

Patient Engagement in Scholarly Publishing

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SPEAKERS:

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cautioned. He attributed the success of *CJASN's* Patient Voice to journal and patient leaders who co-developed the program as a sustainable model that aligns with the overall mission of the American Society of Nephrology.

Shari Leventhal, *CJASN* managing editor, described the editorial process for Patient Voice articles. The journal adopts a similar approach to invited scholarly articles to maintain the same level of editorial oversight and ensure high-quality contributions to the scholarly literature. *CJASN* editors identify original research suitable for patient commentary and send formal invitations to potential editorialists through their peer-review system. At this point, Leventhal and Fowler may take a more hands-on approach to offer encouragement and guidance to patient-authors who aren't accustomed to writing; however, their role is mostly supportive, whether it be answering questions or helping with submission, ensuring that the words and ideas are the author's own. After submission, the manuscript goes through an internal peer review. Finally, both the Patient Voice and original research article are published as open access. "We wanted any patient who reads the Patient Voice article to have access to the original research," said Leventhal.

The Patient-Centered Outcomes Research Institute (PCORI) was established by Congress in 2010 as a publicly funded, private nonprofit organization supporting comparative clinical effectiveness research designed to help patients, clinicians, and policy-makers make informed healthcare decisions. All PCORI-funded studies require meaningful patient input at every stage, from topic selection through design, peer review, results, and dissemination (Fig. 1).

"From very early on, we wanted to make sure that patients and other stakeholders were weighing in on the applicability of the research," said Bill Silberg, Communication Director for PCORI. "Was this research that was potentially going to make a difference for patients in the real world?"

PCORI is legally required to include patients in review of research funding applications and in peer review of completed studies. The results of that research are shared as widely—and inclusively—as possible. All PCORI-funded research is reported on the organization's website in the form of 500-word summaries for professionals and patients (the latter written at an eighth-grade reading level and cognitively tested for understandability). To widen the audience for critical research, PCORI also covers open access fees for selected articles and works with journals to make original

In keeping with the 2019 CSE Annual Meeting theme of inclusivity, the session on "Patient Engagement in Scholarly Publishing" focused on including the patient at all levels of scholarly publishing—from reviewing research proposals to writing to conducting peer review and repurposing and disseminating journal content.

"We're trying to change the disconnect between the way the investigator looks at the research versus the person with the disease and the end result," said Kevin Fowler, editor of the *Clinical Journal of the American Society of Nephrology's* (*CJASN*) Patient Voice section. Fowler kicked off the session describing how *CJASN* "elevates the patient voice" by recruiting patients with kidney disease to write commentaries related to *CJASN* research articles, thereby allowing patients to add their perspectives to scholarly dialogue about the issues that affect them the most. Patient contributors—whom patient voice editors, including Fowler, select to be representative of the population of patients with kidney disease—contextualize medical research with their real-world experiences. "Maybe we need to redefine exercise," commented one patient-author, pointing out that common definitions of "mild, moderate, and rigorous" exercise seemed unrealistic and demoralizing for patients exhausted by chronic kidney disease.¹

Leadership is key to successfully incorporating patients into scholarly publishing. "If your leadership doesn't align with the journal's goal, don't even try something like this," Fowler

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Focusing on Patients Throughout the Process

pcori

Patients are:

- Part of every peer review team assessing completed studies
- On the technical advisory panel that guides our Translation Center's work
- Involved in cognitive testing process for all public abstracts, which serve as tools for reporting study results to participants
- Increasingly serving as authors of journal articles resulting from our funded studies and other projects

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Figure 1. Focusing on patients throughout the process. ©2019, Patient-Centered Outcomes Research Institute. All rights reserved. Used with permission. Learn more at www.pcori.org.

research articles linked to PCORI summaries available to readers at no cost.

The *Annals of Internal Medicine* also takes an inclusive approach to patient engagement, including patients as readers, authors, and reviewers, explained editor-in-chief and former CSE President Christine Laine. Recognizing that the *Annals* is not a go-to source for most patients, Laine and her team reach out to patients-as-readers through several channels. First, they have a proactive media strategy: “The media is the way most of the public gets their information, so we put a lot of effort into helping them get the story right,” Laine said. The *Annals* prepares tip sheets for journalists, video news releases, and news packages about guidelines. The front-end effort often pays off, with media coverage amplifying key *Annals* articles to reach hundreds of thousands of people. Next, the *Annals*’ “In the Clinic” features “practical, pragmatic reviews of common clinical conditions” and includes an information page written for patients that patients can access online or in handouts from their physician. Finally, the *Annals* editors write summaries that translate clinical guidelines and selected original research articles into clear language specifically for

patients. The summaries use a standardized question-and-answer format that sometimes attracts more online traffic than the corresponding scientific abstracts.

As with *CJASN*, the *Annals* does occasionally publish material that includes patient authors. When patients contribute to research articles and clinical guidelines, they must follow standard practices and policies, including disclosing conflicts of interest and honoraria, Laine explained. Patients can also contribute by writing “On Being a Patient” essays about the patient experience.

Lastly, the *Annals* is participating in a pilot study with several journals using patients as reviewers. These patient-reviewers work closely with professional reviewer mentors. However, Laine believes that patient input could be more useful when planning the research design than when reviewing publications. “The earlier we can involve the patient’s voice, the better,” she said.

References and Links

1. Jefferson NM. A patient’s view on exercise and ESKD. *CJASN* 2019;14(2):171.