**A Systematic Review of Cardiac Rehabilitation Registries**

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**ABSTRACT** (248 words)

**Introduction:** Despite cardiac rehabilitation (CR) beingrecommended in clinical practice guidelines internationally these services are under-utilised, programs are not standardised and quality improvement methods and outcomes are rarely published. National registries are an important strategy to characterise service delivery, quality and outcomes, yet the number, type and components of national CR registries has not been reported.

**Aims:** To identify and describe national and international CR registries internationally, and summarise their key features.

**Methods:** The literature reporting on CR registries used to monitor the quality of CR at a national and international-level was systematically reviewed. A search of four databases was conducted in July 2016, with two reviewers independently screening title/abstracts and full-texts for inclusion. Data were extracted from included studies, independently checked by a second reviewer and synthesised qualitatively.

**Results:** Eleven articles were included in the reviewcomprising seven national registries and one international registry (of 12 European countries) for a total sample of 265,608 patients. Data were most commonly provided to the registry via a web-based application, and included individual-level data (i.e., sociodemographic characteristics, medical history, and clinical measurements). When reported, service-level data most commonly included wait times, program enrolment and completion. The overarching governance, funding modes (e.g., industry (n=2), government (n=1)), and incentives for registry participation (e.g., benchmarking, financial reimbursement, or mandatory requirement) varied widely.

**Conclusion:** The use of national and international registries for characterising CR and providing a benchmark for quality improvement is in its early stages but shows promise for national and global benchmarking.

**Keywords:** Acute coronary syndrome; cardiovascular disease, health information systems; quality Improvement

**INTRODUCTION**

Cardiovascular disease (CVD) is the leading cause of mortality globally, accounting for 30% of all deaths in 2013[1](#_ENREF_1). In high-income countries, survival rates following acute coronary syndrome (ACS) (i.e., heart attacks and unstable angina) have improved significantly over recent decades largely due to advancements in pharmaco-therapy and interventional procedures such as angioplasty, stents and bypass grafting[2](#_ENREF_2). As a result, large numbers of people are living with heart disease as a chronic condition and require support to achieve changes in lifestyle and regain or maintain physical capacity, well-being, social and vocational participation[3](#_ENREF_3), [4](#_ENREF_4).

When delivered effectively,cardiac rehabilitation (CR) is pivotal for helping patients achieve secondary prevention targets and prevent readmission. Meta-analyses demonstrate that participation in CR reduces total deaths, cardiovascular deaths and hospital readmission by approximately 25% and increases adherence to pharmaco-therapy, and improves quality of life[5](#_ENREF_5). Clinical practice guidelines have been developed in several countries recommending the provision of CR to patients with coronary heart disease (CHD) as part of integrated cardiac care[6](#_ENREF_6), [7](#_ENREF_7). However, many patients do not receive appropriate CR[8](#_ENREF_8), [9](#_ENREF_9). Recent data from England show that just 50% of referred patients enrol in CR[10](#_ENREF_10) and in Australia and New Zealand only 25% of ACS patients successfully met or maintained optimal secondary prevention targets after discharge[11](#_ENREF_11). In the United States, a third of ACS patients are readmitted to hospital within 30 days, with over 60% readmitted within 1 year[12](#_ENREF_12). Among those that do attend CR, the quality of the programs and consequential benefits vary substantially[13-15](#_ENREF_13).

Audit and evaluation are promoted as core components of CR as reflected in clinical guidelines[6](#_ENREF_6), [7](#_ENREF_7), [16](#_ENREF_16), [17](#_ENREF_17).These processes of systematic monitoring of CR delivery and outcomes is recommended to improve participation[16](#_ENREF_16), [18](#_ENREF_18). Clinical registries are effective instruments for audit and evaluation through standardised, systematic collection and reporting of information on both the appropriateness of care (process) according to clinical practice guidelines and the effectiveness of care (outcomes) for individuals with CVD[19](#_ENREF_19). Well-designed and well-executed registries hold great potential to capture data that reflect “real-world” clinical practice in order to provide insights into patient characteristics and evaluate patterns of care and disparities[19](#_ENREF_19). The American Heart Association (AHA) recently released a Scientific Statement[20](#_ENREF_20) highlighting the need to systematically redesign cardiovascular care to be a ‘learning healthcare system’, which utilises information technology and data infrastructures to enhance optimal healthcare delivery. The AHA has a longstanding commitment to promoting the innovation and effective use of clinical registries[21](#_ENREF_21). While numerous ACS and other CVD registries have existed globally such as the Global Registry of Acute Coronary Events (GRACE[22](#_ENREF_22)) and the Myocardial Ischaemia National Audit Project (MINAP[23](#_ENREF_23)), very few countries have established national CR registries. This is an important deficit because the provision of timely, relevant and reliable information through CR registries can assist in driving improvements in CR quality and increase CR utilisation[19](#_ENREF_19).

Accordingly, the purpose of the current review was to identify CR registries internationally, and characterize the nature of the data collected and their operation/organisation. The focus of the review includes characterising: (i) how these data were provided to the registry (i.e., manual, electronic upload), (ii) who was responsible for collecting and inputting these data, (iii) governance models, (iv) issues related to privacy, (v) the incentives for CR programs to participate and contribute data, (vi) funding sources to support the registry, and (vii) barriers and enablers of implementation.

**METHODS**

**Search strategy**

This review was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [24](#_ENREF_24) (Appendix A). In July of 2016, the following databases were searched: CINAHL (EBSCOHost)[1982-present], Ovid MEDLINE(R)[OvidSP)[1974-present], Pubmed (<https://www.ncbi.nlm.nih.gov/pubmed/>). In addition, Google Scholar (<https://scholar.google.com.au/>) was searched for unpublished studies and grey literature. The following key words were searched: ‘‘cardiac’’, ‘‘acute coronary syndrome’’, "myocardial infarction’’, “percutaneous coronary intervention”, “coronary artery disease”, ‘‘rehabilitation’’, ‘‘audit’’, "registry", and "data". The full search terms and strategies are provided in the Supplementary materials (Appendix B). Reference lists of key articles were further searched to identify any other relevant publications. Additionally, we contacted authors of the included studies and asked if they were aware of any further registries.

**Eligibility criteria**

Specification of inclusion and exclusion criteria was guided by the scientific literature, in particular Cadilhac et. al’s review of stroke registries [25](#_ENREF_25). Studies were included if they: (i) presented data from a register, databank, or database containing a minimum dataset and for which data had been collected prospectively, (ii) captured data on CR as defined by the World Health Organization as “*the sum of activities required to ­influence favourably the underlying cause of the disease, as well as to provide the best possible physical, mental and social conditions, so that patients may, by their own efforts, preserve or resume when lost as normal a place as possible in the community”* [*26*](#_ENREF_26), (iii) comprised patients eligible for CR according to the National Institute of Health and Care Excellence (NICE)[27-29](#_ENREF_27) and European Guidelines[18](#_ENREF_18) which include those following: acute coronary syndrome – including myocardial infarction (both ST elevation and Non-ST elevation), and unstable angina; revascularisation procedures (coronary artery bypass graft surgery and percutaneous coronary intervention); and coronary artery disease (CAD) and, (iv) monitored the quality of CR at a national or international-level where ‘national’ was defined as *“accepted country-wide system for data collection; was titled as ‘national’; or carried the name of a country”* [25](#_ENREF_25) and ‘international’ was defined as “*the collection of uniform data across multiple countries*”. Registries were excluded if they were developed for population disease surveillance or epidemiological disease monitoring without collection of clinical care indicators or were not published in English, no limits on study design were imposed.

**Study selection**

The online systematic review management tool ‘Covidence’ ([www.covidence.org](http://www.covidence.org))[30](#_ENREF_30) was utilised throughout the review to manage the screening process and conflicts. Two reviewers (AP and ET) independently screened all titles and abstracts identified from the search for inclusion. The full text of potentially-relevant papers were retrieved. The same two reviewers also independently assessed the full texts for inclusion or exclusion. Any conflicts were discussed between the reviewers and if necessary, the senior author (AO) provided guidance in order to reach consensus.

**Data extraction and management**

After agreement on the final included studies was reached, one author independently extracted data using a standard data extraction form which was then cross-checked by the second reviewer. The data extraction form included: (i) registry name, (ii) active dates of the registry, (iii) included patients, (iv) data source, (v) number of patient records, (vi) methods of data collection across sites, (vii) data collection time points, (viii) patient-level data collected, (ix) service-level data collected, (x) who was responsible for collecting and inputting data, (xi) governance models, (xii) issues related to privacy, (xi) the incentives for CR programs to participate and contribute data, (xii) funding sources to support the registry, and (xiii) barriers and enablers of implementation.

The corresponding authors of included registries were contacted via email when information on all data points could not be located. If the authors did not respond, two follow-up reminders were sent. If no response, or incomplete responses were received, ‘not reported’ was entered into the data extraction table.

**Synthesis of the literature**

Results from included papers were summarised in tabular format and qualitatively synthesised. Overall findings were then considered in terms of policy implications and directions for future research.

**RESULTS**

**Summary of results**

The search strategy generated 6489 articles, including five papers known to the authors (Figure 1). After duplicates (969) were removed, title and abstract screening was undertaken on 5520 unique papers. One hundred and fifty-five full texts were retrieved and assessed; there was agreement between reviewers on inclusion or exclusion for 144/155 (93%) of the papers, and the remaining 11/155 (7%) papers were passed on to a third reviewer for arbitration. Ultimately, 11 studies met the inclusion criteria.

\*\* Insert FIGURE 1: Study Flow Diagram \*\*

The included 11 papers described CR registries in seven countries: Austria[31](#_ENREF_31), Canada[32-34](#_ENREF_32), Denmark[35](#_ENREF_35), Germany[36](#_ENREF_36), [37](#_ENREF_37), Mexico[38](#_ENREF_38), the United States[39](#_ENREF_39), and the United Kingdom (excluding Scotland)[40](#_ENREF_40) (Figure 2, Table 1). The EuroCaReD registry[41](#_ENREF_41) was the only international registry, and comprised of CR sites from 12 European countries (including three sites that were previously included as national registries; Denmark, Germany and Austria). In total, these registries included 265,608 participants (excluding Mexico which did not report a total number of participants). The German registry[23](#_ENREF_23), [24](#_ENREF_24), which combined two large-scale national registries, had the largest number of patient records (n=117938, 45.8% of all registries) and the earliest recorded data with collection commencing in 2000[36](#_ENREF_36), [37](#_ENREF_37). The remaining registries commenced from 2001 (Austria[31](#_ENREF_31)) to 2015 (Denmark[35](#_ENREF_35)). The registries currently active are Austria[31](#_ENREF_31), Canada[32-34](#_ENREF_32), Denmark[35](#_ENREF_35), the United Kingdom[40](#_ENREF_40) and the United States[39](#_ENREF_39).

\*\* Insert FIGURE 2: Location of included studies \*\*

\*\*Insert Table 1 and Table 2\*\*

**Methods of data collection**

Six registries (75%) established web-based data entry systems in which data could be manually entered from participating sites by a member of the clinical team or a nominated data steward. Two reported alternatives included: 1) the German registry which utilised a standardised case report form (unclear if electronic or paper) which was completed by physicians and sent to a data collection unit[36](#_ENREF_36), [37](#_ENREF_37) and, 2) the staffing details of the United Kingdom registry which were collected via the National Audit of Cardiac Rehabilitation (NACR) annual paper surveys. The burden on the participating sites resulting from the data entry were not reported in any included source, and Denmark[35](#_ENREF_35) was the only registry that reported simultaneous linkage to central patient registries to enable data to be auto-filled and reduce time required for data entry.

**Patient- and service-level data collected**

The number of indicators captured across the registries varied widely, with USA[42](#_ENREF_42) and Canada[33](#_ENREF_33) having more than 180 indicators. As shown in Table 2, at the individual patient level, 100% of the registries collected data on: demographics (e.g., age, sex), medical history (e.g., admitting diagnosis), clinical measures (e.g., lipids, glucose, and blood pressure) and anthropometrics (e.g. body mass index). Most registries (n=6, 75%) also included at least one psycho-social measure (e.g., depression screener) and cardiovascular-related medications. As shown in the second column of Table 2, service-level data were poorly reported. Included indicators were CR referral (n=3, 37.5%), CR enrolment (n=3, 37.5%), CR wait times (n=1, 12.5%), CR completion (n=4, 50%) and staffing requirements (n=2, 25%). The rationale behind the choice of indicators was not always clear, although the authors of the United Kingdom registry stated that the clinical outcome measures were selected based on their importance for risk factor management, and the indicators in the Canadian registry were developed to measure national quality indicators; Canada had a task force that created the data dictionary. Five (62.5%) registries collected data at CR enrolment and CR completion and one registry (United States) enabled sites to submit data at any time depending on the chosen data collection mechanism. Denmark[35](#_ENREF_35) was the only registry that reported follow-up data collection (6 months) after program exit.

**Governance models**

The majority of registries (n= 5; 62.5%) were established by national CR associations and governed by working groups developed from within the associations. For example, the Austrian registry was founded and funded by the independent Austrian Working Group on Outpatient Cardiac Rehabilitation (AGAKAR), the Canadian registry was established by the Canadian Association of Cardiovascular Prevention and Rehabilitation (CACPR). The CACPR created a registry sub-committee to manage data transfer, facilitate training of incoming CR programs, provide support and an avenue for feedback for CR sites, and oversee the use of registry data for dissemination and research, the sub-committee reports to the CACPR board of directors and adheres to the committee’s terms of reference and policies (e.g., research policy).

 At the individual site-level, registries that have web-based data entry systems (n=6, 75%) either enable the clinical team to directly enter data (e.g., Denmark) or nominated a data steward (e.g., Canada, USA) who were responsible for uploading or directly entering data and monitoring data integrity.

**Issues related to privacy**

With respect to patient privacy, the Austrian[31](#_ENREF_31) and the German[36](#_ENREF_36), [37](#_ENREF_37) registries sought informed written consent from individual participants. The Canadian[32-34](#_ENREF_32), United Kingdom[40](#_ENREF_40) and European[41](#_ENREF_41) registries obtained permission (e.g., from ethics committees) to collect de-identified data without consent. The United States[39](#_ENREF_39) registry also utilised a waiver of consent for the registry, however, all patients provided informed consent to participate in CR. The Danish[35](#_ENREF_35) registry reported collecting and maintaining data according to Danish Data Protection Laws and Regulations without the need to obtain consent.

**Incentives**

In Denmark, entry of CR data is a mandatory requirement for all hospitals delivering Phase II CR (initial 8-12 weeks of outpatient rehabilitation)[35](#_ENREF_35). The United Kingdom[40](#_ENREF_40), the United States[39](#_ENREF_39) and Austria[31](#_ENREF_31) incentivised data entry through making it an eligibility criteria for program certification and reimbursement. Canada[33](#_ENREF_33) and the United States[42](#_ENREF_42) enabled participating sites to generate individualised reports on outcome and quality indicators for benchmarking and auditing. Participation in the European registry was entirely voluntary[41](#_ENREF_41).

**Funding sources**

Sources of registry funding varied greatly. The Danish[35](#_ENREF_35) registry is funded solely by the Danish Government. In Austria[31](#_ENREF_31), costs are covered by individual sites and a fixed amount per patient entered is charged for maintenance of the registry. Similarly, in the United States[39](#_ENREF_39), individual sites pay an annual subscription fee and additional support for the ongoing running and maintenance of the registry is provided by multiple industry sponsors. Industry support was also reported for the Canadian[33](#_ENREF_33) and the German[36](#_ENREF_36) registries and major research funding bodies supported the European[41](#_ENREF_41) and United Kingdom[40](#_ENREF_40) registries. The time-length of funding was not reported.

**Barriers and enablers of implementation**

The included papers reported a number of barriers to establishing and maintaining CR registries. Barriers to the recruitment of sites included administrational hurdles such as collecting site agreement signatures, ensuring privacy standards and a lack of human resources for data entry. Data quality issues were reported such as incompleteness of data submissions as well as time delays with the reporting of data. Data gaps were also reported with regard to the inability to link to other datasets (e.g. in order to determine the proportion of eligible patients receiving CR, linkages to in-patient datasets is required). Furthermore, the maintenance of registries requires ongoing funding which was often reported as limited; the continuation of both the European and Canadian registries are uncertain due to lack of funding. Importantly, it was also noted that the presence of a registry does not guarantee quality improvement, but that a comprehensive approach is required including successful implementation of the registry, continuous data quality assurance, and transparent and timely feedback.

**DISCUSSION**

This was the first systematic review of its kind to provide and synthesise evidence for existing national and international CR registries. Globally, we identified seven countries (3.26% of countries globally) that had established national CR registries and one international (Europe) registry. Of the identified registries, five are currently active (Austria[31](#_ENREF_31), Canada[32-34](#_ENREF_32), Denmark[35](#_ENREF_35), the United Kingdom[40](#_ENREF_40) and the United States[39](#_ENREF_39)). The availability of CR programs is low worldwide; only 38.8% of countries provide CR (68% in high-income countries, 23% in low and middle-income countries, and 8.3% in low-income countries)[43](#_ENREF_43). This review demonstrates that systematic evaluation of these programs via registries is extremely limited. Apart from Mexico, all countries included in the review were high-income, which aligns with previous literature on CR programs being predominately available in high-income countries even though 80% of CVD deaths now occur in low- and middle-income countries[43](#_ENREF_43).

The limited number of active CR registries is likely due in part to barriers inherent in establishing and maintaining clinical registries. The AHA[21](#_ENREF_21) provides key recommendations for overcoming major challenges to developing CVD registries including: (i) ensure high quality data, (ii) link clinical registries with clinical data, (iii) integrate clinical registries with electronic health records, (iv) safeguard privacy while reducing barriers to healthcare improvement, and (v) secure adequate funding and develop business models to initiate and sustain clinical registries. Challenges identified within this review are discussed in further detail below and include; the heterogeneity of data collected across CR sites, challenges to ensuring quality of data entry and patient privacy, and lack of timely and transparent feedback.

The establishment of a CR registry largely depends upon consensus related to core minimum data and for these data to be routinely collected across sites in a regular and systematic way. Registries within this review most commonly collected data on: i) demographics; ii) initiating event; iii) clinical measures (e.g. blood pressure, blood glucose control); iv) medical history and co-morbidities; v) anthropometrics; vi) physical activity; and vii) psychosocial measures. The registries provided a variety of top-down (e.g., Denmark which has mandated data entry and is funded by the Government) and bottom-up (e.g., Canada) approaches to develop consensus and uptake on these core minimal standards. The EuroCaReD[41](#_ENREF_41) registry demonstrates that it is feasible to make national comparisons when assessment methods and measures are consistent across countries.

Data linkage to administrative databases and health outcomes is crucial if registries are to determine service-level information (e.g., proportion of eligible patients receiving CR, inequalities in care provision) and long-term health indicators. As reported by Van de Veer and colleagues[44](#_ENREF_44), it is important that audit and feedback does not only include ‘outcome’ measures but also ‘process’ measures (e.g., adherence to guideline recommendations, time to treatment, referral processes, change in program delivery, and use of secondary prevention medication) as these are more easily modified by feedback. The effectiveness of feedback is further influenced by the participant’s trust in the quality of data as well as a range of personal and organisation factors (e.g., outcome expectation, motivation, leadership); as such a range of strategies are required to influence behaviour change and improve quality of care[44](#_ENREF_44). The broader literature on disease registries recognises that data collection does not guarantee change in service provision and quality[19](#_ENREF_19), [21](#_ENREF_21); in-built feedback processes are important for facilitating improvements in quality of care. The National Audit of Cardiac Rehabilitation (United Kingdom) which is based on national guidelines[40](#_ENREF_40) provides one example of how a registry and auditing can be inter-linked.

Web-based applications to input data were a core feature of the majority of registries (n=6, 75%) within this review and likely contributed to the success of the registry because such applications limit the need for double entry onto paper and then into a spread sheet. An additional benefit of web-based systems is their ability to generate site-specific reports, thereby providing timely information which sites can utilise for their own benchmarking and reporting. Tremendous opportunities will result from the increasing use of electronic medical records and advances in data scrapping techniques to extract data into registries. In Australia, the *GRHANITE™* software system is being used to ethically extract patient information from primary care settings in a format that is record-linkable[45](#_ENREF_45) and authors of this review are currently investigating whether this approach can also be applied to CR.

The advancement of ‘big data’ methods could enable registries to be created from centralised systems rather than individual groups and associations developing their own disease-specific registries. Such methods have multiple benefits; it enables greater linkages to other datasets, can track patients across the continuum of care, provides a platform for measuring co-morbidities, minimises the risks associated with individual associations establishing registries (e.g., maintaining funding), and reduces the burden on individual sites to manually enter data. However, use of electronic health records and centralised approaches do not remove the need for governance systems, or the challenges in ensuring appropriate data specifications and data quality[19](#_ENREF_19).

This review had several strengths and limitations. The development of CR registries is a relatively new field of research so the number of included studies is small. Further, we recognise that health systems in many countries, particularly those in low- and middle-income settings may not offer structured, comprehensive CR and therefore are unlikely to monitor and evaluate CR programs. Further work is required to build capacity in such settings and for quality assurance that meets standardised, international standards to be central in its development. Only English language papers were extracted, potentially introducing selection bias. The included papers often lacked detail on: the registry process (e.g., time to enter patient’s record, how data input aligned with work flow), feedback received about the registry (e.g., from users, developers, recipients of feedback derived from the registry, or researchers), and the overall costs of running and maintaining a registry as well as methods to reduce costs. Further, long-term follow-up of patients was lacking.

However, the search was strengthened by the inclusion of a wide variety of study designs including grey literature and the independent assessment of studies by two reviewers with a high level of agreement. The use of the Covidence tool[46](#_ENREF_46) greatly assisted the management of the systematic review. Contact with authors of the included studies provided additional detail on registries and their expertise proved invaluable in identifying missed registries.

Further research is required to evaluate how audit and feedback could be integrated into the development of registries in order to influence system-level change. Additionally, data linkage studies are required to substantiate the impact of national registries on health systems and clinical outcomes.

**CONCLUSIONS**

Clinical registries play an important role in measuring healthcare delivery and supporting quality improvement for individuals with heart disease. Our findings show that very few countries have established CR registries. When properly integrated into the health system, CR registries have enormous potential to systematically collect CR data, provide timely and individualised feedback and improve the provision of care. Successful CR registries require the collection of uniform data (e.g., core minimum data) across sites; linkages to administrative databases to determine service-level information and long-term health indicators and utilisation of web-based applications to input data. Furthermore, CR registries are most useful when data collection is maintained over time and this requires adequate and sustainable funding sources. Well-managed CR registries have the potential to benefit service providers by tracking program performance, driving changes in guidelines, as well as assisting researchers in building an evidence base for the effectiveness of CR in reducing morbidity and mortality from CVD. Further, such data are critical for government funders and health policy-makers to better track CR expenditure and produce cost-effective policies. The results of this review inform the development of future CR registries to mitigate the burden associated with heart disease. Future research is required to evaluate the impact of national registries on health systems and clinical outcomes.

**Competing interests**

The authors declare no conflicts of interest with respect to this research.

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**Author contributions**

Concept and design: AO, AP, ET, SG, LN, RG

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Drafting of the manuscript: ET, AO, SG, JN

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**Figure 1** PRISMA study flow diagram

**Figure 2** The location of included studies with national- and international-level CR registries. Inset: Location of European CR registries. Red pin: identified national-level registries; purple pin: countries involved in the international-level EuroCaReD database; green pin: country has both a national-level CR registry and involved in the EuroCaReD. Developed using ArcMap 10.5.