# Opinion

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# What Is Patient-Centered Care?

Isn't all ophthalmic care patient-centered? Isn't the outcome for an individual patient the whole point of what we do every day? The array of acronyms—including PREM (patient-reported experience measures), PROM (patient-reported outcome measures), PRO (patient-reported outcomes), and SDM (shared decision-making)—can add a sense of confusion around what ophthalmologists have done well for decades.

The emerging buzz about patient-centered care and outcomes seems like a lot of fuss about the obvious. Anne Coleman, MD, the Academy's President-Elect and former Secretary for Quality of Care, suggested that we take a step back, noting that these efforts reflect attempts "to measure what we're already doing."

Evidence-based medicine incorporates the best evidence in making decisions about the care of individual patients. Much of our evidence has been developed through randomized clinical trials. But as we develop research instruments, we sometimes measure things that matter more to the ophthalmologist than to the patient. Patient-centered outcomes are an attempt to measure what's important to the patient, and these priorities can be difficult to quantify.

Patient-centered outcomes research has been around for a long time. In 1999, the Collaborative Initial Glaucoma Treatment Study was the first randomized clinical trial in glaucoma to use PROMs. Now, regulatory science is developing many sophisticated instruments for evaluating patient experience. This seems especially relevant for ophthalmology, which is all about preserving and enhancing a sensory function. PROWL (patient-reported outcomes with LASIK) was developed by the FDA, NEI, and Department of Defense and was validated as a tool to measure what the patient experiences before and after LASIK. The Academy is working with the FDA to develop a PROM for evaluating novel IOLs, and the American Glaucoma Society is working with the FDA to develop a PROM for evaluating the patient experience with minimally invasive glaucoma surgery devices.

PROMs are created by convening focus groups of patients and determining what is important to them in their own words. Flora Lum, MD, the Academy's Vice President for Quality and Data Science, said, "We want to do what makes a difference for patients from their perspective. It has to be in their language." For this reason, focus groups need to be established for each patient population. It's difficult to communicate a visual experience with words. As Anne pointed out, "what one person means by glare might be very different than what another person means." Letting patients put things into their own words without input from the ophthalmologist is important.

Patient-centered care is a corollary to patient-centered outcomes. Perhaps previous generations of patients were comfortable when the physician made decisions and dispensed directions. Today, we are expected to be diligent about sharing evidence when it's available. Shared decision-making is a collaborative model for engaging patients in health care decisions, especially when there are multiple treatment options without one obviously superior choice.

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In 1996, when HIPAA was introduced, it seemed cumbersome to implement a law around something we already did well. Yet HIPAA has been important on many levels, as it holds all of us to a high and verifiable standard of privacy. Similarly, creating reasonable standards and validated tools for measuring what we do might also increase our awareness of the patient perspective. Requiring PROMs in clinical trials certainly refocuses research on what the patient wants and not merely on the evidence that we imagine is most important.

Now, we must integrate the individual patient experience with evidence-based medicine and outcomes. Even as we are trying to save money and time, we are developing expensive instruments for measuring patient experience and emphasizing shared decision-making, which is a time-consuming process. It's a tricky tightrope to walk.