Looking at the American Joint Replacement Registry (AJRR) today, one may be reminded of a slogan from Virginia Slims (circa 1968): “You’ve come a long way, baby.” Although having come a long way, unlike the cigarette brand, the AJRR will make a profoundly positive contribution through its goals of improving quality, improving outcomes, and increasing the cost effectiveness of total joint replacement surgeries. Just over 11 years ago, the Agency for Healthcare Research and Quality and the American Academy of Orthopaedic Surgeons (AAOS) held a Total Joint Registry Workshop in Washington, DC, from December 10 to 11, 2001. The Workshop Final Report was published by the AAOS in May 2002.¹ With the help of its dedicated members, the AAOS has worked to establish a national joint replacement registry since 2001.

For the ensuing years, an AAOS Task Force served to keep the effort ongoing, and the first AAOS organized stakeholders meeting was held in September 2008 at the Brookings Institution in Washington, DC. This pivotal meeting laid the groundwork for the establishment of an AJRR Project Team, and a second stakeholders meeting was held in Washington, DC, on October 26, 2009. Representatives from many facets of the orthopedic community participated in the meeting, including surgeons, industry, private payers, the Centers for Medicare & Medicaid Services, the US Food and Drug Administration, the Agency for Healthcare Research and Quality, hospitals, and the public. The second meeting provided a framework and a timeline for moving forward. The AJRR was incorporated in June 2009, and board members and bylaws were approved in February 2010. A pilot program for the registry began in October 2010 and was completed in June 2011, after which active recruitment of hospitals performing total hip and knee replacement procedures began.

The multi-stakeholder approach chosen for developing this national joint replacement registry is unique. In the case of the AJRR, this multi-stakeholder concept is critical to its success to date, with particular regard to governance and funding. The 13-member board has 4 AAOS orthopedic surgeon representatives, 3 from the specialty societies (1 each from the American Association of Hip and Knee Surgeons, the Hip Society, and the Knee Society), 2 industry representatives (chosen by the AdvaMed Orthopaedic Sector), 2 payer representatives, 1 Public Advisory Board representative, and 1 Hospital Association representative. A sound business plan has secured funding from stakeholders through 2014. The registry now has key staff members, including an Executive Director and Directors of Information Technology, Research, and Policy and Strategic Initiatives, and 4 other full-time employees. The Figure illustrates the tremendous progress obtained in 2012 regarding hospitals contributing data, the number of agreements, and the number of participating hospitals. Emphasis in the past year has been on targeting institutional collaboratives (ie, High Value Healthcare Collaborative), large hospital networks, and major high-volume centers.

The value and effect of national registries are well established. The well-known example of total hip arthroplasty quality improvement in Sweden is often cited as a rationale for registries. The Swedish Hip Arthroplasty Register was implemented in 1979 and has since influenced both the clinical practice and attitudes of arthroplasty surgeons.² Another example highlighting the critical role of registries is the Australian Orthopaedic Association National Joint Replacement Registry’s use of data to serve as a monitoring and warning system and to help identify appropriate patients for specific implants and procedures.³ Documented broad support

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exists among international orthopedic associations for national joint registries. National arthroplasty registries in other countries have been shown to be effective in substantially reducing the revision burden up to 10% and higher. For the United States, a 2% reduction in the national revision rate could mean saving the Centers for Medicare & Medicaid Services more than $65 million in a year.

The AJRR’s mission is to foster a national center for data collection and research on total hip and knee replacement with far-reaching benefits to society, including reduced morbidity and mortality, improved patient safety, improved quality of care and medical decision making, reduced medical spending, and advances in orthopedic science and bioengineering. The AJRR’s vision is to be a national registry dedicated to the improvement in arthroplasty patient care by data-driven modifications in the behavior of collaborating providers, institutions, manufacturers, payers, and patients.

In terms of the protection of data and human patients, Health Insurance Portability and Accountability Act (HIPAA) compliance has been well studied and appropriately addressed by the AJRR. The registry data collection is primarily used for quality improvement and health care operation purposes. The US Department of Health and Human Services Office for Civil Rights and the Office for Human Research Protections endorse central institutional review board waivers for clinical data registries. Through the Western Institutional Review Board, the AJRR has been granted a waiver of HIPAA authorization and Common Rule consent to cover data collection for research purposes. Regarding data ownership, participating sites own the data submitted to the AJRR. However, the AJRR owns the database, aggregate data, and reports. Sites enter into participation agreements and business associate agreements with the AJRR to cover the aforementioned items.

The AJRR will provide publicly available annual reports that will include procedure frequency nationally and by state and region; information on the devices used, with device-specific survivorship; the volume effects by surgeons and hospital type; and early warning surveillance of new technology. More specific data will be available by subscription for surgeons, hospitals, manufacturers, payers, and government agencies. The AJRR’s goal is to voluntarily obtain participation of more than 90% of all hospitals in the United States that are performing joint replacement surgery. Because of the large number of joint replacement surgeries being performed annually in the United States, the potential for excellent data from this registry is huge. The AJRR needs surgeon champions at all hospitals throughout the country, particularly those not yet participating, to emphasize the importance of participation to their surgeon and administrator colleagues.

The AJRR Web site (ajrr.net) is a great source for additional information. I challenge each reader of ORTHOPEDICS to gain more knowledge about the AJRR and to encourage your hospital or institution to become a participant. This national joint replacement registry is a long-awaited and positive step forward for our patients, our profession, and our health care system that addresses quality, patient safety, and improved outcomes. For more information or to enroll in the AJRR, visit their Web site, call (847) 292-0531, or send an e-mail to info@ajrr.net.

REFERENCES