zealand (TSANZ) ASAR Management -Committee responsible for providing strategic, financial, clinical and academic oversight	Non-acute	Australasian Severe Asthma Network	Australasian Severe Asthma Registry. (2019). <i>ASAR: Annual Report 2019</i> . Sydney, New South Wales.	Data collection occurred from 2013 to 2017, originally as the Australasian Severe Asthma Network (ASAN) and was then integrated into ASAR.	26 sites across Australia, New Zealand, and Singapore  691 patients between 2013-2017	Asthma	-	-			<a href="https://www.thoracic.org.au/researchawards/australasian-severe-asthma-registry-asar">https://www.thoracic.org.au/researchawards/australasian-severe-asthma-registry-asar</a>
<b>Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry</b>	Australian Organ and Tissue Authority, New Zealand Ministry of Health, and Kidney Health Australia	ANZDATA Executive Committee responsible for day-to-day management, ensuring compliance with policies, supporting	Non-acute		Produces annual reports ANZADATA Registry. (2020). <i>43rd Annual Report: Australia and New Zealand Dialysis</i>	Data collection has occurred since 1977	All relevant hospitals and dialysis units in Australia and New Zealand participate	End stage kidney disease	-	-	Hospital admission		<a href="https://www.anzdata.org.au/anzdata/">https://www.anzdata.org.au/anzdata/</a>

		working groups, finances ANZDATA Advisory Committee responsible for ensuring staffing is appropriate, data collection and management complies with legislation, advise Executive Committee			<i>and Transplant Registry</i> . Adelaide, Australia.		14,554 dialysis patients and 13,130 transplant patients as of 2020							
<b>Australian Cerebral Palsy Register</b>	Cerebral Palsy Alliance Research Foundation	Each state's CP register is operated independently	Non-acute	CP Registers in each Australian state contribute to national registry	Australian Cerebral Palsy Register. (2020). <i>Australian Cerebral Palsy Register Bulletin Birth years 1995-2014</i> .	Register has been running since 2008	8,637 records as of 2018	Cerebral Palsy	-	-				<a href="https://cpregis ter.com/">https://cpregis ter.com/</a>
<b>Australian Childhood Cancer Registry</b>	Cancer Council Queensland	Managed by the Cancer Council Queensland		Collaborates with the Australasian Association of Cancer Registries, all Australian State and Territory population cancer registries and all paediatric oncology treating hospitals	Produces annual reports  Youlden, D. R. & Aitken, J. F. (2019). <i>Childhood cancer in Australia, 1983-2015</i> . Brisbane, Australia: Cancer Council Queensland.	Data collection has occurred since 1983. It is considered one of the longest running and most comprehensive childhood cancer registries worldwide	>20,000 cases recorded since 1983	Childhood cancer	-	-				<a href="https://cancer qld.org.au/research/viertel-cancer-research-centre/childhood-cancer/australian-childhood-cancer-registry/">https://cancer qld.org.au/research/viertel-cancer-research-centre/childhood-cancer/australian-childhood-cancer-registry/</a>
<b>Australian Cystic Fibrosis Data Registry (ACFDR)</b>	Cystic Fibrosis Australia	Monash University Data Registry Centre is responsible for day-to-day management, and Cystic Fibrosis Australia is responsible for data custodianship. ACFDR Steering Committee provides leadership and advice to the registry.	Non-acute	Cystic Fibrosis Australia and Monash Data Registry Centre	Produces annual reports.  Ahern, S et al. (2021). Redesign of the Australian Cystic Fibrosis Data Registry: A multidisciplinary collaboration. <i>Paediatric Respiratory Reviews</i> , 37, 37-43.	Data collection has occurred since 1998	24 cystic fibrosis-designated centres (adult, paediatric and mixed) across Australia  3,538 patients (2020)	Cystic Fibrosis	-	-			Participation is voluntary, but required for people with CF to receive PBS-subsidised CFTR modulator treatment	<a href="https://www.cysticfibrosis.org.au/dataregistry">https://www.cysticfibrosis.org.au/dataregistry</a>
<b>Australian Orthopaedic Association National Joint Replacement Registry</b>	Commonwealth Department of Health	Managed by the Australian Orthopaedic Association (AOA) Nominated AOANJRR committee develops policies, reports to AOA board of directors SAHMRI provides data management and data analysis services	Acute	Australian Orthopaedic Association, South Australian Health and Medical Research Institute	Produces annual reports; 23 noted Journal Articles	Data collection has occurred since 1998. Legislation passed in 2009 enabling Commonwealth to cost recover funding.	Near 100% participation from public and private hospitals undertaking joint replacement surgery in Australia  >300 hospitals and >7,000 procedures	Joint Replacement (shoulder, elbow, wrist, ankle, spinal disc)	-	-		The registry uses the data collected to release regular reports and journal publications and provides participating sites with ad hoc reports. Surgeons receive access to their individual data.	Participation is voluntary	<a href="https://aoanjrr.sahmri.com/home">https://aoanjrr.sahmri.com/home</a>
<b>Australian Spine Registry (ASR) [Still in pilot stage]</b>	Funded by industry, health insurers and the Spine Society of Australia (SSA)	Steering Committee comprised of SSA membership, participating surgeons, Monash University and funders.	Acute		Produces annual reports.  Ahern, S., Apos, E., McNeil, J.J., Cunningham, J. & Johnson, M. (2018).	ASR lobbying industry and government with hopes to establish sustainable long-term funding	14 sites across Australia  1,332 patients with 1,563	Individuals undergoing spine surgery	-	-		Plans to provide individual surgeons with annual report		<a href="https://www.spineregistry.org.au/">https://www.spineregistry.org.au/</a>

		Management Committee based in Monash University, oversees day-to-day operation SSA and Monash University share data custodianship.			Monitoring outcomes in spine surgery: rationale behind the Australian Spine Registry. <i>ANZ Journal of Surgery</i> , 88(10), 950-951.		procedures (2019-20)						<a href="https://www.spineregistry.org.au/wp-content/uploads/2020/07/ASR_AnnualReport2019_vFweb.pdf">https://www.spineregistry.org.au/wp-content/uploads/2020/07/ASR_AnnualReport2019_vFweb.pdf</a>
<b>Australia and New Zealand Islet and Pancreas Transplant Registry</b>	Grant from the Organ and Tissue Authority	Registry is based at Westmead Hospital in NSW, where a small team is responsible for its day-to-day operation	Acute		Produces annual reports Webster, A., Hedley, J., & Kelly, P. (2020). <i>Australian and New Zealand Islet and Pancreas Transplant Registry Report 2020</i> . Sydney, Australia.	Data collection has occurred since 1984	4 solid-organ pancreas transplant units and 3 islet transplant units across Australia and New Zealand  889 individuals and 910 transplants from 1984-2019	Islet and pancreas transplants	-	-			<a href="http://anziptr.org/">http://anziptr.org/</a>  Webster, A., Hedley, J., & Kelly, P. (2020). <i>Australian and New Zealand Islet and Pancreas Transplant Registry Report 2020</i> . Sydney, Australia.
<b>Cooperative National Registry of Acute Coronary care, Guideline Adherence and Clinical Events (CONCORDANCE)</b>	Pharmaceutical and non-government agencies	Nationally representative Steering Committee provides advice on scientific issues Executive Committee, Management Committee, Publications Committee, and Biomarker data bank Committee devolves from steering committee	Acute		Aliprandi-Costa, B et al. (2013). The Design and Rationale of the Australian Cooperative National Registry of Acute Coronary care, Guideline Adherence and Clinical Events (CONCORDANCE). <i>Heart, Lung and Circulation</i> . 22(7), 533-541.	In it launch, the registry was described as an ongoing, prospective initiative	43 hospitals (2018)  8,245 patients (2019)	Acute Coronary Syndromes (ACS)	-	-			Aliprandi-Costa, B et al. (2013). The Design and Rationale of the Australian Cooperative National Registry of Acute Coronary care, Guideline Adherence and Clinical Events (CONCORDANCE). <i>Heart, Lung and Circulation</i> . 22(7), 533-541. Ayad, M, et al. (2021). Factors that influence whether patients with acute coronary syndromes undergo cardiac catheterisation. <i>Medical Journal of Australia</i> , 214(7), 310-317.

<b>GenesisCare Cardiac Implantable Electronic Devices (CIED) Database/ Device Registry</b>		Owned and operated by doctors & management within GenesisCare	Acute		Produces annual reports  GenesisCare. (2020). <i>Cardiology Annual Research Report 2019</i> . Alexandria, New South Wales.	Data collection has occurred since 2016	>7,500 procedures (2020)	Patients undergoing a cardiac implantable device (e.g., pacemaker or defibrillator )	-	-	Approx. 100	Performance and outcome measure feedback is provided to participating hospitals and cardiologists to allow benchmarking against national and international results	GenesisCare. (2019). <i>Cardiology Annual Research Report 2018</i> . Alexandria, New South Wales.  GenesisCare. (2020). <i>Cardiology Annual Research Report 2019</i> . Alexandria, New South Wales.
<b>GenesisCare Heart Failure Registry</b>		(As above)			(As above)	Data collection has occurred since 2014	23 clinics across Australia >1,300 patients (2019)	Heart failure	-	-			(As above)
<b>GenesisCare Percutaneous Coronary Intervention (PCI) Registry</b>		(As above)	Acute		(As above)	Data collection has occurred since 2008 and it is the only national PCI database in Australia	>14,000 (2020)	Patients undergoing angioplasty	-	-	Approx. 200		(As above)
<b>Myeloma and Related Diseases Registry (MRDR)</b>	Funded by Amgen Inc., Celgene Pty Ltd, Janssen-Cilag Pty Ltd, Sanofi.  Research funded by Medical Research Future Fund, Monash Partners Advanced Health Research Translation Centre, and National Blood Authority.	Steering Committee responsible for monitoring, reviewing and advising on the program.  Registry is managed by the Transfusion Research Unit, School of Public Health and Preventive Medicine, Monash University.		Monash University and Alfred Health	Bergin, K., et al. (2021). The Myeloma Landscape in Australia and New Zealand: The First 8 Years of the Myeloma and Related Diseases Registry (MRDR). <i>Clinical Lymphoma, Myeloma &amp; Leukemia</i> , 21(6), 510-519.	Data collection has occurred since 2012	38 sites across Australia 2,405 patients (2020)	myeloma, plasmacytoma, plasma cell leukaemia and monoclonal gammopathy of undetermined significance (MGUS)	-	-		Participating sites receive six-monthly data reports with the aim to improve quality of care	<a href="http://www.mrd.net.au/">http://www.mrd.net.au/</a>
<b>National Rheumatic Heart Disease Data Collection (NRHDDC)</b>	Funded as part of the Australian Rheumatic Fever Strategy by the Australian Government Department of Health		Acute	Engagement from NSW, QLD, WA, SA & NT.	Produces regular (unpublished) jurisdictional-level data reports	Data collection has occurred since 2009	>2,200 notifications between 2015-19	Rheumatic Heart Disease	-	-		Supplies individual jurisdictions with unpublished data reports	<a href="https://www.aihw.gov.au/about-our-data/our-data-collections/national-rheumatic-heart-disease-data-collection">https://www.aihw.gov.au/about-our-data/our-data-collections/national-rheumatic-heart-disease-data-collection</a>

<b>Prostate Cancer Outcomes Registry Australia and New Zealand</b>	Movember Foundation	Steering Committee governs project direction and ensures objectives and vision are met. Registry is managed by Trans-Tasman Data Coordination Centre (DCC)		Other state-based prostate cancer outcomes	Produces annual reports. Papa N., O'Callaghan M., James E., & Millar J. (2021). <i>Prostate Cancer in Australian and New Zealand Men: Patterns of care withing PCOR-ANZ 2015-2018</i> . Melbourne, Victoria: Monash University.	2016	39,953 (2020)	Prostate cancer	-	-			Participation is voluntary on an opt-out method	<a href="https://prostatecancerregistry.org/">https://prostatecancerregistry.org/</a>
<b>Pulmonary Hypertension Society of Australia and New Zealand (PHSANZ) Registry</b>	Pulmonary Hypertension Society of Australia and New Zealand	Registry Committee oversee the running of the project	Non-acute		Produces regular newsletters. Ratwatt, S., et al. (2020). Pulmonary arterial hypertension with below threshold pulmonary vascular resistance. <i>The European Respiratory Journal</i> 56(1), doi: 10.1183.	Data collection has occurred since 2011	21 specialist centres across Australia & New Zealand 3,900 (2021)	Pulmonary hypertension	-	-				<a href="https://www.phsanz.org/phsanz-registry/">https://www.phsanz.org/phsanz-registry/</a> Anderson, J., et al. (2020). Pharmacological Treatment of Pulmonary Arterial Hypertension in Australia: Current Trends and Challenges. <i>Heart, Lung and Circulation</i> , 29(10), 1459-1468.
<b>Queensland Perineural Invasion Registry Database</b>		Based at University of Queensland's Dermatology Research Centre			Adams, A., et al. (2020). Keratinocyte cancer with incidental perineural invasion: A registry analysis of management and 5-year outcomes. <i>Australasian Journal of Dermatology</i> . 61(3), 226-230.		3 dermatology and plastic surgery practices in Brisbane 322 patients (2020)	Keratinocyte cancers with documented incidental perineural invasion	-	-				Adams, A., et al. (2020). Keratinocyte cancer with incidental perineural invasion: A registry analysis of management and 5-year outcomes. <i>Australasian Journal of Dermatology</i> . 61(3), 226-230.
<b>Registry of Senior Australians</b>	SA Premier's Research and Industry Fund, MRFF	Steering committee, Consumer and Community Committee, ATSI Advisory Committee	Non acute	Healthy Ageing Research Consortium, a cross-sectoral partnership of researchers, clinicians, aged care providers and consumer advocacy groups from 13 organisations	Inacio M, Lang C, Caughey G, Bray S, Harrison S, Whitehead C, Visvanathan R, Evans K, Corlis M, Cornell V, Wesselingh S. The Registry of Senior Australians (ROSA) Outcome Monitoring System: Quality and Safety Indicators for Aged Care. <i>International Journal of Quality in Health Care</i>	Established 2017	Brings together datasets across the country relevant to older Australians	Aged care						<a href="https://rosaresearch.org/">https://rosaresearch.org/</a>

<b>The Australia Dementia Network (ADNeT) Registry</b>	NHMRC National Institute for Dementia Research Grant	Registry is managed by the Australian Dementia Network	Non-acute	Registry of Senior Australians (ROSA)	Plans to produce annual reports  Lin, X., et al. (2020). The protocol of a clinical quality registry for dementia and mild cognitive impairment (MCI): the Australian dementia network (ADNeT) Registry. <i>BMC Geriatrics</i> , 20(330), doi:10.1186.	Data collection commenced in February 2020 and the registry anticipates 10,000 participants by 2023	Received governance approval for 7 sites to participate (2 currently undertaking data collection)	Dementia	-	-				<a href="https://www.australiandementianetwork.org.au/initiatives/clinical-quality-registry/">https://www.australiandementianetwork.org.au/initiatives/clinical-quality-registry/</a>
<b>The Australia New Zealand Trauma Registry</b>	Australian Department of Health and Department of Infrastructure, Regional Development and Cities	Registry governed by Steering Committee with representation from all states and territories. Management Committee reports to Steering Committee. Data Working Group formed to review data collection processes.		Alfred Health, National Trauma Research Institute (NTRI), Monash University Department of Epidemiology and Preventative Medicine	Produces annual reports.  Australian Trauma Quality Improvement (AusTQIP) Collaboration (2021). <i>Australia New Zealand Trauma Registry. Management of the Severely Injured, 1 July 2019 to 30 June 2020</i> . Alfred Health: Melbourne, Victoria.	Data collection has occurred since 2012. Registry has secured funding until 2022.	Data supplied by 33 major trauma centres across Australia and New Zealand (2020)  10,170 cases (2019-20)	Severely injured or death after injury	-	-	67	Participating sites receive regular reports with benchmarks and outliers, with the aim to improve quality of care.		<a href="https://atr.org.au/">https://atr.org.au/</a>
<b>The Australian &amp; New Zealand Fontan Registry</b>	National Health and Medical Research Council; Heart Foundation; ANZ Trustees; HeartKids, Murdoch Children's Research Institute	Registry is governed by Steering Committee with representation from all states	Acute		Australian & New Zealand Fontan Registry: Annual Report 2019. (2020).	Data collection has occurred since 2009	15 participating centres across Australia  1,682 participants (2020)	Hypoplastic Left Heart Syndrome Surgery (Fontan Procedure)	-	-				<a href="https://www.fontanregistry.com/">https://www.fontanregistry.com/</a>  Iyengar A. J, et al. (2013). The Australia and New Zealand Fontan Registry: description and initial results from the first population-based Fontan registry. <i>Internal Medicine Journal</i> . 44(2), 148-155.
<b>Victorian Cancer Registry</b>	Victorian State Government	Managed by the Cancer Council Victoria		Records linked monthly to the Victorian Registry of Births, Deaths and Marriages, and annually to the National Death Index.	Produces annual reports; uses registry data to develop cancer fact sheets.  Cancer Council Victoria. (2020) <i>Cancer in Victoria: Statistics and Trends 2019</i> . Melbourne, Victoria.	The registry has had full population coverage of cancer notifications across Victoria since 1982	240 hospitals and 30 pathology laboratories  35,924 cases of cancer were reported in 2019	Cancer	-	-		Reporting cancer diagnoses to the registry is mandatory for all health services in Victoria		<a href="https://www.cancervic.org.au/research/vcr">https://www.cancervic.org.au/research/vcr</a>  Cancer Council Victoria. (2020). <i>Cancer in Victoria: Statistics and Trends 2019</i> . Melbourne, Victoria.  Afshar, N., et al. (2020). Differences in cancer survival by remoteness of residence: an analysis of data from a population-based cancer registry. <i>Cancer Causes Control</i> . 31, 617-629.