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Grace, Sherry L, Hagström, Emil, Harrison, Alexander S orcid.org/0000-0002-2257-6508 et al. (7 more authors) (2024) Cardiac rehabilitation registries around the globe:Current status and future needs. *European journal of preventive cardiology*. zwae182. ISSN 2047-4881

<https://doi.org/10.1093/eurjpc/zwae182>

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Cardiac rehabilitation registries around the globe: current status and future needs

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Received 23 January 2024; revised 15 May 2024; accepted 20 May 2024; online publish-ahead-of-print 22 May 2024

The number of people with prevalent cardiovascular disease (CVD) globally is estimated to be ~523 million, with greater burden in resource-poor settings.¹ While rates vary geographically, the five-year rate of major acute coronary events among patients with known CVD has been estimated to be 20–30%; this is about four to five times greater than the rate among high-risk individuals without CVD.² Therefore, secondary prevention is key;³ cardiac rehabilitation (CR) is an established outpatient model systematically delivering the guideline-recommended preventative strategies,^{4,5} proved to mitigate the heightened morbidity.⁶

Indeed, many trials in high⁷ and low-resource countries⁸ alike have demonstrated lower morbidity as well as improvements in function and quality of life with CR participation. However, trials enrol select patient groups that often do not mirror complex patients in the real world. Additionally, there are limited studies of cardiac outpatients. Moreover, CR is a multi-component, complex intervention, of widely varying dose worldwide.^{9,10} Thus, registries can play an important role in standardizing processes of care and hence improving patient outcomes.^{11,12}

Reviews of CR registries identified 10 globally,^{13,14} since, some have ceased operation (i.e. Europe and Canada¹⁵) and others have been developed (e.g. China; [Table 1](#); <https://globalcardiacrehab.com/Other-CR-Registries>). The International Council of Cardiovascular Prevention and Rehabilitation (ICCP) launched the most recent CR registry ([Table 1](#)), targeted for low-resource settings.²⁵ Given their mission, the International Cardiac Rehab Registry (ICRR) has a liaison sub-committee to connect with other CR registries to bolster learning and amplify efforts.¹⁶ Indeed, of nine current registries, all expressed interest in contributing data for this work, however, the American

Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) registry had to defer due to an impending initial descriptive publication and the Chinese registry also was not in a position to contribute at this time. The AACVPR registry launched in 2012, and as of February 2021 had ~500 000 patients entered, with data on ~300 000 post-programme.²⁶

As shown in [Table 1](#), the registries have many common variables assessed consistently,¹⁶ enabling an international comparison for the first time. Many have ethics waivers given routine-collected data are used anonymously for quality purposes, but all spend considerable time ensuring utmost privacy and security and compliance with applicable regulations. Some registries are part of an electronic medical record to reduce duplication of efforts. Several of the registries have worked to optimize usability for program data stewards.^{27–29} They also report that data completeness is problematic for some variables, particularly lipids.^{25,26} Finally, retention for the post-programme assessment is reported to be a challenge, and many registries have even longer follow-ups.^{25,26} Some registries such as that in Sweden have been able to link to administrative data, so can passively follow-up 100% of patients.²¹ ICRR has a function for automatic and electronic email or text of follow-up for patient-reported outcomes for the post-programme and annual assessments to mitigate this challenge, however many patients in low-resource settings do not own a device or have the literacy skills to complete them without an interview with CR staff.²⁵

Patient characteristics, use and post-programme data are shown across seven of the nine existing registries in [Table 1](#), for variables that are measured in a comparable manner across at least three of the registries (note many of these variables are also assessed in the American and Chinese registries). Caution is warranted in

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Table 1 Available data on patient characteristics and outcomes from cardiac rehabilitation registries globally, *n* = 7/9

	In ternational ^{b16}	Australia (Queensland state only ¹⁷)	Austria ¹⁸	Denmark ¹⁹	Japan ²⁰	Sweden ²¹	UK ^{a22}
Registry inception date	October 2021	July 2017	January 2005	January 2015	October 2001	January 2006	April 2005
Data reported from	Inception to 23 April 2023	Inception to 31 December 2022	Inception to December 2015	Inception to 1 July 2020		Inception to 31 December 2022	1 April 2021–31 March 2023
Number of patients at CR enrolment	2149	39 827	5734	35 764	29 629	102 199	104 455
Number of CR centres contributing data during period reported	17	35	—	36	17	74	214
Sociodemographic							
Age (mean ± SD)	58.5 ± 11.3	64.9 ± 12.4	58.7 ± 11.6	67.0	68.4 ± 14.3	63.3 ± 9.0	65.5 ± 12.0
Sex (<i>n</i> , % female)	407 (18.9%)	17 662 (29.0%)	990 (17.3%)	5555 (21.8%)	9604 (32.4%)	29 275 (25.6%)	27 690 (27.5%)
Work status (<i>n</i> , % full or part-time for pay)	658 (30.6%)	7311 (18.4%)	—	—	—	29 178 (26.1%)	19 169 (30.3%)
Clinical characteristics							
Referral diagnosis (<i>n</i> , %)							
Acute coronary syndrome	1137 (52.9%)	29 584 (48.6%)	3880 (67.7%)	13 145 (60.3%)	3924 (13.2%)	114 342 (100.0%) ^d	59 080 (56.6%) ^d
Heart failure	96 (4.5%)	1941 (3.2%)	248 (4.3%)	n/a	5428 (18.3%)	3949 (3.9%)	8541 (8.2%)
Other	192 (8.9%)	29 314 (48.2%)	435 (7.8%)	9642 (39.7%)	—	n/a	36 834 (35.3%)
Procedure associated with referral (<i>n</i> , %)							
Percutaneous coronary intervention	1052 (49.0%)	19 884 (32.7%)	—	5617 (31.5%)	4449 (15.0%)	—	53 874 (51.6%)
Bypass surgery	574 (26.7%)	8083 (13.3%)	—	1678 (9.4%)	—	—	12 761 (13.6%)
Other (e.g. device, VAD, transplant, and TAVI)	84 (3.9%)	6687 (11.0%)	—	28 469 (59.1%)	—	—	27 344 (29.2%)
Comorbidities—diabetes (<i>n</i> , %)	798 (37.4%)	10 718 (26.9%)	—	5085 (14.2%)	6988 (23.6%)	21, 457 (21.0%)	19 840 (24.5%)
Comorbidities (<i>n</i> , % other)	2014 (49.4%)	—	—	—	—	29 871 (29.2%) ^e	55 257 (68.2%)
Process of care and utilization							
Average full programme duration (mean weeks ± SD)	10.7 ± 5.1	—	5	12	—	14	13.7 ± 8.1
Programme completion ^c (<i>n</i> , % yes)	977 (45.5%)	15 259 (42.3%)	4771 (83.2%)	21 788 (60.9%)	—	8181 (82.0%) ^f	78 614 (75.3%)
Outcomes (post-programme)							
Number of patients with any follow-up data (<i>n</i> , %)	1832 (85.2%)	15 259 (42.3%)	4711	21 788 (60.9%)	—	114 342 (100.0%)	70 516 (67.5%)
Functional capacity (mean ± SD peak METs)	7.0 ± 4.1	462.2 + 109.8 ^g	7.6 ± 3.8	—	—	103.6 ± 38.3 ^h	6.2 ± 3.6
Lipids (mean ± SD LDL in mg/dL)	77.0 ± 33.1	68.7 + 30.9	108.0 ± 40.2	64.6 ± 26.3	98.4 ± 32.3	74.6 ± 32.0	73.3 ± 34.4
Blood pressure (mean ± SD SBP/DBP)	120.2 ± 15.8/71.8 ± 9.1	—	127.7 ± 17.9/80.8 ± 8.5	133.0 ± 16.2/77.8 ± 10.1	122.9 ± 21.6/72.0 ± 12.9	129.9 ± 16.0/76.2 ± 9.7	127.1 ± 17.2/74.2 ± 10.5

Continued

Table 1 Continued

	International ^{b16}	Australia (Queensland state only ¹⁷)	Austria ¹⁸	Denmark ¹⁹	Japan ²⁰	Sweden ²¹	UK ^{a22}
Cardiac medication use (n, % any filled)	1767 (82.2%)	—	—	—	—	98 767 (96.6%)	46 529 (66.0%)
Statins	—	—	—	20 024 (94.3%)	10 498 (35.4%)	92 288 (92.0%)	40 093 (86.2%)
Beta-blockers	—	—	—	13 798 (70.7%)	13 020 (43.9%)	82 875 (82.7%)	37 623 (80.9%)
ACEi/ARB	—	—	—	—	ACEi 5688 (19.2%) ARB 5748 (19.4%)	80 706 (79.0%)	34 048 (73.2%)
Body mass index (mean ± SD)	27.0 ± 4.5	29.6 ± 6.5	28.0 ± 4.5	28.2	23.06 ± 3.91	27.8 ± 4.9	28.1 ± 5.9
Depressive symptoms (n, % elevated)	194 (10.6%)	644 (5.2%)	381 (5.6%)	—	—	651 (12.3%)	4077 (14.7%)
Quality of life measure (min–max; mean ± SD)	Cantril's ladder of life ²³ (0–10) 7.5 ± 1.2	Assessment of QoL Tool (0–1) 0.8 ± 0.3	Visual analogue scale (0–100) 64.8 ± 22.6	—	—	Visual analogue scale (0–100) 72.8 ± 19.0	Dartmouth COOP sum (9–45) 19.6 ± 5.8
Physical activity (n, % ≥ 150 min/week MVPA)	57 (68.9%)	10 013 (70.9%)	—	—	—	40 489 (40.8%)	30 351 (73.4%)
Tobacco use (n, % current smoker, vaper, etc.)	191 (8.9%)	987 (6.1%)	—	—	3301 (11.1%)	12 845 (12.8%)	3741 (6.8%)
Morbidity/adverse events/ re-hospitalization/ED visits (n, % any)	75 (3.5%)	—	—	—	—	16 309 (16.3%) ⁱ	—
All-cause mortality (n, % yes)	2 (0.1%)	—	—	—	—	2070 (1.8%)	—

Valid percentages shown taking into consideration missing data. — = not collected, or assessed in a manner inconsistent with other registries. n/a = not applicable.

ACE, angiotensin converting enzyme; ARB, angiotensin receptor blocker; CR, cardiac rehabilitation; CVD, cardiovascular disease; DBP, diastolic blood pressure; ED, emergency department; HbA_{1c}, glycated haemoglobin; LDL, low density lipoprotein; MET, metabolic equivalent; MVPA, moderate-to-vigorous physical activity; SD, standard deviation; SBP, systolic blood pressure; UK, United Kingdom; VAD, ventricular assist device; TAVI, transcatheter aortic valve implantation; QoL, quality of life; COOP, Primary Care Cooperative Information Project.

^aExcluding Scotland.

^bCountries represented: Mexico, Colombia, Brazil, Malaysia, Taiwan, India, Pakistan, Iran, Czech Republic, and Senegal.

^cPatient participated in at least some of the cardiac rehabilitation intervention components and also completed a formal re-assessment by the cardiac rehabilitation staff at the conclusion of the programme (can be virtual).²⁴

^dOnly myocardial infarction patients.

^eChronic obstructive pulmonary disease, cancer, stroke, hypertension.

^fTwelve-month follow-up data.

^gHospitalization for angina, myocardial infarction, stroke, heart failure or other heart disease or bleeding.

^hSix-minute walk test distance in metres.

ⁱAdjusted highest Watt according to the Strandell equation on sub-maximal ergometer stress test.

over-interpretation of differences given registry dissimilarities, such as in terms of included patient populations and their characteristics, the nature of the CR programmes themselves (e.g. duration), as well as timing and completeness of outcome assessments, and the number and nature of morbidities assessed for example.

Overall, patients across the registries are around 60 years of age at CR inception, with 20–30% females enrolled and under 30% working (Table 1). Most have had an acute coronary syndrome, many also having undergone percutaneous coronary intervention, and comorbidity burden is high. In comparison to data from the largest cardiac outpatient registry available (mostly patients from the USA³⁰), age is comparable (64.0 in USA), but the proportion of women in the CR registries is much lower, consistent with CR use patterns.³¹ Moreover, the burden of heart failure is lower (except for the Japanese registry; ~13% in USA), but rates of comorbid diabetes appear consistent. In comparison to the CR-indicated cardiac outpatients in EUROASPIRE V (27 European countries³²), age (63.6 in EU) and sex (25.8% female in EU) were comparable, percutaneous coronary intervention rates were higher (80.2% in EU), but bypass surgery rates comparable (18.6% in EU).

Programme completion rates can be inflated in registries,³³ but do appear to be much lower in lower-resource settings (68.7% vs. 45.5%; Table 1). Average blood pressure values were generally within target range (120.2–133.0 mmHg³) and medication use quite high for real-world data (although it may represent prescription rather than long-term patient adherence). Average body mass indices were in the overweight range (27.0–29.6 kg/m²). Across most of the registries, depressive symptomatology was consistent with rates in cardiovascular patient populations (5.2–14.7%³⁴). About 70% of patients were meeting physical activity targets post-programme, and tobacco use rates were consistently low, around 10%. This is lower than the use of tobacco in USA (26.7%³⁰) and EU outpatients (19%), and levels of physical activity are higher than in outpatients the EU (34%),³⁰ in line with an impact of CR participation.

Quality assessment has been a primary purpose and benefit for users across the CR registries. Most of the registries have online dashboards where sites can compare their outcomes to other participating programmes in real time,¹⁶ or regular reports with this information are provided.^{21,22} Some registries also use the data to recognize programmes through some form of certification (e.g. UK, USA, and ICRR³⁵). ICRR also supports programmes in quality improvement efforts (<https://globalcardiacrehab.com/ICRR-Quality-Improvement-Initiatives>), for example recently for improving programme utilization by marginalized patient groups. Also ICRR and the Australian registry support generation of patient lay summaries of post-programme health status, proffering further secondary preventive goals, which could also serve as a point-of-care tool and be communicated to referring clinicians. Quality improvement is an area where the registries could further leverage their assets to support participating programmes and hence optimize patient outcomes.³⁶ Indeed, some CR registries report on quality at the site level publicly, and in other jurisdictions funding is allocated based on quality indicators derived from registry data (e.g. England).

In the future, the CR registries could embark on further collaborative research. Changes in outcomes were not presented in this work, but in future, this could be analysed to further establish the real-world efficacy of CR across broad populations. As with other registries, randomized trials could be embedded.³⁷ Registries could begin to collect genetic data or assess newer biomarkers in the CR patients as well, or link data from wearable sensors. Moreover, many of the registries are continuing follow-ups of their cohort from inception;³⁸ these data could be analysed to inform future care policies.

In closing, this first description of CR registry populations globally as well as post-programme outcomes reinforces the benefits of CR across all areas of the globe. We will continue to work together to support

programmes in assessing their processes of care, and ensuring that patients are optimally benefiting from CR. It is hoped that data from the registries can be used in participating countries to advocate governments for service capacity augmentation.³⁹

Acknowledgements

This study was supported by data obtained, whole or in part, from the International Cardiac Rehab Registry (ICRR; June 2023). The opinions and conclusions reported in this article are those of the authors and are independent from the ICRR. No endorsement by ICRR is intended or should be inferred. We are grateful to ICRR committee members and contributing sites who made this registry possible (<https://globalcardiacrehab.com/ICRR-Governance>). The Australian (Queensland) registry gratefully acknowledges the Statewide Cardiac Clinical Informatics Unit, Queensland Cardiac Clinical Network, Health Improvement Unit, Clinical Excellence Queensland of the Queensland Government Department of Health as well as Queensland Public Cardiac Rehabilitation programmes. The United Kingdom Audit acknowledges the support of the NACR team, the NACR steering group and also the continued support from stakeholders such as NHS England, BACPR, CCP-UK, and BHF. They also thank all patients for agreeing to share their data and the cardiac rehabilitation teams that have supported and participated in the audit since 2005. We also gratefully acknowledge Dr Yoshihiro Fukumoto, Deputy President of the Japanese Association of Cardiac Rehabilitation, for support in procuring the Japanese registry data. The Austrian registry gratefully acknowledges Bernhard Reich, PhD.

Author contribution

S.L.G., A.S.H., S.P., M.N.Y., J.N., S.M., and M.B. contributed to the funding acquisition. S.L.G. contributed to the conception or design of the work, writing—original draft, resources, supervision, and visualization. S.L.G., E.H., A.S.H., S.P., A.B., M.N.Y., J.N., S.M., and M.B. contributed to the investigation, methodology, and validation. S.L.G. and F.R. contributed to the project administration. All authors contributed to the formal analysis, and data curation for the work. E.H., A.S.H., S.P., A.B., M.N.Y., J.N., S.M., and M.B. contributed to the writing—review & editing of the manuscript. All gave final approval and agreed to be accountable for all aspects of work ensuring integrity and accuracy.

Funding

The ICRR was co-funded by Qatar University grant number IRCC-2020–005, and York University, Canada (no grant number). The Austrian registry is being financed by the member institutes of the Austrian Association of Prevention and Rehabilitation. UK's National Audit of Cardiac Rehabilitation (NACR) was funded by the British Heart Foundation during the data collection period and is now commissioned and funded by NHS England. The Queensland Cardiac Outcomes Registry (QCOR) is funded by Queensland Government Department of Health. The SWEDEHEART registry is mainly financed by the Swedish Association of Local Authorities and Regions and with support from the Swedish Heart-Lung Foundation. The Japanese registry system and work were supported by the Japanese Association of Cardiac Rehabilitation.

Conflict of interest: none declared.

Data availability

The availability of data from each registry participating in this article is subject to registry-specific availability policies. For example, the International Cardiac Rehab Registry data are available through an application process, as outlined at https://globalcardiacrehab.com/resources/Documents/ICRR_Data%20Access%20Dissemination%20Policy_v3-clean.pdf. For the

Japanese registry, the dataset will not be publicly available because patient consent in each institute does not allow for such publication; the corresponding author will respond to inquiries regarding data analyses. Please contact the corresponding author from the applicable registry publication shown in the column heading of [Table 1](#) for the relevant policies.

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