AACVPR Outpatient Pulmonary 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 has established a national database for outpatient pulmonary rehabilitation program outcome benchmarking through the Outpatient Pulmonary Rehabilitation Data Registry. The AACVPR PR registry will offer the first large scale, national evaluation of the impact of PR in chronic lung disease. The purpose of the PR Registry is to:

- Collect, analyze and report PR outcomes data for quality assessment and improvement and benchmarking
- Improve the overall care provided to patients in outpatient PR programs
- Better understand the impact of PR in chronic lung disease.

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 pulmonary rehabilitation developed the data sets and interface using internationally recognized, up-to-date 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.

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

- Pulmonary disease and comorbid conditions
- Patient centered outcomes (dyspnea, functional capacity, health related quality of life (HRQOL), psychosocial status)
- Physical activity
- Oxygen use, prescription at rest, ADL, exercise, and sleep, and oxygen system used
- Smoking history, abstinence
- Total PR visits
- Health care utilization and exacerbations
- Untoward events
- PR dropout and reason
- Mortality

Data sets are measured at start of care (SOC), PR completion and 6 months after SOC.

Registry Enhancements Update:
The Pulmonary 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 dyspnea assessment section within the registry
- 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

Advancing the field
Despite several decades of growing evidence of effectiveness of PR, the field continues to be challenged with poor reimbursement, low patient referral rates, limited use, and lack of robust evidence of the impact of PR in large, diverse samples. The registry will address these challenges through measuring, analyzing and reporting the above data sets.
Requirements for participation:

- Internet access
- Annual subscription fee based on program size
- Signed Participation Agreement
- Online data entry training

Program & Record Information (as of September 2017):

- 230 participating programs from across the country
- Over 40,000 individual patient records entered
- For 2016-2017, 97% of all subscribers renewed their subscriptions to the Outpatient Pulmonary 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

Legal background, data security

The PR registry is modeled after the Cardiac Rehabilitation Outpatient Data Registry, which 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 secured on 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 CR registry project protocol was reviewed by a large, internationally recognized academic center IRB. Their opinion was that the CR 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. The PR registry follows the same protocols as the CR registry.

Outside IRB review of this project was therefore not explored. Because the purpose of the registry is to track outcomes of patients for healthcare monitoring and quality improvement at the program level, patient consent to have their data included in the registry is not required. 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 this case, the 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 being developed by Cissec Corporation of Kingston, Ontario, in cooperation with AACVPR and SmithBucklin.