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SYSTEMATIC REVIEW

The role of Australian clinical quality registries in pregnancy care: A scoping review

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Background: Pregnancy represents a time of increased morbidity and mortality for women and their infants. Clinical quality registries (CQRs) collect, analyse and report key healthcare quality indicators for patient cohorts to improve patient care. There are limited data regarding existing CQRs in pregnancy. This scoping review aimed to: (1) identify Australian CQRs specific to pregnancy care and describe their general characteristics; and (2) outline their aims and measured outcomes

Methods: The scoping review was undertaken according to Joanna Briggs Institute guidelines. CQRs were identified using a systematic approach from publications (Ovid MEDLINE, PubMed, Google Scholar), peer consultation, the Australian register of clinical registries and web searches. Details surrounding general characteristics, aims and outcomes were collated.

Results: We identified two primary sources of information about pregnancy care. (1) Six CQRs are specific to pregnancy (Australia and New Zealand twin-twin transfusion syndrome registry, Australian Pregnancy Register for women with epilepsy and those taking anti-epileptic drugs, National Register of Antipsychotic Medication in Pregnancy, Australasian Maternity Outcomes Surveillance System, Neonatal Alloimmune Thrombocytopaenia Registry and the Diabetes in Pregnancy clinical register). (2) Fourteen observational cohort studies were facilitated by non-pregnancy-specific CQRs where a subsection of patients underwent pregnancy.

Conclusions: Australian CQRs currently report varied information regarding some selected conditions during pregnancy and offer therapeutic and epidemiological insight into their care. Further research into their effectiveness is warranted. We note the lack of a CQR spanning the common problems of pregnancy in general, where significant health, service and economic gains are possible.

KEYWORDS

clinical quality registry, pregnancy, quality, registry, scoping review

INTRODUCTION

Australia maintains a low maternal mortality rate of 6.7 per 100 000 births, on par with the rest of the developed world.[1] That being said, pregnancy remains a high-risk and high-morbidity period for Australian women, with lifelong implications for mothers and their babies. In 2019, 11% and 2% of mothers had gestational diabetes and gestational hypertension, respectively, while 36% gave birth by caesarean section.[1] There were 6.6% of live births being low birthweight, with perinatal mortality at 9.4 per 1000 births.[1] A study involving 211 060 pregnant women in Victoria estimated the prevalence of serious maternal morbidity, defined using the Australian maternity morbidity outcome indicator covering key International Classification of Diseases-10 codes, to be 0.53%.[2] Pregnancy is a period of increased care requirements, with anecdotal variation existing in the care provided to mothers. A way to comprehensively address these issues is a population-wide registry dedicated to continually monitoring and improving pregnancy care.

Patient registries are organised systems that collect, handle and disseminate information on particular cohorts of interest who either have a disease, a risk factor that predisposes them to a health-related event or prior exposures suspected to cause adverse outcomes.[3(p2)] Unlike administrative data collections, eg National Hospital Morbidity Database, which specifically collect health system activity information on patient episodes of care, diagnoses and procedures, registries also collect data on processes of care and patient outcomes.[4,5] When registries identify benchmarks and significant outcome variance between sites, they are clinical quality registries (CQRs) and can inform improvements in healthcare quality.[6–8] As such, CQRs are designed to systematically collect, analyse and report risk-adjusted outcomes that inform the appropriateness and effectiveness of care, reporting findings back to jurisdictions, healthcare providers, funders, clinical colleges and researchers.[6,9,10] CQRs recruit patients, intending to prospectively establish a baseline cohort that is then systematically followed up by continually collecting bespoke data sets from all participants. This allows tracking of individual patients' longitudinal trajectories and consequent understanding of real-world outcomes. This is in contrast to the 'snapshot' approach of most existing quality improvement mechanisms, which provide a cross-sectional glimpse into key outcomes using administrative datasets. CQRs are most beneficial in clinical domains with known variation and where sub-optimal performance increases costs or diminishes the quality of life.[6]

Well-functioning CQRs drive clinical improvement and improve morbidity and mortality while being economically viable. The Victorian State Trauma Registry (VSTR) has recorded a reduction of in-hospital mortality from 11.9% in 2006–2007 to 9.9% in 2008–2009 and improvements in functional status outcomes.[11] The Adult Patient Database of the Australian and New Zealand Intensive Care Society (ANZICS- APD) and Australasian Rehabilitation Outcomes Centre have demonstrated improvements in key care indicators over time.[9] An economic evaluation of five Australian CQRs found they improved clinical practice at relatively low costs and conferred benefit-to-cost ratios ranging from 2:1 to 7:1.[12]

Fundamental mechanisms underpin the ability of successful CQRs to drive quality improvement. These include: opt-out consent to maximise patient capture; trained, experienced staff to undertake data entry at sites to maximise data quality; improvement measures based on accepted clinical guidelines; and regular feedback reporting to participating hospitals and clinicians.[13] Opt-out recruitment is approved by the National Health and Medical Research Council for CQRs to ensure population-level coverage and is essential for a successful CQR.[14] For example, an opt-in Breast Implant Registry in Australia from 2012–14 only captured 3% of patients; however, since 2015, the Australian government has funded an opt-out Breast Device Registry with over 40 000 patients and a 1% opt-out rate.[15] Additionally, the opt-out process provides information to participants about the CQR, and the data used for reporting and research has patient identifiers removed. This provides confidentiality and security of sensitive patient information.

Supplying clinicians with personalised feedback matched against national benchmarks maximises the impact of registries,[16,17] while accounting for differences in lower and higher risk patient cohorts that may affect outcomes. The VSTR emphasises opt-out consent to maximise patient capture, incorporating patient-reported outcome measures (PROMs) and data collection by clinically experienced staff who operate at a single site, facilitating quality control.[18] Stakeholders value CQR data for its potential to drive improvement.[9,19] Wilcox and McNeill[9] highlight the following mature Australian CQRs as exemplary in effective reporting – the Australian and New Zealand Dialysis and Transplant Registry, the Adult Patient Database of the Australian and New Zealand Intensive Care Society, the Australasian Rehabilitation Outcomes Centre and The Palliative Care Outcomes Collaboration. When mature, CQRs monitor clinical practice compliance against existing guidelines, as noted by the VSTR.[20] In emerging clinical areas, they can create the clinical evidence for the development of guidelines, as exemplified by the Burns Registry of Australia and New Zealand.[21]

While CQRs are often clinician-led, they require the support of the jurisdictions, institutions and agencies, including universities, professional colleges and the Australian Commission on Safety and Quality in Health Care (ACSQHC). In 2008, the ACSQHC, in collaboration with the National E-Health Transition Authority (NEHTA) and Monash University, published the operating principles and technical standards for Australian CQRs.[22] This was updated in 2014,[8] followed by a list of prioritised clinical domains for CQR development in 2016.[23] These guidelines advise that collaboration between the ACSQHC, clinicians, and governments is likely to ensure the development of sustainably funded national CQRs that are quality assured, clinician-led and patient-centred.[24] Research Australia emphasises that CQRs should encompass the healthcare experiences of patients and carers beyond traditional clinician-patient interactions.[25] The Australian Medical Association stresses

that practising clinicians must direct CQR design and be inspired to willingly participate.[26] While CQRs have not been consistently funded in the past, the Department of Health's National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030, endorsed by all Australian states and territories in 2020, provides a roadmap toward embedding CQRs as routine quality improvement activities across the health sector.[27]

Quality improvement within pregnancy care is ideally data-driven. Existing quality improvement initiatives such as the Australian Council on Healthcare Standards (ACHS) indicators and Women's Healthcare Australasia allow benchmarking but mainly use administrative data to produce 'snapshot' reports about clinical indicators.[28,29] These reports are largely not risk-adjusted and do not systematically follow a recruited baseline cohort of women. While mandatory perinatal data collections are maintained across Australian healthcare providers and institutions, they also report cross-sectionally, with limited publicly reported information and variation between states concerning definitions used and variables reported.

Maternity care is included in the ACSQHC list of prioritised clinical domains for CQR development, based on serious consequences of poor quality care, the moderate burden of disease and high cost.[23] However, the current scope of Australian CQRs in this space remains unclear.

The role of CQR data in pregnancy care within Australia is yet to be characterised. A 2011 study that evaluated 28 Australian CQRs did not identify any directly relevant to pregnancy care.[30] The register of CQRs being developed by the ACSQHC does not currently feature any registries of direct relevance to pregnancy care.[31]

We, therefore, sought to undertake a scoping review of Australian CQRs documenting pregnancy-specific outcomes and conditions. We considered a CQR to be a dataset that collects prospective information regarding an ongoing cohort (register) of eligible participants where systematic data collection occurs at specified timepoints, and where such information is benchmarked and regularly provided to clinicians to improve clinical practice. This differs from similar quality improvement activities, which compare 'snapshot' data at a point in time, which while valuable, may not have sufficient granularity of data to meet the needs of clinicians. We aimed to describe: (i) the general characteristics of the CQRs; and (ii) the aims and the outcomes they measured. We hope this review may be helpful as a reference point for healthcare professionals and researchers seeking collated details surrounding CQRs, the primary focus of which is to monitor pregnancy.

METHODS

Scoping review guidelines by the Joanna Briggs Institute underpin our methodology.[32] We identified CQRs in pregnancy care by searching databases (Ovid MEDLINE, PubMed, Google Scholar) for publications about relevant registries (1980–2021), web searching using Google, hand searching reference lists of publications and clinical registries and searching the Australian Register of Clinical Quality Registries.[31] Our database search strategies used the Medical Subject Heading (MeSH) terms and Boolean operators pregnancy *OR* pregnancy complications *OR* obstetrics *AND* registry *OR* clinical quality registry *AND* Australia *OR* eight individual states and territories (See Appendix S1 for detailed Ovid MEDLINE search parameters, available as supplementary online material). We screened titles and abstracts from publications and applied our inclusion and exclusion criteria (Table 1).

For each identified CQR, we extracted relevant information from full-text articles using a standardised data extraction form based on operational frameworks described in the United States and Australian Registry operating principles.[33,34] Where details could not be obtained from publications or registry websites, we contacted registry custodians by email (T. Campion). The following information was collated:

TABLE 1 Inclusion and exclusion criteria to identify Australian clinical quality registries that primarily measure pregnancy specific outcomes

	Inclusion criteria	Exclusion criteria
Theme	• Registries documenting pregnancy-specific outcomes and conditions	• Registries that do not primarily focus on pregnancy and pregnancy outcomes, eg neonatal and paediatric registries with limited data about pregnancy-specific parameters
Characteristics	• Registries that collect patient level data continuously from multiple sites • Registries that measure predefined quality indicators • Registries that report quality indicators back to treating clinicians • Registries that operate fully within Australia • Registries that recruited a baseline cohort of subjects and systematically followed them up at predefined timepoints	• Cohort studies where data are reported publicly but not specifically to clinicians contributing data • Studies focusing on a specific research question rather than predefined quality indicators • Administrative data collections that report in a cross-sectional manner, eg perinatal data collections • Drug, device and product safety registries • Registries owned and operated by pharmaceutical companies
Reporting details	• Publication of least one report on the outcomes or protocol of the registry	• Registries that did not report in English

1. theme and aims
2. central location and key contact details
3. current status (active or inactive) and year established
4. funding details
5. core population (inclusion and exclusion criteria, geographic location, time period)
6. participating services
7. data collection, data management and data dissemination practices
8. outcomes measured
9. privacy and security measures.

RESULTS

As demonstrated by Figure 1, 100 records about registries in pregnancy were initially identified. The following records were excluded: 15 pertaining to non-Australian registries; 14 pertaining to administrative data collections; seven that did not relate to pregnancy; and two pertaining to proposed registries without current publications. From the resulting 62 records, we identified six CQRs with a primary focus on pregnancy care. They are as follows, listed in chronological order of inception.

1. Australia and New Zealand Twin-Twin Transfusion Syndrome Registry[35]
2. National Register of Antipsychotic Medication in Pregnancy (NRAMP)[36]
3. Australian Pregnancy Register (APR) for women with epilepsy and those taking anti-epileptic drugs (AEDs)[37–39]
4. Australasian Maternity Outcomes Surveillance System (AMOSS)[40–42]
5. Neonatal Alloimmune Thrombocytopaenia Registry (NAIT)[43, 44]
6. Diabetes in Pregnancy (DIP) clinical register[45]

Each CQR's characteristics are shown in Table 2 and aims and outcomes in Table 3. Practices surrounding data collection and management are included in Appendix S2 (available as an online supplement). Additionally, our search identified 14 publications

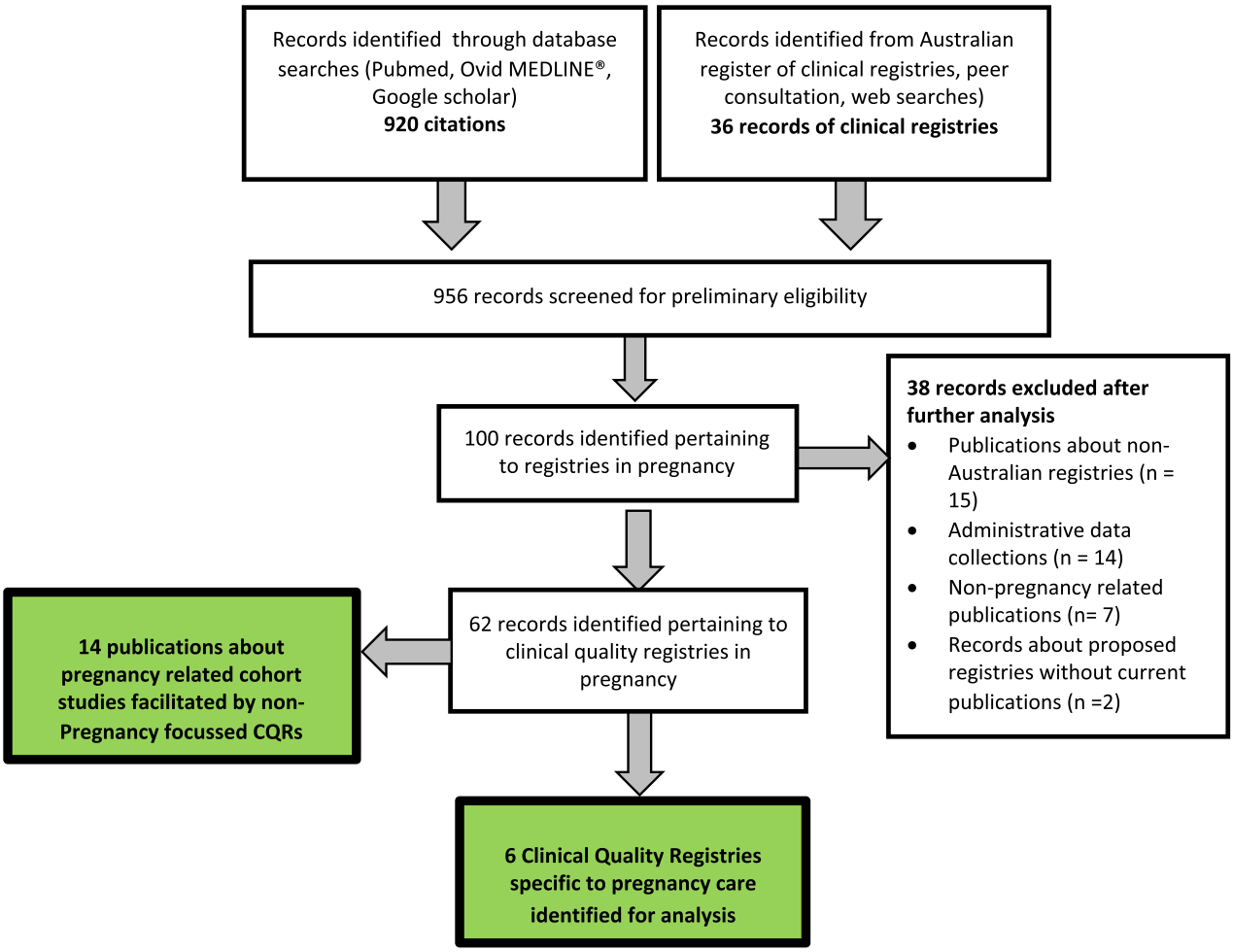

FIGURE 1 Systematic approach to determining eligible Australian clinical quality registries (CQRs) with a primary focus on pregnancy. Records from databases (1980-2021), web searches, Australian Register of Clinical Registries and peer consultation (n = 956) were subject to inclusion and exclusion criteria. Reasons for exclusion have been detailed. Six CQRs were identified for analysis.

TABLE 2 General characteristics of Australian clinical quality registries that primarily measure pregnancy-specific outcomes

Registry	Status	Established	Coverage	Central location	Funding	Patient population	Participating services
Australia and New Zealand twin-twin transfusion syndrome registry[26]	Inactive	1995; ceased 1998	National	Women and Infants Research Foundation, Perth WA	Information not available	Patients with prenatally diagnosed twin-twin transfusion syndrome	Tertiary obstetric units in Australia and New Zealand
Australian Pregnancy Register (APR) for women with epilepsy and those taking anti-epileptic drugs (AEDs)[28–30]	Active	1998	National	St. Vincent's Hospital; Monash University; Royal Melbourne Hospital, Melbourne, VIC	Epilepsy Action Australia, Epilepsy Society of Australia, National Health and Medical Research Council, Royal Melbourne Hospital Neuroscience Foundation, pharmaceutical sponsors (Sanofi Aventis, Sanofi Genzyme, UCB Pharma, Eisai)	(i) Australian women taking AEDs for any indication throughout pregnancy (91.8% of participants; 98.3% were women with epilepsy) (ii) Australian women not treated with AEDs in first half of pregnancy (8.2% of participants; 98.3% were women with epilepsy)	(i) Healthcare professionals involved with medical management (over 50% were Australian neurologists) (ii) Relevant institutions and societies
National Register of Antipsychotic Medication in Pregnancy (NRAMP)[27]	Active (Data analysis only with no new data being collected)	2005	National	Monash Alfred Psychiatry Research Centre, Melbourne VIC	Sponsors and donors (Janssen Cilag, Astra Zeneca, Hospira, Rotary), in-kind support (Alfred Health and Monash University)	Australian pregnant women treated with an antipsychotic medication with a history of psychosis (schizophrenia, schizoaffective disorder, first-episode psychosis and bipolar affective disorder with psychosis) (318 as at 2017)	Clinicians, health services and professional bodies (30 sites)
Australasian Maternity Outcomes Surveillance System (AMOSS)[31,33,34]	Active	2008	National	University of Technology, Sydney	Initially funded by National Health and Medical Research Council; specific studies funded by varying organisations	96% of Australian births captured, to study patients with rare pregnancy conditions	Clinicians at 260/275 Australian and 24/24 New Zealand units with >50 annual births
Neonatal Alloimmune Thrombocytopaenia Registry (NAIT)[35,36]	Active	2009	National	Monash University, Melbourne VIC	Formal funding ceased in 2014; Monash University maintains site governance, ethics and case acquisition	(i) Pregnant women who develop or have a history of neonatal alloimmune thrombocytopaenia (ii) Their children before and after birth	(i) Clinicians from specialist units at hospitals (ii) Laboratories that perform diagnostic testing for neonatal alloimmune thrombocytopaenia
Diabetes in Pregnancy clinical register (DIP)[37]	Active	2012	State-wide, Northern Territory (NT)	Menzies School of Health Research, Darwin NT	Institutions (National Health and Medical Research Council, Global Alliance of Chronic Diseases, Diabetes Australia Research Program, Channel 7 Children Research Foundation, Australian Government Department of Health, Central Australia Academic Health Science network); private donations	All pregnant women residing in the NT >16 years old with type 1, type 2 or gestational diabetes	Referring health practitioner (doctor, midwife diabetes educator or Aboriginal health practitioner)

TABLE 3 Aims and corresponding outcomes of Australian clinical quality registries that primarily measure pregnancy-specific outcomes

Registry	Aims	Outcomes measured
Australia and New Zealand twin-twin transfusion syndrome registry[26]	(i) To study the antenatal course and perinatal outcomes of twin-twin transfusion registry in a large population (ii) To assess contemporary management strategies and outcomes in prenatally identified cases of twin-twin transfusion syndrome	**Fetal and neonatal outcomes:** (i) Gestation at diagnosis and delivery (ii) Oligohydramnios-polyhydramnios sequence (iii) Fetal hydrops (iv) Use of therapeutic amnioreduction (iii) Birthweight of donor and recipient twin (ii) Cord haemoglobin difference between donor and recipient twin (g/L) (iv) Fetal death in utero (v) Neonatal death (vi) Perinatal survival
National Register of Antipsychotic Medication in Pregnancy (NRAMP)[27]	(i) To provide a better understanding of antipsychotic medication use during pregnancy, birth and for the first year of the baby's life (ii) To allow development of evidence-based guidelines for the best use and effect of antipsychotic medication during pregnancy, birth and the postnatal phase (iii) Assist healthcare professionals, and women with mental illness, to make informed decisions about appropriate treatment options, and encourage safer outcomes for both mother and baby, during pregnancy, birth and the postnatal phase (iv) Enhance our knowledge regarding the care of women with mental illness during pregnancy, birth and the postnatal phase	**Maternal and fetal outcomes:** (i) Demographics and family history (ii) Physical health (iii) Psychiatric information and medication (iv) Rating scales (Positive and Negative Symptom Scale *PANSS;* Edinburgh Postnatal Depression Scale *EPDS)* (v) Obstetric details (vi) Birth outcomes including APGAR scores (vii) Child outcomes including developmental milestones (viii) Maternal outcome including Mothering Attitudes Questionnaire *MAQ*
Australian Pregnancy Register (APR) for women with epilepsy and those taking anti-epileptic drugs (AEDs)[28–30]	(i) To evaluate the incidence of adverse fetal outcomes resulting from pregnancies exposed to AEDs (ii) To determine if certain AEDs or combinations are associated with a higher incidence or specific types of adverse pregnancy outcomes (iii) To determine the influence of the seizures, the epilepsy type, the genetic background and environmental factors (iv) To study the comparative efficacy of AEDs on seizure protection in pregnancy, assessed on the basis of self-reporting and increased dose or additional drug requirements	(i) Maternal health status (particular focus on seizure control) (ii) Pregnancy outcomes (current and previous): live births; stillbirths; abortions (iii) Fetal outcomes: no defects; malformations categorised according to Victorian Birth Defect Classification. Examples identified from analysis of 20 years of registry data (spina bifida, cardiac malformations, digits, skull bones and brain, hypospadias, urinary tract malformations)
Australasian Maternity Outcomes Surveillance System (AMOSS)[31,33,34]	To study severe and often rare maternal conditions in pregnancy, childbirth and six weeks after birth using a clinical and population approach to improve safety and quality of maternity care in Australia and New Zealand by: (i) development of evidence-based information on severe maternal morbidity (ii) use of developed information in clinical care, service planning and for patient information	Cumulative list of outcomes since AMOSS' inception defined by consultation with AMOSS project board, advisory group, collaborators, stakeholders and consumers; only few rare outcomes (<1:1000 incidence) being studied at any given time as part of cohort studies lasting 1–2 years **(outcomes 1–4 in bold being studied currently)** 1. **Massive obstetric haemorrhage** 2. **Rheumatic heart disease**; in First Nations populations 3. **Gestational breast cancer** (i) In utero exposure to breast cancer treatment (ii) Pregnancy outcomes after breast cancer diagnosis (ii) Patient experiences 4. **Serious kidney disease in pregnancy** 5. Vasa previa 6. Morbid obesity 7. Cardiac disease in pregnancy 8. Placenta accreta 9. Vasa previa; women's experiences 10. Impact of socioeconomic status on maternal morbidity 11. Influenza outcomes 12. Antenatal pulmonary embolism 13. Peripartum hysterectomy 14. Amniotic fluid embolism

TABLE 3 (Continued)

Registry	Aims	Outcomes measured
Neonatal Alloimmune Thrombocytopaenia Registry (NAIT)[35,36]	(i) To provide the opportunity to more accurately define incidence, natural history and clinical outcomes of neonatal alloimmune thrombocytopaenia (ii) To explore range of treatment approaches, clinical and laboratory factors that influence outcomes (iii) To better define optimal management of NAIT patients (iv) To inform and inspire future hypothesis-driven research	**Maternal and fetal outcomes:** (i) Diagnoses (ii) Clinical and laboratory and imaging results (iii) Therapy (iv) Complications of disease and therapy (v) Transfusion (intravenous immunoglobulin and platelets) (vi) Clinical outcomes
Diabetes in Pregnancy Clinical Register (DIP)[37]	(i) Improve management of women with diabetes in pregnancy by improving coordination of care and centrally collating information between primary and tertiary systems (ii) Improve follow up of women with DIP (iii) To act as a quality assurance tool (iv) To be used as an epidemiological tool to highlight the burden of DIP and variability over time, place and ethnicity	**Maternal outcomes:** (i) Number of pregnancies, type, births (ii) Maternal indigenous status, ethnicity (iii) Location, ultrasound details, smoking and alcohol outcomes **Diabetes outcomes:**(i) Type (ii) Average glycated haemoglobin concentration (HbA1C %) with median gestation **Birth outcomes:** (i) Number of births according to type of diabetes (ii) Livebirths, stillbirths (iii) Mode of delivery **Neonatal outcomes:** (i) Neonatal deaths (ii) Birthweight, gestational age (iii) Congenital malformations (iv) Miscarriage/abortion

pertaining to Australian CQRs without a primary focus on pregnancy, but which had facilitated cohort studies on their pregnant participants. Details surrounding these are summarised in Appendix S3 (available as an online supplement).

General characteristics of CQRs

Table 2 describes the general characteristics of identified CQRs. Registries are listed in chronological order of inception and classed as active (n = 6) or inactive (n = 1) and as national (n = 6) or state-wide (n = 1). Date of establishment, central location and institution are described. Funding organisations declared include the Australian National Health and Medical Research Council (n = 3), the Australian government (n = 2), universities (n = 3), research organisations (n = 4), private donations (n = 2) and pharmaceutical sponsors (n = 2). Key populations were captured through independent engagement with clinicians (n = 3), at birthing units (n = 6), specialist units at tertiary hospitals (n = 5) and pathology laboratories (n = 7).

Aims and outcomes of CQRs

These CQRs demonstrate established aims and a corresponding set of measurable primary and secondary outcomes, defined by investigators and institutions. These are described in Table 3. Those registries designed to study conditions in pregnancy aim to better elucidate epidemiological and clinical parameters of the condition to benchmark, monitor and consequently improve care (n = 7).

DISCUSSION

CQRs monitor quality indicators and facilitate benchmarking among healthcare providers. However, there have been limited data collating the existence of such registries within pregnancy care in Australia. We identified six such pregnancy-specific CQRs and have described their characteristics. No registry focused on broad complications or outcomes of pregnancy itself; all six focused on either individual conditions within pregnancy or collectively rare pregnancy outcomes.

The five pregnancy-specific CQRs aim to clarify the knowledge, benchmark outcomes and improve quality of care for pregnant women with epilepsy, psychiatric diagnoses, NAIT, twin-twin transfusion syndrome (inactive CQR) and diabetes in pregnancy. AMOSS differs because it is an established infrastructure designed to facilitate prospective cohort studies on rare conditions in pregnancy. Four such studies are currently in progress, using a version of the original infrastructure for data collection.

Our findings suggest that CQRs not primarily designed to monitor pregnancy can also provide information on pregnancy care by facilitating cohort studies where a subsection of patients happened to experience pregnancy (Appendix S3, available as an online supplement). These yielded conclusions about pregnancy care in renal patients, those with Fontan circulation, trauma in pregnant patients, haemorrhage and pregnancy-associated cancers.

Although they did not meet our inclusion criteria due to not having published a report yet, we identified two emerging CQRs of relevance. The Coronavirus Health Outcomes in Pregnancy And

Newborns (CHOPAN) registry is a prospective CQR that aims to better characterise risks associated with COVID-19 during pregnancy, and the Newborn Obstetrics Network Australasia (NONA) registry aims to identify complex pregnancies such as those complicated by conditions with increased perinatal and childhood morbidity and mortality such as fetal growth restriction, multiple pregnancies and congenital anomalies.[46, 47]

We found that all six CQRs systematically collected predefined outcome and process measures in keeping with good registry practice. Outcome measures are of intrinsic importance as health indicators; variance may reflect a genuine difference in the quality of care or presence of confounders such as random chance, differences in the type of patient and measurement.[48] Process of care measures are less susceptible to confounders and are often easier to measure. They can be beneficial for rare outcomes where an improvement in a process measure may be used as a proxy for improvement in outcomes.[48,49] The APR for women with epilepsy and those taking AEDs and the NRAMP recorded PROMs. PROMs across health, quality of life and functioning are ideally collected directly from patients by telephone follow up or surveys.[19] Their potential to inform quality improvement is recognised internationally, leading a 2016 report to recommend that the ACSQHC undertake further work to ascertain barriers and facilitators to the inclusion of PROMs in Australian CQRs.[50]

CQRs are capable of producing reliable findings when epidemiologically sound data is collected from a high percentage of eligible patients within a population.[19,30] However, in a 2011 survey of Australian multi-site CQRs, it was recorded that 46% recruited fewer than 80% of the eligible population and 82% did not reliably audit at the clinical level.[30] We observed that CQRs employed an opt-out consent/waiver of consent process, brief web-based forms and clinician follow up with reminders to maximise patient capture. However, clinicians were still required to identify patients and submit data collection forms, a process that may present hurdles and introduce selection bias. The APR for women with epilepsy and those taking AEDs estimated in 2014 that it captures one out of every 12 eligible pregnancies.[51] The DIP registry identified data entry as a significant resource and capacity issue, leading them to restrict data collected to increase sustainability.[45] Participants submitting cases to AMOSS highlighted busy maternity units, limited computer-to-staff ratios and difficulty accessing the necessary specific information post-event as barriers to data entry.[41] Widespread implementation of electronic medical record systems provide opportunities to address these issues.[30] Eventually, it is hoped that full integration of electronic medical records with CQRs will streamline enrolment and data collection, as observed in the Swedish pregnancy register.[30,52] This would ensure complete patient datasets are captured, yielding generalisable and representative findings.[9]

Recording easily accessible balancing metrics like age and comorbidities facilitates risk adjustment of outcomes by accounting for confounding factors.[6] Risk-adjusted reports allow healthcare providers to identify actual variation in healthcare quality and drive improvement.[22] Nevertheless, Evans *et al*.[30] identified that 18% of Australian CQRs did not record sufficient data for basic risk adjustment. While data items collected by the registries we identified may plausibly be used to risk adjust, only the Australian Pregnancy Register for epilepsy outcomes (APR) explicitly stated the use of a multivariate regression analysis. The use of propensity scores – numbers that reduce a set of confounders to a single score – has been suggested as a better method to compare outcomes among different groups, promoting efficient benchmarking.[3,53]

Feeding registry findings back to clinicians allows continuous monitoring and quality assurance. In the CQRs we identified, this predominantly occurred through publications in scientific journals, reports and presentations at conferences. Strategies to ameliorate the time lag associated with these methods include updating findings on registry web pages and a 'descriptive dashboard of real-time data' as proposed by the CHOPAN registry.[47] This is in keeping with recommendations that registries integrate tools for rapid feedback to participants, as has been implemented by the Swedish National Register of Information and Knowledge about Swedish Heart Intensive care admissions (RIKS-HIA) and the Global Registry of Acute Coronary Events (GRACE).[54] Maternity care providers in Sweden can visualise quality measures across pregnancy, fetal diagnosis and delivery over time, using the Swedish pregnancy register interface.[52] The register also facilitates benchmarking by generating case-mix-adjusted dashboards in real-time.

CQRs require funding for establishment and to sustain functioning.[19] All five active CQRs appeared to rely on aggregate models of funding. The DIP registry, the neonatal alloimmune thrombocytopaenia registry (NAIT) and the NRAMP flagged significant funding concerns. This is despite health economics studies demonstrating that relatively small injections of funding to supplement existing efforts are likely to be highly cost effective.[12,55]

Ideological divisions in maternity care are likely to impact the prioritisation of pregnancy-related CQRs in the future, given the diversity of clinical foci. We believe further research into prioritising areas within maternity care that would benefit most from CQRs is warranted. Additionally, given that CQRs aim to collect a minimum data set of critical items at selected points along the clinical trajectory, we are hopeful that this may generate a central spine of baseline data and critical follow up measures. Extra data items about more specific research questions can then be added by contributing sites to build on the fundamental research infrastructure of the CQR.

The inactive twin-twin transfusion syndrome registry (1995–1998) is the only registry we identified covering fetal therapeutic interventions, namely amnioreduction.[35] The role of CQRs in fetal therapy is taking shape internationally, as demonstrated by the International Fetal Cardiac Intervention Registry (IFCIR).[56,57] This highlights a gap in Australian registry practice, and further research by care providers to establish the feasibility of setting up CQRs with a focus on fetal therapy is warranted.

Although each Australian state maintains a core perinatal data collection to monitor key maternity outcome data, these

datasets do not meet the definition of a CQR. They use administrative data to produce cross-sectional reports at a population level and do not provide regular risk-adjusted feedback to sites about their performance against quality indicators.[58] While Victoria produces a perinatal services performance indicator report, other than taking into account the size of the hospital, outcome measures are not risk-adjusted, making benchmarking and analysis of variation challenging.[59,60] Such reports of aggregated data across a health service provide little insight into care and outcomes of high-risk groups, eg patients with hypertensive disease in pregnancy. Given that CQRs are purposefully designed to systematically measure processes and outcomes of care for a defined cohort, we excluded these collections from this scoping review.

In highlighting the key strengths of this review, we have identified active, inactive and prospective Australian CQRs focused on pregnancy that have published data within the public domain (scientific literature or the Internet). However, our study was not without limitations. Although we hand-searched reference lists and used peer consultation, our search strategy primarily relied on publications by registries, and we may have consequently left out registries without scientific publications. As a scoping review, we could not collate details surrounding registry governance and ethics or systematically assess if each CQR was achieving its respective aims and objectives. Further in-depth surveys of registry custodians would provide valuable data on the experiences and challenges in establishing CQRs in pregnancy. Likewise, qualitative studies of registry participants are likely to generate useful inferences about the capacity of registries to accurately assess quality of care and stakeholder experiences.[30,41,45]

In conclusion, this scoping review characterised the information of relevance to pregnancy that is currently collected within existing Australian CQRs. This may inform future registry development and cross-registry collaboration. Pregnancy care in Australia provides rich opportunities for future development of CQRs to support and monitor maternal, fetal, and neonatal health improvements.[23,52,59]

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1. Search strategy using Ovid MEDLINE, conducted on 18/05/2021.
Appendix S2. Data procedures of identified clinical quality registries primarily measuring pregnancy-specific outcomes.
Appendix S3. Key characteristics of registry-based cohort studies.