AACVPR Outpatient Cardiac Rehabilitation Registry
Frequently Asked Questions
Updated 6/5/2012

Why Participate?

Q: Why should our program participate in the registry?
A: Through the AACVPR Outpatient Cardiac Rehabilitation Registry, cardiac rehabilitation programs will be able to:

- Create and manage patient profiles
- Enter and view outcomes data on enrolled patients in real time
- Track and quantify progress of the cardiac rehabilitation program in meeting performance goals
- Produce individual and grouped outcomes reports
- Automatically download their program profile and outcomes data to the AACVPR Program Certification application

By assisting in the collection, management, and interpretation of outcomes data, the registry will help cardiac rehabilitation programs:

- Compare outcomes and processes to evidence-based goals and national benchmarks
- Implement quality improvement projects based on real data
- Enhance documentation and communication with the program's key audiences, such as hospital administrators and referring physicians
- Promote the role of cardiac rehabilitation in the management of chronic heart and vascular disease
- Increase support from physicians
- Improve 3rd-party payer coverage and reimbursement rates

Q: Can small cardiac rehabilitation programs benefit and make a difference?
A: Every program's data will be valuable and will make a difference. In the Wisconsin Cardiac Rehabilitation Outcomes Registry (WiCORE), 60 percent of the participating programs are small programs (fewer than 100 new Phase 2 patients per year). Of the more than 45,000 patients entered in WiCORE, 27,000 are from small programs.

For benchmarking, the registry will offer reports that show how your patient outcomes compare not only to general averages across the country but also to programs in your state and to similar-size programs. The information you get from the registry will help you manage your patients' outcomes data and build a better program.

In fact, small programs may have the most to gain. You get an easy-to-use tool to:

- Organize the collection, analysis, and reporting of outcomes
- Demonstrate program performance to your administrators, physicians, and medical director
- Transfer data for AACVPR Program Certification

Plus, you'll get the support of AACVPR and experts working on the registry – all for a very fair price.

Subscription

Q: How do I subscribe to the registry?
A: Click here to fill out the registry contact form and subscribe.

Q: What is the cost to participate in the registry?
A: Participation in the registry is based on an annual program subscription. The fee is dependent on program size, based on the number of new Phase 2 patients who enroll in your program annually. AACVPR is working to keep prices low and is also exploring discounts for AACVPR-certified programs. The current fee structure is as follows:

- Annual enrollment of fewer than 100 patients: $100
- Annual enrollment of 100 to 200 patients: $125
- Annual enrollment of more than 200 patients: $150

Q: When will our program be able to start using the registry?
A: The registry officially launches in June 2012. After the launch date, subscribing programs will be able to enter patient data as soon as their subscription and fees are processed, a Participation Agreement has been signed, and their identified principal user/primary data coordinator has taken the mandatory training.

Q: What does the mandatory training entail?
A: AACVPR will be developing Webinars and online videos to assist programs in understanding the procedures for the accurate collection of data for the registry. One person from your program will be designated as the principal user/primary data coordinator for your program and will be required to view the training materials to learn how to use the interface and to understand the data definitions and data collection guidelines. After the training, the principal user will begin the process of updating your program procedures so that the outcomes data you collect for the registry is accurate and compliant with the registry definitions. Once your program's procedures are updated, you can start entering data into the registry. This is to ensure that we have the highest quality data available for the registry. Exhibit A in the Participation Agreement provides a description of the role of the principal user.

Data Collection

Q: Who will be able to access our program's data?
A: Registry subscribers will have access *only* to their program's patient information and to aggregated data from the registry as a whole. Subscribers will not be able to access or view other programs' data. AACVPR-approved nonsubscribers, such as researchers, will have access only to aggregated and/or de-identified registry data. The data will be de-identified with respect to patient and program identifiers unless specifically permitted by the participating programs and required by the researcher. Hospital systems with multiple participating programs may request files of de-identified patient data from all programs within their system.

In addition, registry subscribers and AACVPR will sign a Participation Agreement for limited data use giving AACVPR access to patient-specific information. AACVPR may use this information to provide reports of national outcomes and trends and to track morbidity and mortality rates. (Read more about the Participation Agreement.)

Q: Will we still be able to use our current patient management system?
A: An application programming interface (API) is designed to work with existing electronic patient management programs to seamlessly deliver data to the registry. Contact the sales representative or manufacturer of your current telemetry system or patient management system to see if an API to the AACVPR registry is being created for your particular system. For programs using a paper-based patient management system, the registry provides an easy-to-use graphical user interface (GUI) that utilizes table-driven lookups and checkboxes to minimize typing and has multiple levels of validation to ensure data is entered correctly before it is submitted. You may decide to modify your current paper-based practices to complement the registry or switch entirely to the registry for your patient management needs.

Q: Will we need to change any of our program's policies or procedures?
A: In order to standardize definitions so that all programs are measuring the same outcomes, you may have to modify your procedures so the data you collect conforms to the registry standards.

Q: What data is being collected in the registry?
A: The proposed data set includes:

- Program and hospital system information
- Patient demographics
- Medical history, such as:
    - Diagnoses
    - Comorbidities
    - Tobacco use
- Cardiac rehabilitation referral and enrollment dates
- Healthcare utilization
- Pre- and post-clinical assessments, such as:
    - Lipids
    - Blood glucose
    - Blood pressure
    - Dietary habits
    - BMI
    - Functional exercise test data
    - Medication adherence
- Psychosocial status

Not all of the data fields included in the registry will be required fields; only a handful will need to be completed in order to save a record. Programs should collect and enter as much information as their resources allow. The more data entered, the better the feedback will be with respect to overall program performance.

Click here for a more detailed list of data elements in the registry.

Q: Our program doesn't use the same measurement tools and tests as the registry. Can we still participate?
A: Yes, you can. Many of the variables in the registry are not required; you don't have to enter the data if you don't have it or don't use the tool. Also, it's okay to use tools that are not in the registry; you just won't be able to get feedback on your patients' scores compared to other programs for parameters not tracked within the registry. What's more important is that you're using validated tools and you're using

the scores to educate your patients and provide appropriate and individualized services based on the results. However, you may want to review some of the tools that are supported in the registry and see whether your current tools could be updated to these. Click here to see the data elements collected in the registry and the supported assessment tools.

Reporting

Q: What reports will we be able to view?
A: Pre-configured reports will include:

- Individual Patient Report showing the patient's pre- and post-program values, percent change, and comparison to secondary prevention goals
- Grouped Outcomes (Program) Report showing aggregated pre- and post-outcomes and change in scores
- Performance Measures Report, designed to assess the program's success at getting its patients to national guideline goals in secondary prevention areas

Reports will reflect user-specified time frames and may be sorted by diagnosis, age, sex, and/or clinical status. In addition, internal reports will allow ongoing calculation of national benchmark data by AACVPR, while a special interface will allow aggregated data mining by approved outside agencies.

Please note: Until there is a critical amount of data in the registry, program-level reports and aggregated data may not be very meaningful. Comparative data may change significantly as more records are added.

Q: How will the registry ensure accuracy of data?
A: Each participating program must designate a principal user who is responsible for monitoring data integrity. There will be an extensive training process for each participating program. In addition, the registry will apply rigorous data validation techniques.

Patient Privacy and HIPAA Compliance

Q: Is the registry HIPAA compliant?
A: To enable AACVPR and researchers to track morbidity and mortality, and to link AACVPR registry data to other data sources, such as the registries of the American College of Cardiology (ACC) or Medicare administrative databases, the AACVPR Outpatient Cardiac Rehabilitation Registry will need to use unique patient identifiers. **This is the only reason the registry is asking programs to enter patient identifiers.** Unique patient identifiers include last name, date of birth, hospital medical record number, and dates of rehab admission and discharge. The identifiers *will not* include the patient's social security number.

To be compliant with HIPAA regulations, AACVPR is required to demonstrate that the data is appropriately secured and that all users of the data have had appropriate training and agree to certain requirements regarding the handling of patient protected health information (PHI). The potential linkages noted above are for research purposes and would require AACVPR permission, data use agreements, and IRB review before the data could be used.

Q: Do patients need to provide consent to have their data included in the registry?
A: The purpose of the registry is to monitor patient outcomes and promote quality improvement efforts. HIPAA provides that, in this case, the program can disclose the patient's PHI to the registry without the need for separate patient consent.

Q: Do I need to get Institutional Review Board (IRB) approval before using the registry?
A: The AACVPR Outpatient Cardiac Rehabilitation Registry is a quality assurance database and does not involve human subjects research as defined by the Office for Human Research Protections. As such, it has been determined that the registry does not require IRB oversight. Individual institutions, however, may require quality assurance activities to have IRB review. Programs should verify with their administration that participation in the registry complies with institutional requirements. In addition, a request to use data from the registry for a research project may require IRB review from the investigator's own IRB. The registry protocol document is available for use as a starting point if needed; click here to download the protocol.

Q: What is the Participation Agreement?
A: Because of the inclusion of PHI, each participating program will need to have a signed Participation Agreement on file with AACVPR before it can enter or submit data to the registry. This agreement includes both a business associate agreement and a data use agreement. It is a standard legal document that identifies:

- The parties that are sharing PHI – in this case, AACVPR and your program – and their responsibilities in maintaining the confidentiality and security of PHI
- Who owns the data
- What data each party can expect to get back
- Who is liable if security is breached

Click here to download the AACVPR Registry Participation Agreement. Please present this document to your administrators, as it is very specific about how AACVPR can use data and closely follows basic HIPAA requirements.

In order to make the submission process as efficient as possible for you and for us, please do the following:

- Insert the full and legal name of the entity that will be entering into the agreement on page 12 where indicated;
- In section 9.12, add the address where you would like notices sent, including the name of the person to whom the notice should be addressed;
- If you have any suggested revisions, please make those revisions directly on the document in a way that clearly shows the changes (e.g., "track" changes in the Word document); and
- Please do not make revisions and send us a PDF document. We cannot accept PDFs. Please send back a Word document with your tracked changes.

Signed participation agreements should be returned to AACVPR Headquarters, Attn: Registry, 401 N. Michigan Ave., Suite 2200, Chicago, IL 60611-4267; faxed to 312/312-673-6924; or scanned and e-mailed to jray@aacvpr.org with "Registry Participation Agreement" in the subject line.

Q: How secure is my data?
A: Whether your program uses the web-based application (graphical user interface) to enter data in the registry or uploads data through an API, the data will be securely encrypted using industry-standard procedures. Programs are required to enter data only on hospital-approved computers, as these will most likely be much more secure than home computers. All data will be stored on a secured server at SmithBucklin, AACVPR's business management group. AACVPR will be the owner of the data and will meet the HIPAA requirements for safeguarding data.

AACVPR Program Certification Integration

Q: How will this affect my AACVPR Program Certification?
A: The AACVPR Outpatient Cardiac Rehabilitation Registry will be integrated with the AACVPR Certification Center. Programs that participate in the registry will be able to automatically download their program profile and outcomes data to the certification application, and vice versa.

Registry Development

Q: Who is Cissec Corporation?
A: Cissec Corporation, a Canadian-based software development firm specializing in healthcare technology, is responsible for the IT development of the AACVPR Outpatient Cardiac Rehabilitation Registry. Cissec is an experienced vendor that has created previous registries, including the Canadian Cardiac Rehab Registry of the Canadian Association of Cardiac Rehabilitation. AACVPR and the cardiac rehabilitation experts who make up its Registry Committee have developed the registry content and will oversee its operations.

Q: Who is SmithBucklin?
A: SmithBucklin is an association management company, delivering exceptional service to its client organizations and their leaders, members, and stakeholders. Registry data will be on a secured computer located at SmithBucklin.