

## AJRR launches pilot data collection project

By Jennie McKee

### U.S. joint registry is poised to begin accepting data

The American Joint Replacement Registry (AJRR) recently kicked off its pilot data collection project after receiving a “huge response” from hospitals and orthopaedists eager to take part, said **David G. Lewallen, MD**, chair of the AJRR board of directors.

“Seventy-five hospitals volunteered to participate,” he said. “Of those, we selected 16 that reflect the diversity of hospitals across the country in geographic location, size, and practice type.”



*David G. Lewallen, MD,  
chair of the AJRR board  
of directors*

The main purpose of the pilot project, which will conclude after collecting 3 months of data from each institution, is to understand the burden of reporting data and identify the methods that work best for hospitals in preparation for launching the large-scale U.S. joint registry in 2011. Additionally, the trial provides the opportunity for AJRR staff to develop an efficient process for recruiting and training contributing institutions and receiving and storing their data.

### Preparing for the pilot

Before the pilot project began, the AJRR selected a Web-based software system for manual entry of Level 1 data (see sidebar) and ensured those involved in data collection at each site were trained on the software system. Another key task has been selecting a data storage server that meets privacy and security requirements under the Health Insurance Portability and Accountability Act. All sites also signed contracts confirming their participation in the pilot project.

The 16 organizations, ranging from academic centers to smaller community hospitals to private orthopaedic practices, were selected by the members of the AJRR’s Hospital Surgeon Participation Workgroup, headed by **Kevin J. Bozic, MD, MBA**, and Catherine MacLean, MD, PhD. Each institution has strong surgeon champions charged with coordinating involvement in the registry.

**James D. Slover, MD**, attending orthopaedic surgeon at the NYU Hospital for Joint Diseases, is his institution’s surgeon champion. Some of his key responsibilities have been helping to assemble and organize a team and outline a process for interfacing with the AJRR to ensure that data are collected and protected properly.

Although the AJRR has commercial Institutional Review Board (IRB), approval, as well as a HIPAA waiver of authorization and waiver of informed consent needed to conduct the pilot project, many hospitals, including Dr. Slover’s, had to obtain local IRB approval.

“We had to engage all the stakeholders in this, including all the orthopaedic surgeons doing joint replacements, the

operating room staff, and the support staff who will be helping us," said Dr. Slover. "Our information technology department helped us develop the infrastructure to communicate with the AJRR and ensure that we keep data protected. We also had to go through our local institutional review board process."

Dr. Slover said that the main challenge of contributing to the registry is making sure all the data are collected and entered accurately and in a timely fashion.

"Ensuring that data collection for the registry doesn't add too much to the workload is also a challenge; however, because our institution is totally committed to it and we have buy-in from everyone, it's not going to be too overbearing for any one person," he said.

Because some institutions will require patient consent for data collection, educating patients about the registry is important, said Dr. Slover.

"We hope that patients understand how the registry may help other patients," he added.

### **Analyzing "lessons learned"**

Randolph R. Meinzer, AJRR's director of information technology, noted that the pilot program will help clarify the methods needed to acquire data.

"For example, some hospitals already have data systems and registries in place," he said. "We need to know what to incorporate into the application to enable the AJRR to acquire their data."

After the conclusion of the pilot program, the AJRR's goal is to have a production system up and running next summer.

"Our forecast, which is aggressive, is to sign up an additional 160 hospitals," said Mr. Meinzer. "We think there are at least that many hospitals eager to participate."

The registry will develop criteria for evaluating both commercially available and custom software applications before making the final decision on technology for the large-scale national registry.

According to Mr. Meinzer, much of the data the AJRR intends to collect is already contained in electronic systems at many institutions.

"We need to be able to provide automated interfaces to these institutions to reduce the burden on manual data entry," he said.

### **Planning for the future**

Dr. Lewallen noted that the AJRR has developed a business plan that supports its goal of going live with the large-scale registry in 2011.

"This will be a freestanding and self-supporting registry over time," he said. "In the ramp-up phase, we have to manage the flow of income and resources expended very carefully. I think we've got a solid plan that we've developed through collaboration with the other stakeholders on our board. It is being fully vetted and the details are still being fleshed out, but we are well on our way to finalizing it."

The AJRR's long-term goal is to capture data from 90 percent of U.S. hospitals where hip and knee arthroplasty procedures are performed, which amounts to between 5,000 and 6,000 different hospitals, in the next 5 years.

"We are going to try to get the registry up and running very quickly to allow us to report back to the community and provide early warning information as well as data on outlier performance by hospitals or individual surgeons," said Dr. Lewallen.

The AJRR draws much of its strength from its collaboration with the various associations and organizations that participate in the delivery of hip and knee arthroplasty, said Dr. Lewallen.

"This is a collaboration not just with the AAOS, but also with organizations such as The Hip Society, The Knee Society, and the American Association of Hip and Knee Surgeons, all of which have supported this endeavor financially, and are represented on the board," he said.

Representatives from industry, hospitals/institutions, and payers also are represented on the board, he noted, as are patients. The experience and perspective of all the various stakeholders will help the AJRR as it moves forward.

"If you think about the delivery of arthroplasty care," said Dr. Lewallen, "every one of these groups has an impact on

the quality of the outcome, and that is why we want them involved.”

“We will face ongoing challenges as we try to finalize the financial end,” said Dr. Lewallen. “We’re really starting a small business, and we want to do that carefully. We will continue to receive a lot of great advice from smart people to help us ensure the AJRR succeeds.”

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### **Level 1 data being collected in the AJRR pilot program**

#### *Patient-related data*

- Name
- Date-of-birth
- Social security number
- Diagnosis (ICD-9 code)
- Sex

#### *Surgeon-related data*

- Name
- Address

#### *Hospital-related data*

- Name
- Address

#### *Procedure-related data*

- Procedure code (ICD-9 code)
- Date of surgery
- Implant information (manufacturer, catalog number)
- Laterality (right and/or left)
- Type of procedure (hip or knee)

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