Review

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A systematic review of cardiac rehabilitation registries

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Abstract

Introduction: Despite cardiac rehabilitation being recommended in clinical practice guidelines internationally these services are underutilised, programmes 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 cardiac rehabilitation registries have not been reported.

Aims: To identify and describe national and international cardiac rehabilitation registries, and summarise their key features.

Methods: We systematically reviewed the literature reporting on cardiac rehabilitation registries at a national and international level. A search of four databases was conducted in July 2016, with two reviewers independently screening titles/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 review comprising 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 by 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, programme 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 cardiac rehabilitation 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

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Introduction

Cardiovascular disease (CVD) is the leading cause of mortality globally, accounting for 30% of all deaths in 2013.[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 pharmacotherapy and interventional procedures such as angioplasty, stents and bypass grafting.[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, wellbeing, social and vocational participation.[3,4]

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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 readmissions by approximately 25% and in addition to increasinges adherence to pharmacotherapy, and improvinges quality of life.[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.[6,7] However, many patients do not receive appropriate CR.[8,9] Recent data from England show that just 50% of referred patients enrol in CR,[10] and in Australia and New Zealand only 25% of ACS patients successfully met or maintained optimal secondary prevention targets after discharge.[8] In the United States, a third of ACS patients are readmitted to hospital within 30 days, with over 60% readmitted within 1 year.[11] Among those that do attend CR, the quality of the programmes and consequential benefits vary substantially.[12–14]

Audit and evaluation are promoted as core components of CR as reflected in clinical guidelines[6,7,15,16] and recommended to improve CR participation, delivery and outcomes.[15,17] 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.[18] 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.[18] The American Heart Association (AHA) recently released a scientific statement[19] highlighting the need to redesign cardiovascular care systematically to be a 'learning healthcare system', which utilises information technology and data infrastructures to enhance optimal healthcare delivery. The AHA has a long-standing commitment to promoting the innovation and effective use of clinical registries.[20] While numerous ACS and other CVD registries have existed globally, such as the Global Registry of Acute Coronary Events (GRACE)[21] and the Myocardial Ischaemia National Audit Project (MINAP),[22] 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.[18]

Accordingly, the purpose of the current review was to identify CR registries internationally, and characterise the nature of the data collected and their operation/organisation. The focus of the review includes characterising: (a) how these data were provided to the registry (i.e. manual, electronic upload); (b) who was responsible for collecting and inputting these data; (c) governance models; (d) issues related to privacy; (e) the incentives for CR programmes to participate and contribute data; (f) funding sources to support the registry; and (g) 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[23] (Supplementary Appendix 1). In July 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 (Supplementary Appendix 2). Reference lists of key articles were further searched to identify any other relevant publications. In addition, 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 the review of stroke registries by Cadilhac et al.[24] Studies were included if they: (a) presented data from a register, databank, or database containing a minimum dataset and for which data had been collected prospectively; (b) 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';[25] (c) comprised patients eligible for CR according to the National Institute of Health and Care Excellence (NICE)[26–28] and European guidelines,[17] which include the 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 (d) monitored the quality of CR at a national- or international-level where ''national'' was defined as; or 'carried the name of a country'[24] 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 the 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)[29] 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 texts 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: (a) registry name; (b) active dates of the registry; (c) included patients; (d) data source; (e) number of patient records; (f) methods of data collection across sites; (g) data collection time points; (h) patient-level data collected; (i) service-level data collected; (j) who was responsible for collecting and inputting data; (k) governance models; (l) issues related to privacy; (m) the incentives for CR programmes to participate and contribute data; (n) funding sources to support the registry; and (o) barriers and enablers of implementation.

The corresponding authors of included registries were contacted by 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. A total of 155 full texts were retrieved and assessed; there was agreement between reviewers on inclusion or exclusion for 144 of 155 (93%) of the papers, and the remaining 11 of 155 (7%) papers were passed on to a third reviewer for arbitration. Ultimately, 11 studies met the inclusion criteria.

The included 11 papers described CR registries in seven countries: Austria,[30] Canada,[31–33] Denmark,[34] Germany,[35,36] Mexico,[37] the USA[38] and the United Kingdom (excluding Scotland)[39] (Figure 2, Table 1). The EuroCaReD registry[40] was the only international registry, and consisted 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,[22,23] 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.[35,36] The remaining registries commenced from 2001 (Austria)[30] to 2015 (Denmark).[34] The registries currently active are Austria,[30] Canada,[31–33] Denmark,[34] the UK[39] and the USA.[38]

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: (a) 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;[35,36] and (b) the staffing details of the UK registry, which were collected by 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[34] 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.

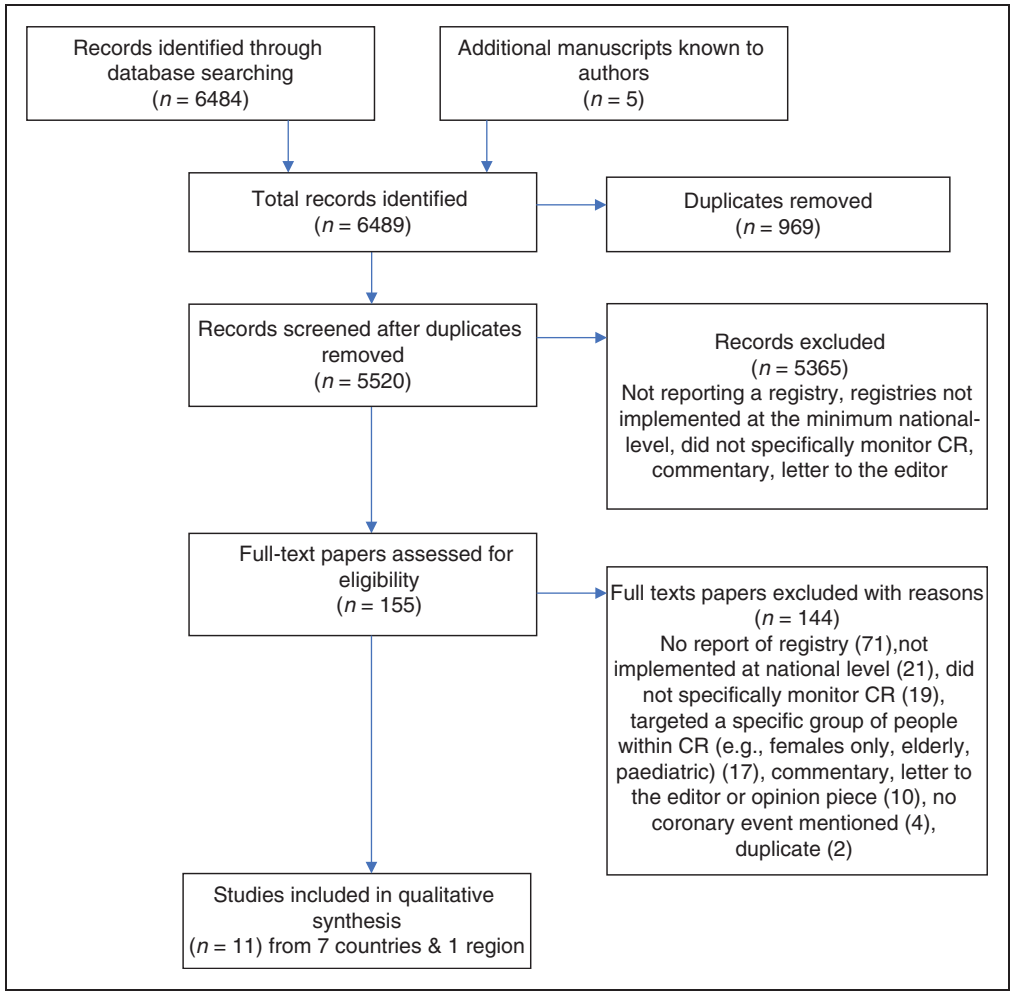

Figure 1. Preferred reporting items for systematic reviews and meta-analyses (PRISMA) study flow diagram.

Patient and service-level data collected

The number of indicators captured across the registries varied widely, with the USA[41] and Canada[32] 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 psychosocial 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 UK 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 (USA) enabled sites to submit data at any time depending on the chosen data collection mechanism. Denmark[34] was the only registry that reported follow-up data collection (6 months) after programme 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

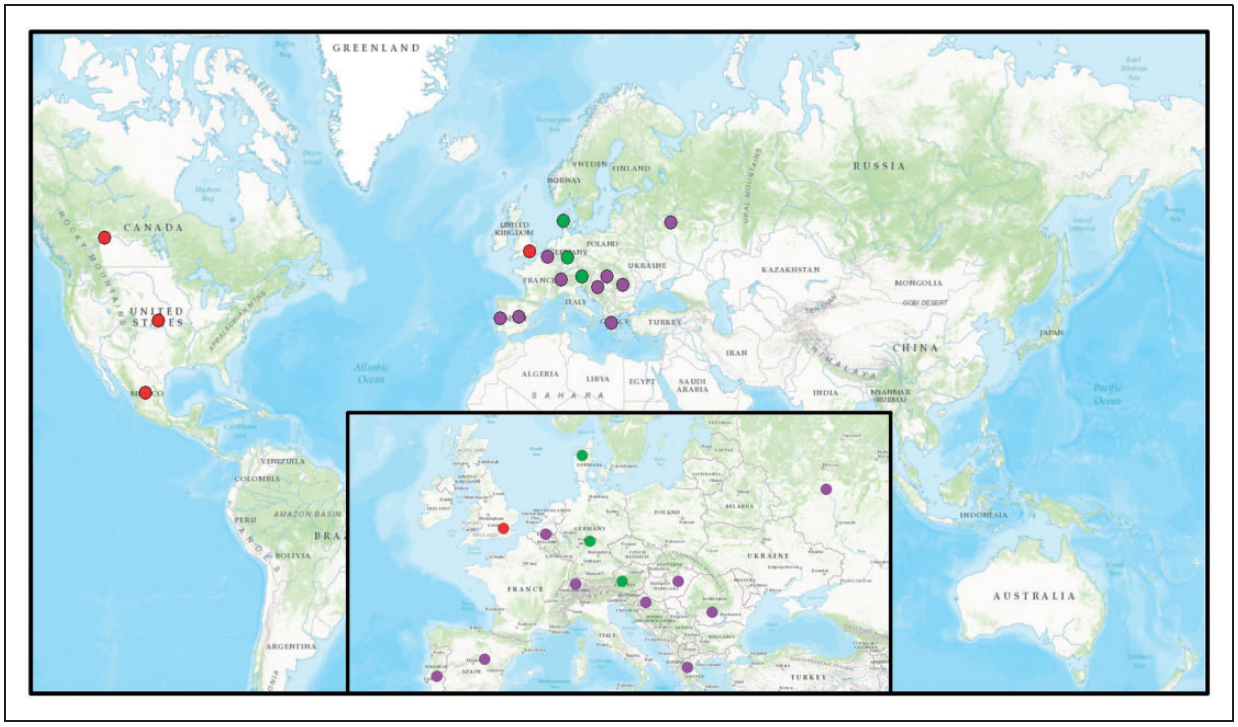

Figure 2. The location of included studies with national and international-level cardiac rehabilitation (CR) registries. Inset: Location of European CR registries. Red pin: identified national-level registries; purple pin: countries involved in the international-level EuroCaReD database; green pin: country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

registry subcommittee to manage data transfer, facilitate the training of incoming CR programmes, provide support and an avenue for feedback for CR sites, and oversee the use of registry data for dissemination and research; the subcommittee 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 enter data directly (e.g. Denmark) or nominate a data steward (e.g. Canada, USA) who are responsible for uploading or directly entering data and monitoring data integrity.

Issues related to privacy

With respect to patient privacy, the Austrian[30] and the German[35,36] registries sought informed written consent from individual participants. The Canadian,[31–33] UK[39] and European[40] registries obtained permission (e.g. from ethics committees) to collect de-identified data without consent. The US[38] registry also utilised a waiver of consent for the registry; however, all patients provided informed consent to participate in CR. The Danish[34] 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).[34] The UK,[39] the USA[38] and Austria[30] incentivised data entry through making it an eligibility criterion for programme certification and reimbursement. Canada[32] and the USA[41] enabled participating sites to generate individualised reports on outcome and quality indicators for benchmarking and auditing. Participation in the European registry was entirely voluntary.[40]

Funding sources

Sources of registry funding varied greatly. The Danish[34] registry is funded solely by the Danish government. In Austria,[30] costs are covered by individual sites and a fixed amount per patient entered is charged for maintenance of the registry. Similarly, in the USA,[38] individual sites pay an annual subscription fee, and additional support for the ongoing running and maintenance of the registry is provided by multiple

Table 1. Description of included registries.

Registry name	Active dates	Included patients	Data sources	Patient records (*n*)	Method of data collection across sites	Data collection time points
Austria[26] AGAKAR Registry (Working group on outpatient cardiac rehabilitation)	2001–	Patients who completed phase II (60 hours over 4–6 weeks) or phase III (up to 90 hours over 6–12 months) CR after cardiac events, cardiac interventions and operations on vessels, valves and devices; heart failure, patients at high risk to develop CAD	All ($n=8$) Austrian outpatient CR centres accredited by the AGAKAR entered data into a database of all consecutive patients who completed phase II (4–6 weeks) and/or III (6–12 months) rehabilitation since 2001	>10,900 phase II and/or phase III	Data entered manually into web-based electronic case report form	Enrolment into phase II, end of phase II, enrolment into phase III, end of phase III
Canada[27–29,41] Canadian Cardiac Rehabilitation Registry (CCRR) www.cacpr.ca/resources/registry.cfm	2005–	Patients enrolled in CR. Canadian guidelines state the following indications for CR: myocardial infarction, chronic stable angina, heart failure and recent revascularisation, heart transplantation, and device implantation	17/170 CR centres from across Canada (7.8%)	7154	Direct entry of consecutive data to the CCRR via a web-based interface done manually, or through electronic upload if the site pays a nominal amount to set this up	CR enrolment, CR completion
Denmark[30] The Danish Cardiac Rehabilitation Database (DCRD) www.danheart.dk	2015–	All patients who received CR following hospitalisation for CHD	All patients receiving CR following hospitalisation for CHD*	Approx. 14,000 patients annually	Online database with simultaneous linkage to other central patient registers	Patient-level data includes: CR referral, CR enrolment, CR completion, post-CR follow-up (6 months) Programme-level data collected every 3 years
Europe[36] European Cardiac Rehabilitation Registry and Database (EuroCaReD)	Oct–Nov 2010; Oct 2011–Feb 2012	Patients attending CR, primarily with CAD	69 CR centres in 12 European countries (Austria, Belgium, Croatia, Denmark, Germany, Greece, Hungary, Portugal, Romania, Russia, Spain, Switzerland)	2095	Collected electronically using a web-based data entry system (http://www.eurocared.org)	CR enrolment, CR completion
Germany[31,32] (ROG; 2000–2002; TROL 2003–2008)	2000–2008	Patients receiving inpatient CR following hospitalisation for a cardiac event (STEMI, NSTEMI, unstable angina pectoris)	219 inpatient CR centres (TROL: 116; ROG: 103)	117,983 (TROL: 41,300; ROG: 76,683)	Physicians documented on standardised case report forms	Discharge documentation from inpatient CR centres
Mexico[33] National Registry of Cardiac Rehabilitation Programmes in Mexico II (RENAPREC II)	Not reported	Not reported	24 CR centres	Not reported	Not reported	Not reported
UK[35] The National Audit of Cardiac Rehabilitation (NACR) www.cardiacrehabilitation.org.uk/	2005–	Patients who received CR following hospitalisation for myocardial infarction, percutaneous coronary intervention and coronary artery bypass surgery	178 hospital and community-based CR centres	48,476	Electronic data collection as part of the NACR. Staffing details collected from NACR paper surveys.	CR enrolment, CR completion

(continued)

Table 1. Continued

Registry name	Active dates	Included patients	Data sources	Patient records (*n*)	Method of data collection across sites	Data collection time points
USA[37] American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) Outpatient Cardiac Rehab Registry www.aacvpr.org/Registry/Cardiac-Rehab-Registry	2012–	Patients referred and enrolled in CR programmes	Over 400 participating sites	More than 65,000 records	Data are entered manually into a web-based application	Participating programmes are able to submit data at any time. Options for data submission correspond directly with the programme's chosen data collection mechanism

CR: cardiac rehabilitation; CAD: coronary artery disease; AGAKAR: Arbeitsgruppe für ambulante kardiologische Rehabilitation (working group on outpatient cardiac rehabilitation); CCRR: Canadian Cardiac Rehabilitation Registry; DCRD: Danish Cardiac Rehabilitation Database; STEMI: ST-segment elevation myocardial infarction; NSTEMI: non-ST-segment elevation myocardial infarction; TROL: Transparency Registry to Objectify Guideline-oriented Risk Factor Management; ROG: the Registry of Guideline-Based Therapy; NACR: National Audit of Cardiac Rehabilitation.

industry sponsors. Industry support was also reported for the Canadian[32] and the German[35] registries, and major research funding bodies supported the European[40] and UK[39] 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 inpatient 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 is 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,[30] Canada,[31–33] Denmark,[34] the UK[39] and the USA).[38] The availability of CR programmes 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).[42] This review demonstrates that systematic evaluation of these programmes by registries is extremely limited. Apart from Mexico, all countries included in the review were high income, which aligns with previous literature on CR programmes being predominantly available in high-income countries even though 80% of CVD deaths now occur in low and middle-income countries.[42]

The limited number of active CR registries is probably due in part to barriers inherent in establishing and maintaining clinical registries. The AHA[20] provides key recommendations for overcoming major challenges to

Table 2. Characteristics of included studies.

Registry	Patient-level data captured	Service-level data captured	Data custodians	Governance	Privacy	Incentives	Funding
Austria[26] AGAKAR Registry (working group on outpatient cardiac rehabilitation)	• Medical diagnosis/surgical procedure • *Clinical*: systolic and diastolic BP, glucose, HDL, LDL, triglycerides • *Anthropometrics:* BMI, waist circumference • *Physical:* resistance training measures, physical work capacity • *Psychosocial measures*: MacNew questionnaire (global, physical, social and emotional components), HADS-A, HADS-D	Not reported	Data are maintained by a professional and independent external provider	All outpatient CR is carried out mainly by centres accredited by the AGAKAR	The ethical committee of the State of Salzburg approved the protocol. Patients gave written informed consent. The researchers complied with all privacy laws. Data are entered anonymously and are de-identified	To be eligible for reimbursement all centres accredited by AGAKAR are obliged to enter data of all patients into a web-based database	Each CR site covers the cost themselves; a fixed amount per patient entered is charged for maintenance of the registry
Canada[27–29,33,41] Canadian Cardiac Rehabilitation Registry (CCRR) www.cacpr.ca/resources/registry.cfm	Approx. 200 data elements are collected on each patient • *Demographics:* age, sex, ethnicity, marital status, language preference, education, work, family support, residence, travel time to rehab • *Medical history:* referral event; interim events (any cardiac events that occurred during the CR period); comorbidities • *Medication:* all cardiovascular-related medications at intake and discharge, dosages and contraindications, including herbals • *Clinical*: BP, lipid control, blood glucose control, sleep apnoea; CV severity (e.g. angina class, left ventricular ejection fraction); exercise capacity • *Anthropometric*: waist circumference, weight, height • *Behavioural:* smoking status, diet, exercise 150 minutes, resistance training • *Psychosocial measures:* depression, QoL • *Vocational measures:* return to work and date	Referral, type, and provider; enrolment; wait times; mpletion, and premature termination; sessions completed; components received; referral to services to reduce risk factors, e.g. smoking cessation, psychology; discharge summary	Each participating CR site nominates a data steward, whose responsibilities include the uploading or direct entry of data to the CCRR	The CCRR committee, a subcommittee of the Canadian Association of Cardiovascular Prevention and Rehabilitation's board of directors provides leadership and direction, while overseeing subcommittee work in the areas of data transfer compatibility verification, programme liaison, and research	A privacy impact assessment was completed and changes made in order to respond to identified privacy threats. Only anonymised data go to the CCRR	Benchmarking – each programme receives a quarterly report on outcome and quality indicators; can see programme reports online in real time	Funded through unrestricted grants from Pfiser Canada Inc. and Servier Canada Inc. (industry)
Denmark[30] The Danish Cardiac Rehabilitation Database (DCRD)	• *Demographics:* age, sex, education, marital status, cohabitation status, driving licence • *Medical history/co-morbidities:* COPD, DM, smoking status, alcohol intake, other	Programme-level data are collected every 3 years including: referral procedures, programme content, organisation,	Patient-level data are entered by the clinical team directly into the online system at the time of entry into CR.	Initiated by a national working group on preventive cardiology and rehabilitation, under the Danish Society of Cardiology The database is headed by a	Data are collected and maintained according to Danish data protection laws and regulations, without	It is a mandatory requirement for all hospitals delivering phase II CR to register all patients onto the registry	Funded by the Danish government

(continued)

Table 2. Continued

Registry	Patient-level data captured	Service-level data captured	Data custodians	Governance	Privacy	Incentives	Funding
www.danheart.dk	• *Cardiovascular-related medications:* e.g. statins, beta blockers • *Clinical*: CHD characteristics, LVEF, cardiac rhythm • *Anthropometrics:* BMI • *Psychosocial measures:* depression screening, sick leave	safety and documentation	Simultaneous data linkages to national administrative patient registers have been established	steering committee with an elected chair, an executive committee, and an academic secretariat	the need to obtain patient consent		
Europe[36] European Cardiac Rehabilitation Registry and Database (EuroCaReD)	• *Initiating clinical event* • *Demographic details* (e.g. age, gender, employment status) • *History of CV risk factors:* hypertension, hyperlipidaemia, diabetes, overweight/obesity, smoking, physical inactivity, depression • *CV risk factors at start and end of CR:* BP, LDL-cholesterol, fasting glucose, BMI, smoking status • *Current medications*	CR programme completion, CR drop out rates, programme content me length	Data are anonymously entered online into the eCRF at each individual study site and stored in the central EuroCaReD database The Institut für Herzinfarktforschung (IHF) Ludwigshafen, Germany provided overall data management, statistical analysis and site-specific reports	All collected data were offered to the national coordinators for benchmarking and quality control within the country where the data were collected. Benchmarking of the individual centre's data with pooled data was possible after permission by the EUROCaReD steering committee and the national coordinators	Patients are de-identified and only ID numbers were transferred to the central database. Re-identification was only possible at the sites. No data from any individual centre were released to other centres	CR sites volunteered to be part of the study. All European countries that are members of the EACPR were invited to take part. Benchmarking of individual centres' data with the pooled data of the other centres was possible after permission by the EuroCaReD steering committee and the national coordinators	Supported by a research grant of the European Association for CV Prevention and Rehabilitation
Germany[31,32] (ROG; 2000-02; TROL 2003 - 2008)	• *Demographics:* sex, age, education • *Medical history/risk factors:* e.g. DM, hypertension, hyperlipidaemia, family history, smoking status • *Clinical*: systolic and diastolic BP, cholesterol, triglycerides, fasting blood glucose • *Medications:* prescribed cardiovascular-related medications e.g. beta blockers, statins, ACE inhibitors • *Anthropometrics:* BMI • *Physical:* exercise capacity	Not reported	Data came from two large-scale German registries (ROG and TROL). Participating physicians documented CR patients' information on standardised case report forms	A steering committee comprising representatives of the scientific society (DGPR) and additional members with expertise in registries supervised both registries	The ethics committee of the Bavarian Physician Chamber approved the registry, and all patients provided informed consent. Patient data protection was closely observed	Quality data and benchmarking	Funding was provided by an unrestricted grant from MSD Sharp & Dohme, Germany
Mexico[33] National Registry of Cardiac Rehabilitation Programmes in Mexico II (RENAPREC II)	• *Demographics:* sex, age, • *Diagnostic:* e.g. heart failure, ischaemic heart disease, etc. • *Clinical*: systolic and diastolic BP, cholesterol, triglycerides, fasting blood glucose • *Medications:* prescribed cardiovascular-related medications e.g. beta blockers, statins, ACE inhibitors	Name of centres, geographical distribution, types of professionals employed in the centres, number of patients included in CR programmes	Not reported	Not reported	Not reported	Not reported	Not reported

(continued)

Table 2. Continued

Registry	Patient-level data captured	Service-level data captured	Data custodians	Governance	Privacy	Incentives	Funding
UK[35] The National Audit of Cardiac Rehabilitation (NACR) www.cardiacrehabilitation.org.uk/	• *Anthropometrics:* BMI • *Physical:* exercise capacity • *Clinical*: systolic and diastolic BP, total cholesterol • *Anthropometric:* BMI • *Behavioural:* smoking status, self-reported physical activity • *Physical:* exercise capacity through the ISWT • *Mental health measures:* HADS-A, HADS-D These clinical outcome measures were deemed important for risk factor management and routinely reported to the NACR	CR enrolment (the total number of patients who had started CR), CR completion, and associated staffing requirements per centre (e.g. types of staff, hours worked, no. of staff per programme)	The NACR is a routinely administered audit within the NHS	Data governance and approval is obtained through NHS Digital and also monitored through the Department of Health Sciences data governance committee	Approval is provided by the NHS to collected anonymised patient data. These data are hosted by the HSCIC. The NACR can seek annual approval to use these data	There are no financial incentives for entering data. Centres do use the data to audit their own patients and generate reports. Since the study in 2015 the NACR now supplies data to programmes as part of a National Certification Programme for Cardiac Rehabilitation	The Research was performed by the NACR team, which is funded by the British Heart Foundation
USA[37] American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) Outpatient Cardiac Rehab Registry www.aacvpr.org/Registry/Cardiac-Rehab-Registry	Consists of approx. 180 data elements including: • *Demographics:* medical record ID, DOB, sex • *Medical history:* admitting diagnosis, risk factors, comorbid conditions • *Medication:* all cardiovascular-related medications • *Clinical*: lipids, glucose, BP, dietary outcomes, functional capacity • *Anthropometric*: waist circumference, weight, height, • *Behavioural:* smoking status, exercise behaviour • *Psychosocial measures:* depression screening, health related QoL	Referral, enrolment and discharge dates; health care utilisation including adverse and unexpected events	Each participating programme designates a principal user who is responsible for monitoring data integrity	AACVPR own and operate the registry. Oversight is provided by the AACVPR board of directors and the AACVPR registry committee	Privacy of included patients complies with the Health Insurance and Portability and Accountability Act. The programme has a number of safeguards in place to protect the security of AACVPR data	Benchmarking, quality assessment and improvement. Participating sites receive preconfigured reports at the individual, group and programme level and enable the site to assess their performance in relation to guidelines	Each participating site is required to pay an annual fee to subscribe to the programme. Multiple industry sponsors including: Janssen Pharmaceutical Companies, Quinton & ScottCare Cardiovascular Solutions

AGAKAR: Arbeitsgruppe für ambulante kardiologische Rehabilitation (working group on outpatient cardiac rehabilitation); BP: blood pressure; HDL: high-density lipoprotein; LDL: low-density lipoprotein; HADS-A: Hospital Anxiety and Depression Scale – Anxiety component; HADS-D: Hospital Anxiety and Depression – Depression component; CR: cardiac rehabilitation; CCRR: Canadian Cardiac Rehabilitation Registry; QoL: quality of life; COPD: chronic obstructive pulmonary disease; ROG: the Registry of Guideline-based Therapy; TROL: Transparency Registry to Objectify Guideline-oriented Risk Factor Management; DM: diabetes mellitus; CHD: coronary heart disease; LVEF: left ventricular ejection fraction; BMI: body mass index; ACE inhibitors: angiotensin-converting enzyme inhibitors; DPGR: German Society of Prevention and Rehabilitation; NACR: National Audit of Cardiac Rehabilitation; ISWT: incremental shuttle walking test; NHS: National Health Service; HSCIC: Health and Social Care Information Centre; AACVPR: American Association of Cardiovascular and Pulmonary Rehabilitation.

developing CVD registries including: (a) ensure high quality data; (b) link clinical registries with clinical data; (c) integrate clinical registries with electronic health records; (d) safeguard privacy while reducing barriers to healthcare improvement; and (e) 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 on 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: (a) demographics; (b) initiating event; (c) clinical measures (e.g. blood pressure, blood glucose control); (d) medical history and comorbidities; (e) anthropometrics; (f) physical activity; and (g) 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[40] 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 der Veer and colleagues,[43] 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 programme delivery, and use of secondary prevention medication) as these are more easily modified by feedback. The effectiveness of feedback is further influenced by the participants' 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 is required to influence behaviour change and improve quality of care.[43] The broader literature on disease registries recognises that data collection does not guarantee change in service provision and quality;[18,20] inbuilt feedback processes are important for facilitating improvements in quality of care. The NACR (UK) which is based on national guidelines[39] provides one example of how a registry and auditing can be interlinked.

Web-based applications to input data were a core feature of the majority of registries ($n = 6$, 75%) within this review and probably contributed to the success of the registry because such applications limit the need for double entry onto paper and then into a spreadsheet. 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 extract patient information ethically from primary care settings in a format that is record linkable,[44] 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; they enable greater linkages to other datasets, can track patients across the continuum of care, provide a platform for measuring comorbidities, minimise the risks associated with individual associations establishing registries (e.g. maintaining funding), and reduce the burden on individual sites to enter data manually. However, the 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.[18]

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. Furthermore, 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 programmes. 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. Furthermore, the 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[45] 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. In addition, 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 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. 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 programme 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. Furthermore, such data are critical for government funders and health policy-makers better to 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.

Author contribution

Concept and design: AO, AP, ET, SLG, LN, RG; screening of titles and abstracts: AP, ET; screening of full texts: AP, ET, AO; drafting of the manuscript: ET, AO, SLG, JN; critical revisions of the manuscript: ET, AO, AP, SLG, LN, JN, RG; final approval of the manuscript: ET, AO, AP, SLG, LN, JN, RG.

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