The IRIS Registry Makes Its Debut

Ophthalmology’s long-standing culture of clinical and scientific innovation meets big data. The result: a national eye care registry that is expected to have a groundbreaking impact for individual physicians and the entire profession.

By Jean Shaw, Contributing Writer

The nation’s first comprehensive eye disease registry is on its way. Known as the IRIS Registry (for Intelligent Research in Sight), the centralized software system is expected to have a revolutionary impact on ophthalmology.

“The IRIS Registry will provide every ophthalmologist with the opportunity to determine whether he or she is delivering consistent high-quality processes and outcomes of medical and surgical care. Physicians all seek that uniform excellence; this is the first instrument that will quantify those answers,” said David W. Parke II, MD, the executive vice president and CEO of the Academy.

How It Works

As an illustration of how the IRIS Registry will work, let’s say that you are a pediatric ophthalmologist and you perform surgery on a child with exotropia. “The surgical measurements will be part of your electronic health record [EHR]; the operative note will be put into the registry as part of the interface from the operating room,” said William L. Rich III, MD, the Academy medical director for Health Policy. “Then, the follow-up data at 90 days or six months on this patient and any others with exotropia will show you your outcomes measures. You’ll be able to assess which surgical variations led to better outcomes, for instance.”

In addition to being able to search by type of operation, clinicians will be able to search by such parameters as risk factors, medical conditions, and demographics. And via prompt feedback and monthly reports, they will be able to compare themselves with other ophthalmologists in...
their subspecialty and to established best practices, Dr. Rich said. “The advantage of the IRIS Registry to the individual physician is improved performance; the advantage to the profession is improved quality.”

**Why Participate?**

Drs. Parke and Rich outlined four primary benefits of participation in the IRIS Registry.

1. **Best practices.** As a profession, ophthalmology has a tradition of excellence, and “ophthalmologists love data,” said Dr. Rich. “With the IRIS Registry, you’ll be able to compare your performance with that of your peers.” Moreover, it will provide immediate feedback, he said. “To date, with randomized clinical trials, implementation of findings has been abysmally low. But with the IRIS Registry, decision support will be built into the program. We’ll know immediately if we forgot to do x or y.”

2. **MOC compliance.** “For the 50 percent of ophthalmologists who are involved in the American Board of Ophthalmology’s Maintenance of Certification [MOC] process, the use of the IRIS Registry may facilitate their participation and save them hours of work,” Dr. Parke said.

   As he explained, physicians who are engaged in MOC are required by the practice improvement modules to provide patient data. “Essentially, its ‘Give us some examples from your own patients; have you done the right thing?’ But complying with this requires manual acquisition and transmission of data.” In contrast, it is envisioned that the IRIS Registry will automate the collection of this data directly from the EHRs. This will reduce or eliminate the need for manual data input by physicians and their staff. The MOC–IRIS Registry application will be a voluntary one—it will be there as an optional tool.

3. **Financial return.** The IRIS Registry is expected to convey financial advantages to users, Dr. Rich said. “This is not being done without the recognition that there will be financial benefits.” Dr. Parke explained, “The IRIS Registry can be used to satisfy a number of payment incentive systems within Medicare and Medicaid. We estimate that the economic value of participation on the bottom line will be in the range of $15,000 to $20,000 per physician per year, once health care reform is fully in place.”

   Dr. Rich added, “Medicare recognizes the power of clinical registries and is making sure that the people who participate are being rewarded. One gold star for participating in a registry is that you get rewarded” with regard to qualifying for Physician Quality Reporting System (PQRS) incentives and portions of EHR Meaningful Use, not to mention the impact of the Value-Based Payment Modifier (slated to begin in 2015). Private payers also are interested in working with registries, Dr. Rich said, although the shape that these relationships will take is less certain at this point.

4. **Scientific advances.** One obvious benefit of any clinical registry is the potential to generate information that can be further evaluated in clinical studies and postmarketing surveys. “The IRIS Registry has the potential to make a significant con-

---

**How BIG DATA Will BOOST RESEARCH**

In this era of high-volume, high-velocity information, data sets are so large and complex that they can’t be analyzed by traditional means. Hence the term “big data.”

“The classic scientific inquiry begins with a hypothesis that is then tested through a clinical trial. But big data isn’t about beginning with a hypothesis; it’s about correlations,” said Dr. Rich. With the IRIS Registry, “We’re projecting that we’ll have 20 million patients that we’ll be following within four years,” he said. “We’ll be able to look at correlations, and the correlations will be reportable. This will engender randomized clinical trials and lead to advances in science.”

Dr. Rich referenced the work famously done by David F. Chang, MD, in discovering the connection between Flomax and intraoperative floppy iris syndrome. “He had to evaluate his OR videos and parse the findings. But with the IRIS Registry, it won’t take years to find out these kinds of correlations. We’ll be able to see them by pressing a button.”

The ultimate effect? The IRIS Registry will “compress the evolution and dissemination of science,” Dr. Rich said.
distribution to the postmarket analyses of new drugs and devices,” Dr. Parke said. Moreover, it has the potential to bring more clinical correlations and scientific discoveries to light (see “How Big Data Will Boost Research”).

**How the IRIS Registry Compares**

Other medical and surgical registries exist, some of which have been successfully shown to improve surgical outcomes. However, they have—from the ophthalmic point of view—several limitations.

**Inpatient vs. outpatient.** Most existing registries are hospital-based, Dr. Parke said, and hospital staff takes care of the data uploads. In contrast, the IRIS Registry will be an outpatient registry, which fits the reality of how ophthalmologists practice. “Only 13 percent of our surgeries are performed in hospitals, so that model wasn’t going to work for ophthalmology,” said Dr. Rich.

**Limited vs. longitudinal.** The best-known existing registry is run by the Society of Thoracic Surgeons. “The thoracic surgeons have been doing this for 18 years, and their registry has had a dramatic impact on surgical outcomes,” said Dr. Rich. “But they can’t track data beyond 90 days or so. They literally don’t know what happens to their patients over the long term. At one point, they went to the Social Security administration to try and buy death files.”

In contrast, the IRIS Registry is set up to track data longitudinally. “Think again of cardiac patients, who are followed by multiple specialists,” Dr. Rich said. “The simple fact is that, as ophthalmologists, we follow our patients throughout their lives. Even without a national patient identifier, we will be able to follow patients longitudinally using probabilistic matching. We also will be able to track such parameters as quality of life and ability to function as well as the long-term costs of an intervention.”

**Generalists vs. specialists.** An additional advantage of the IRIS Registry is that it will be a “big tent” with room for all. From generalists to subspecialists, “We’ll have one source to go to that is all-inclusive,” Dr. Rich said. And the broader the base, the more powerful the aggregated data.

**Practical Concerns**

Anybody considering the IRIS Registry is likely to ask one or more of the following questions.

**Will it slow me down?** As Dr. Rich said, “Anything that interferes with workflow won’t be accepted.” Ophthalmology is already “the most productive of all medical and surgical specialties,” he said. And workforce projections indicate that the numbers of older patients with such conditions as glaucoma, macular degeneration, and diabetic retinopathy will rise exponentially in the coming years. Thus, the IRIS Registry “has to work in the background. In addition, there has to be real-time feedback: The sooner you get a feedback loop, the more useful the information is,” he said.

Practices that participate in the IRIS Registry will go through an initial setup process that includes matching of data fields. This mapping process will require some limited involvement from the practice’s EHR expert. And once the system...
is installed, the daily upload of data can literally occur outside of office hours while the physician is asleep, Dr. Rich said. “There is little or minimal burden” on either the physician or the office and little impact on patient flow.

**Is it secure?** “Issues of privacy and security should be a concern for anyone in any business that handles personal data—and that’s obviously a significant concern in health care,” Dr. Parke said. The systems that the IRIS Registry is using have been tested with these issues in mind, he said. “They have been found to meet all privacy standards and to be secure and, in fact, have been used for years in hospital-based registries.” Thus, the IRIS Registry will be in compliance with HIPAA.

**Is it private?** Many physicians mistrust the process of being measured and reported, Dr. Rich acknowledged. “Everyone thinks their patients are sicker than anyone else’s, among other things, so there’s a huge mistrust of being measured. You want to make sure that the tools are fair and risk adjusted.”

He added, “It’s unfair to publish your outcomes until you’ve had a chance to improve. Thus, one of the tenets of the IRIS Registry is that no one has access to your data. The physician has to have the ability to improve without outcomes being reported up front.”

**Who owns the data?** “You own your own data, you get the feedback, and you decide what happens with the data—whether it’s released to a health plan, for instance,” Dr. Rich said.

Dr. Parke emphasized, “The individual patient data is owned by the physician, not by the Academy, and the physician retains ownership and unique access to that data. The only way that data would be released is through the express request and permission of that physician.”

The aggregated data will be owned by the Academy, Drs. Parke and Rich said. This information is needed to produce the national benchmarks.

**Why Now?**

In order for the IRIS Registry to be developed and launched, two technical conditions needed to be met, said Dr. Parke. “One, we needed a critical mass of ophthalmologists using EHRs; two, we needed technology that would permit the ophthalmic registry to be nonburdensome to the physician.”

Both of these components are now in place. A significant percentage of ophthalmologists (30 to 35 percent and growing) in the United States have transitioned to EHRs, and, as noted above, the IRIS Registry will run on a platform that requires little manual data management (but you will have the option of inputting data manually).

**Final Thoughts**

“We’re doing something unique with the IRIS Registry, but it’s consistent with ophthalmology’s long-term history” of clinical and scientific innovation, Dr. Rich said. In his mind, the ophthalmology registry is fully in keeping with such milestones as Arnall Patz’s study of blindness in premature infants, the ETDRS (Early Treatment of Diabetic Retinopathy Study), and CATT (the Comparison of Age-related Macular Degeneration Treatments Trials). “It will improve science.”

Moreover, it’s important to recognize that the IRIS Registry will be a “living database” in that the inaugural version won’t be a static product, Dr. Parke said. “It will be modified and enhanced, and new data fields will be entered. As it progresses, it will become increasingly complete—and increasingly valuable.”

---

**REGISTER NOW**

For the first 2,000 users, the IRIS Registry will be free for the first two years. This opportunity is limited to U.S. Academy members and providers who work for them. Although the IRIS Registry won’t be fully operational until early next year, you can register now.

**How to get started.** Visit [www.aao.org/irisregistry](http://www.aao.org/irisregistry) and click “Participating in the IRIS Registry.”

**At the Annual Meeting, visit the Academy Resource Center** (Hall G, Booth 3239). Visit the “New From the Academy” area, and ask about the registration process.

---

**MEET THE EXPERTS**

**DAVID W. PARKE II, MD**

Executive vice president and chief executive officer of the Academy. Financial disclosure: No related financial interests.

**WILLIAM L. RICH III, MD**

Medical director of Health Policy for the Academy, chair of the IRIS Registry work group, and in practice with Northern Virginia Ophthalmology Associates in Fairfax, Va. Financial disclosure: No related financial interests.