

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
AUDITS														
Australian and New Zealand Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI)	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		https://www.surgeons.org/research-audit/morbidity-audits/morbidity-audits-managed-by-racs/anz-emergency-laparotomy-audit-quality-improvement
Australian Appendicectomy Mortality Audit	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.
Australian Capital Territory Audit of Surgical Mortality (ACTASM)	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.	https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/actasm
Australian National Diabetes Audit (ANDA)	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	https://nadc.net.au/anda/

Australian National Diabetes Information Audit & Benchmarking	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. https://doi.org/doi:10.1111/dme.13635	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. https://doi.org/doi:10.1111/dme.13635
Audit of children and adolescents in the Australasian Diabetes Data Network (ADDN)			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.
Audit of Surgical Mortality from Oral Squamous Cell Carcinoma (OSCC) Resection	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.
Australian Vascular Surgical Audit (AVA)	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	https://www.anzsvs.org.au/audit/

Binational Colorectal Cancer Audit (BCCA)	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	https://www.bowelcanceraudit.com/
BreastSurgANZ Quality Audit (BQA)	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.
Collaborative Hospitals Audit of Surgical Mortality (CHASM)	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	https://www.ec.health.nsw.gov.au/Review-incidents/mortality-review-authorised-committees/chasm
Genetic Heart Disease national clinical audit	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.
Inflammatory Bowel Disease Audit	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.	https://www.crohnsandcolitis.com.au/ibdqc/ibd-audit-report/

National Standard Medication Chart (NSMC) audit	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	
The Perth Emergency Laparotomy Audit			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.
Queensland Audit of Surgical Mortality (QASM)	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	https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/qasm
SNAPSHOT ACS Audit	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.
South Australian Audit of Surgical Mortality (SAASM)	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	https://www.surgeons.org/research-audit/surgical-mortality-audits/regional-audits/saasm

				Australasian College of Dental Surgeons (RACDS), and the Australian Orthopaedic Association (AOA)										
Tasmanian Audit of Surgical Mortality (TASM)	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	https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/tasm
Western Australian Audit of Surgical Mortality (WAASM)	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	https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/waasm
The Australian and New Zealand Audit of Surgical Mortality (ANZASM)	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	https://www.surgeons.org/research-audit/surgical-mortality-audits Royal Australasian College of Surgeons. (2016). <i>Australian and New Zealand Audit of Surgical Mortality: National Report 2016</i> . Adelaide, Australia, 1-82.
Victorian Audit of Surgical Mortality (VASM)	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	https://www.surgeons.org/research-audit/surgical-mortality-audits/regiona1-audits/vasm

REGISTRIES													
Australasian Diabetes Data Network (ADDN)	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	-	-			https://www.addn.org.au/
Australasian Oncofertility Registry (AOFR)	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	-	-			http://www.futurefertility.com.au/registry/
Australian Rehabilitation Outcomes Centre (AROC)	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: uow.edu.au/ahsri/aroc 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	https://www.uow.edu.au/ahsri/aroc
Australasian Severe Asthma Registry (ASAR)	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	-	-			https://www.thoracic.org.au/researchawards/australasian-severe-asthma-registry-asar
Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry	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		https://www.anzdata.org.au/anzdata/

		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							
Australian Cerebral Palsy Register	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	-	-				https://cpregister.com/
Australian Childhood Cancer Registry	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	-	-				https://cancerqld.org.au/research/viertel-cancer-research-centre/childhood-cancer/australian-childhood-cancer-registry/
Australian Cystic Fibrosis Data Registry (ACFDR)	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	https://www.cysticfibrosis.org.au/dataregistry
Australian Orthopaedic Association National Joint Replacement Registry	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	https://aoanjrr.sahmri.com/home
Australian Spine Registry (ASR) [Still in pilot stage]	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		https://www.spineregistry.org.au/

		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)						https://www.spinerregistry.org.au/wp-content/uploads/2020/07/ASR_AnnualReport2019_vFweb.pdf
Australia and New Zealand Islet and Pancreas Transplant Registry	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	-	-			http://anziptr.org/ Webster, A., Hedley, J., & Kelly, P. (2020). <i>Australian and New Zealand Islet and Pancreas Transplant Registry Report 2020</i> . Sydney, Australia.
Cooperative National Registry of Acute Coronary care, Guideline Adherence and Clinical Events (CONCORDANCE)	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.

GenesisCare Cardiac Implantable Electronic Devices (CIED) Database/ Device Registry		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.
GenesisCare Heart Failure Registry		(As above)			(As above)	Data collection has occurred since 2014	23 clinics across Australia >1,300 patients (2019)	Heart failure	-	-			(As above)
GenesisCare Percutaneous Coronary Intervention (PCI) Registry		(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)
Myeloma and Related Diseases Registry (MRDR)	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 & 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	http://www.mrd.net.au/
National Rheumatic Heart Disease Data Collection (NRHDDC)	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	https://www.aihw.gov.au/about-our-data/our-data-collections/national-rheumatic-heart-disease-data-collection

Prostate Cancer Outcomes Registry Australia and New Zealand	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	https://prostatecancerregistry.org/
Pulmonary Hypertension Society of Australia and New Zealand (PHSANZ) Registry	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	-	-				https://www.phsanz.org/phsanz-registry/ 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.
Queensland Perineural Invasion Registry Database		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.
Registry of Senior Australians	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						https://rosaresearch.org/

The Australia Dementia Network (ADNeT) Registry	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	-	-				https://www.australiandementianetwork.org.au/initiatives/clinical-quality-registry/
The Australia New Zealand Trauma Registry	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.		https://atr.org.au/
The Australian & New Zealand Fontan Registry	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)	-	-				https://www.fontanregistry.com/ 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.
Victorian Cancer Registry	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		https://www.cancervic.org.au/research/vcr 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.