

## **NCDR™ Research Frequently Asked Questions**

### **1. What is the NCDR™?**

The National Cardiovascular Data Registry (NCDR™) the NCDR™ is the preeminent cardiovascular data repository for measures of care in the United States. The NCDR™'s mission is to be the leading provider of services to improve the quality of cardiovascular care through the collection, analysis, and reporting of data and providing educational and research activities.

The NCDR™ began in 1998, with the CathPCI Registry™ that includes data collection and reporting for diagnostic and interventional cardiac catheterization and percutaneous coronary intervention (PCI) procedures. The CathPCI Registry™ has since become the gold standard for cardiac data collection, reporting and benchmarking. The CathPCI Registry™ consists of data of over 6 million patient records and more than 700 institutions, including hospitals, free-standing laboratories, and adult cardiology practices.

The ICD Registry™ began with data collection in June 2005 and was developed in partnership with the Heart Rhythm Society. The ICD Registry™ includes all required data fields for the Centers for Medicare and Medicaid Services (CMS), as well as optional extended information.

The CARE Registry™, launched in September 2006, is the first national vascular data registry that will support multiple disciplines of medicine (cardiology, neurology, radiology and vascular surgery) with the collection, reporting, and benchmarking of carotid stenting procedures. The CARE Registry™ will also meet CMS requirements for data collection and reporting.

Beginning on January 1, 2007, Genentech's NRMI Registry and the CRUSADE Registry will be replaced by the new NCDR™ ACTION Registry™. Hospitals currently participating in either NRMI or CRUSADE will transition to become ACTION Registry™ participants. As a result of this effort, myocardial infarction data from hundreds of hospitals across the country will come together into one unified platform with standardized clinical data elements to facilitate benchmark outcomes, analyze treatment regimens, and support our mutually shared mission to improve the quality of patient care.

Each registry includes a standardized set of data elements and definitions, systematic data entry and transmission procedures, and rigorous data quality assurance standards. Data are collected retrospectively and/or concurrently and represent consecutive patients treated at each institution. Participants obtain software from vendors certified by the ACC as compliant with clinical and coding data standards. Risk-adjustment protocols are embedded and data elements link to clinical practice guidelines and JCAHO core measures to track performance. Confidential institutional reports are published for all enrolled participants on a quarterly and annual basis. The reports compare each institution's outcomes, including risk-adjusted mortality, with the overall experience of the registry and a comparison group.

### **2. What is the CathPCI Registry™?**

The NCDR™ CathPCI Registry™, a national, voluntary cardiac catheterization laboratory registry, includes a standardized set of data elements and definitions, systematic data entry and transmission procedures, and rigorous data quality assurance standards. Data are collected retrospectively and/or concurrently and represent consecutive patients treated at each institution.

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It provides institutions with the ability to understand, measure, and improve quality of cardiovascular care through a comprehensive measurement system linked to ACC clinical practice guidelines and performance measures that rely on a set of nationally recognized standardized data elements and definitions.

At this time, over 700 sites enrolled in the registry nationwide, with increasing national representation due to growing consumer, payer and regulator demand for quality in the catheterization lab. The multi-phased data quality program launched its national on-site data auditing program in January 2004.

The registry contains over 6 million patient records, including over 1 million PCI procedures representing 7 years of data. The PCI mortality rate is risk-adjusted. Each year the National Quality Forum and the Leapfrog Group have adopted the CathPCI Registry™ PCI risk-adjusted mortality rate measure as a standard of quality in lieu of procedure volume requirements.

### **3. What is the ICD Registry™?**

On January 27, 2005, the Centers for Medicare and Medicaid Services (CMS) announced its expanded implantable cardioverter defibrillator (ICD) coverage decision for primary prevention ICD therapy. Immediately, coverage for primary prevention was expanded to include most SCD-HeFT patients and an expanded MADIT II population. Along with this expanded coverage, CMS also implemented an ICD data collection requirement called “QualityNet” or “QNet”. Relevant patient information is collected and stored, but CMS does not provide any benchmark reports or any clinical support to participants.

The Centers for Medicare and Medicaid Services’ mandate to provide data on the implantation of ICD devices creates new challenges for electrophysiologists and their teams. The NCDR™ responded to those challenges with the launch of a brand new ICD Registry™ on June 30, 2005.

The ICD Registry™ was designed in partnership with the Heart Rhythm Society and includes all required data fields, as well as optional extended information. In addition to meeting CMS data collection requirements for ICD implantation, national ICD Registry™ participants will receive quarterly benchmark reports that can be used to measure patient outcomes, volume and utilization. As of November 1, 2006, the ICD Registry™ contains over 1389 sites and 68,000 patient records.

The NCDR™ will begin accepting applications for research of the ICD Registry™ data on January 1, 2007.

### **4. What is the CARE Registry™?**

The national CARE Registry™, launched in September 2006, was developed to capture key elements and definitions needed to accurately measure patient outcomes and clinical practice related to patients receiving carotid artery stents. Participants will immediately fulfill CMS data collection requirements for Carotid implantation, as well as, receive quarterly benchmark reports that can be used to measure patient outcomes, volume and utilization. The CARE Registry™ was designed in partnership with the Society for Cardiovascular Angiography and Interventions, the Society of Interventional Radiology, and the American Academy of Neurology.

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### 5. How are data collected, cleaned, and reported?

NCDR™ participants collect and submit quarterly patient data using ACC-certified software programs. With each data submission, participants receive quarterly Data Quality Reports that provide data completeness and consistency statistics that facilitate data cleaning efforts required for the submission process. All data reported in the NCDR™ comparative national results pass stringent completeness thresholds. Confidential Institutional Outcome Reports are distributed on a quarterly and annual basis and include NCDR™ and peer group comparisons. In addition, the NCDR™ data quality program includes a nationwide onsite audits to confirm data accuracy. A random sample of submitting facilities are randomly selected each year.

### 6. What data are currently available?

The available data currently include version 2.0 and 3.0 data elements from the CathPCI Registry™. Data from the new ICD Registry™ will be available after January 1, 2007.

### 7. How can I conduct research with NCDR™ data?

The NCDR™ promotes research activities geared toward informing cardiovascular evidence-based medicine. The NCDR™ encourages original contributions that potentially can impact patient care. Individuals or organizations interested in using NCDR™ data for research projects, including abstract submission and manuscript development are welcome to submit a [Research Proposal Application](#). The NCDR™ also accepts [Data Request Applications](#) for other research and analyses.

All applications are reviewed by the NCDR™ Research and Publications Subcommittee, which meets bimonthly. Depending on the type of request, the review process may take from 4 to 8 weeks. The Subcommittee will evaluate requests for data analysis based on information supplied on the application.

- a) **Complete an Application Form:** The Research Proposal Application (and/or Data Request Application) is available on the NCDR™ website (<http://www.accncdr.com>). Please feel free to include any additional information on the application form that you feel would be beneficial to the review process on the form.
- b) **Application Submission:** To be eligible for consideration, all applications must be complete and include an email address for correspondence purposes. Send the application (MSWord format) as an attachment to: **research@acc.org**

Analyses will be conducted by the ACC according to the NCDR™ Research and Publications Subcommittee's prioritization list at assigned analytic centers. Submissions are evaluated on several criteria including but not limited to: innovation, feasibility, clinical significance, policy implications, timeliness, and cost. Approved applications will be fully supported in achievement of the goals outlined in the proposal.

### 8. How much are the fees to conduct research?

Analyses of research proposals may be wholly or partially funded by the ACC depending upon the requester's eligibility status. The ACCF has allocated resources to develop abstracts and manuscripts for numerous scientific sessions annually. All research proposals are evaluated and prioritized by the Research and Publications Subcommittee. Eligibility for ACC-sponsorship of research activities

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requires membership in the American College of Cardiology including full members and fellows in training.

Research proposals funded by the investigator(s) are also evaluated by the Research and Publications Subcommittee. These applications are placed in a separate queue from the NCDR™-sponsored research.

### **9. What is the NCDR™ research proposal review and approval process?**

Proposals for analysis of NCDR™ data are submitted to NCDR™ whenever an investigator fills out and submits an application form, but NCDR™ may also issue periodic announcements of research opportunities using the data.

Analyses will be conducted by the ACC according to the NCDR™ Research and Publications Subcommittee's prioritization list at assigned analytic centers. Submissions are evaluated on several criteria including but not limited to: innovation, feasibility, clinical significance, policy implications, timeliness, and cost. Approved applications will be fully supported in achievement of the goals outlined in the proposal.

Analysis may lead to abstract submission to a national conference (optional), but the primary goal will be manuscript preparation and submission. Abstracts, presentations, and manuscripts will require approval of the Research and Publications Subcommittee prior to submission.

### **10. What is the NCDR™ research publication review and approval process?**

Any abstract or manuscript developed using data from the NCDR™ must be reviewed and approved by the Research and Publications Subcommittee prior to submission to a conference or journal.