## **Current Perspective**

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## Happy Birthday to the IRIS Registry

n March 24, the IRIS Registry (Intelligent Research in Sight) celebrated its seventh birthday. The IRIS Registry represents an amazing accomplishment both for the Academy and for the ophthalmologists who actively use and support it. All ophthalmologists and their patients benefit from it.

It is an incredible story. In late 2012 a committee was formed, chaired by Bill Rich, MD, to evaluate the feasibility of a profession-wide clinical data registry to be used principally as a quality improvement tool, but with the potential to report under Medicare programs, such as PQRS (and later MIPS), and to contribute to the science of ophthalmology. It was essential that the registry be secure and that identifying patient data not be shared (to be HIPAA compliant). Equally essential, the registry could not share any physician-specific information without the physician's express, prior approval, such as when reporting to CMS under the MIPS program or to the American Board of Ophthalmology for continuing certification.

In 2013, the Academy Board of Trustees voted to approve the project and to fund it out of Academy reserves rather than accept federal funds or partner with industry. The Board deemed it important that the registry be totally under Academy governance. They also decided, unlike many other societies, to make it a member benefit with no charge for initial setup or participation.

Eighteen months after launch, more than 10,000 ophthalmologists had contracted with the registry, and the database had grown to include 49 million patient visits. The registry now has participation from over 14,000 ophthalmologists and their 3,300 employed optometrists, and it includes approximately 400 million patient encounters from about 70 million unique patients! It supports 62 electronic health record systems.

In 2017 the Academy licensed to Verana Health the commercialization of de-identified, anonymized data to help accelerate clinical research and drive innovations in real-world evidence. Verana in turn is responsible for most of the Academy's over \$5 million annual software and database costs. Because of its accuracy and controls, more and more practices are also migrating to Verana for direct data ingestion from their EHRs. It has executed similar relationships with the American Academy of Neurology and the American Urological Association. Verana has never released (and cannot release) any physician-specific or patient-specific information to a third party.

So what has been the impact for Academy members? The Academy arranges for files to be submitted to CMS under MIPS at no charge to members. And not a single Academy member submitting electronically via the IRIS Registry has ever received a penalty. On the other hand, for the 2018 reporting year alone, of those ophthalmologists *not* submitting electronically through the IRIS Registry, 548 had penalties totaling \$11 million. For 2017-2020, reporting MIPS through the IRIS Registry is saving about \$103,000 in avoided penalties per ophthalmologist, and about \$1.05 billion cumulatively for all ophthalmologists.

Over 25 peer-reviewed scientific papers have been published using IRIS Registry data—and over 100 presentations and posters (including two Jackson Lectures). It has sparked novel observations in areas as diverse as diabetic retinopathy, myopic macular degeneration, glaucoma, and endophthalmitis. It has informed discussions on health equity and disparities in care in glaucoma and in amblyopia. The American Board of Ophthalmology has accepted it as a tool for continuing certification.

The IRIS Registry should be a source of great pride for ophthalmologists. We all contribute the data that permit the scientific innovation. We have built something to a scale that is unique not only in American ophthalmology but also in medicine worldwide. And we've only scratched the surface. The dataset should expand to include images, genomics, and patient-reported outcomes. New artificial intelligence–infused analytic software is needed. We have yet to explore its true potential in practice management. Much more is yet to come.

This has all been accomplished without sacrificing integrity and privacy. No financial conflicts of interest exist between Academy leaders and Verana. No individual data have been released—ever. Patients and physicians are protected, and systems and legal documents are in place to ensure that it stays that way.

Happy Birthday to the IRIS Registry!