AACVPR Outpatient Cardiac Rehabilitation Registry Overview

Founded in 1985, the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) is dedicated to our mission of reducing morbidity, mortality and disability from cardiovascular and pulmonary disease through education, prevention, rehabilitation, research and disease management. Central to the core mission is improvement in quality of life for patients and their families.

Purpose of the Registry
AACVPR launched the Outpatient Cardiac Rehabilitation Data Registry in July 2012. The purpose of the registry is to assist cardiac rehabilitation programs in tracking patient care information and outcomes resulting in improvement of the quality of care for patients. The registry allows programs to create and manage programmatic, personal and patient profiles, enter real-time, ongoing patient outcomes, track and quantify progress, and create individual and aggregated outcome reports.

The mission of the Registry is to demonstrate to patients, physicians, hospital administrators, healthcare payers, and governmental regulators the clinical value of cardiac rehabilitation therapy in the management of patients with heart and vascular disease. Registry data will support AACVPR’s efforts to guide policy decision making with regards to cardiac rehabilitation utilization and insurance coverage.

The Registry is:
- **Web-based.** Subscribers get “real-time” performance feedback with on-demand reports and 24-hour access to their raw data.
- **Easy to use.** There are minimal technical and resource requirements needed to participate.
- **Current.** The nation’s top experts in cardiac rehabilitation were consulted to create the data set and interface using nationally recognized, up-to-date secondary prevention guidelines, and the data sets are continually reviewed and adjusted as needed.
- **Benchmarking.** Programs can compare their program outcomes with like-size, state, or national aggregated data for quality improvement tracking.

Information being collected:
The registry includes collection of individual patient information regarding:

- Information about the program and hospital system
- Patient demographics such as age, gender, ethnicity, education status
- Recent health status such as cardiac-related diagnoses and comorbid conditions
- Clinical measures such as functional capacity, lipids, blood pressure, blood glucose, and anthropometrics
- Psychosocial Status, including depression
- Behavioral measures such as smoking status, physical activity and dietary habits
- Event surveillance
- Medication prescription and adherence
- Vaccination status
- Mortality and morbidity measures

Registry Enhancements Update
The Cardiac Rehabilitation Registry is currently undergoing updates to better align with the new Program Certification application. Updates include but are not limited to:

- New tobacco cessation fields
- A new Heart Failure section within the registry with a number of key heart failure assessment fields
- New reporting features to match the Performance Measures
- New reports to track completion rates, enrollment rates, number of referrals, and other program utilization metrics
- New quarterly trend reports to track your program’s progress on a number of key outcomes
Requirements for participation:
- Internet access
- Annual subscription fee based on program size
- Signed Participation Agreement
- Online data entry training

Programs & Record Information (as of September 2017):
- Over 485 participating programs from across the country
- Over 311,000 individual patient records entered
- For 2016-2017, 94% of all programs renewed their subscriptions to the Outpatient Cardiac Rehabilitation Registry

Registry User Resources
Over the past two years, the Registry Super User Committee has worked to provide registry users with additional resources to enhance the registry user experience. New items include an updated training video, a regular newsletter with user case studies and resource highlights, program enrollment and user training checklists, and more. To access the new Registry User Resource Page, visit the AACVPR website here: [https://www.aacvpr.org/Registry/Registry-User-Resources](https://www.aacvpr.org/Registry/Registry-User-Resources)

Legal background, data security
The registry underwent review by legal experts at AACVPR with experience in registries. This review included assuring compliance with existing HIPAA regulations regarding use of patient protected health information. Data is stored on secured servers at AACVPR using industry-standard procedures. Data is also encrypted during transfer from the user’s computer to servers, and is encrypted at the server level.

Review of IRB background, patient confidentiality
The registry protocol was reviewed by a large, internationally recognized academic center Institutional Review Board (IRB). Their opinion was that the registry was not research-oriented, that the outcomes measured were the result of “usual care” as provided by CR, and that the risk potential to patients was low, therefore, IRB review would not be required for individual programs to participate in the registry. However, some hospitals may require review of the registry protocol before allowing their CR program to participate.

A limited number of direct patient identifiers will be collected (last name, medical record number and date of birth). These data are used to allow the participating program to correctly identify a patient record for editing purposes. Dates of service are used to identify service intervals. Data from the registry provided either to AACVPR (for use in educational or promotional activities) or to outside researchers will be de-identified per HIPAA definitions. In some cases, a limited data set may be supplied, but all direct patient identifiers are stripped out. In all research-based inquiries, the designated primary investigator will be required to go through IRB review at their institution and to sign a data use agreement.

Registry Sponsors & Development
AACVPR would like to thank the following sponsors of the Outpatient Pulmonary Rehabilitation Data Registry for their support:

The registry is developed by Cissec Corporation of Kingston, Ontario, in cooperation with AACVPR and SmithBucklin.