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## EDITORIAL

# Publishing Patient-Centered Outcomes Research

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The still new Patient-Centered Outcomes Research Institute (PCORI) is changing the world of clinical research by bringing the voice of patients and other stakeholders into the design, conduct, and interpretation of research. PCORI is both championing and riding the wave of movements that combine rigor and relevance, carefulness and openness, expertise and inclusive participation. These movements challenge entrenched oligarchies. Now PCORI is seeking to add to the process of timely, accessible, transparent communication of research results to increase the credibility of patient-centered outcomes research.

Having just completed a public comment period, PCORI will soon declare a process for peer review and

public release of its sponsored research findings. The exact details still are being determined, but we know that the process must comply with the legal statutes that created PCORI as an independent, but federally funded organization. We also know that PCORI will be working to find the sweet spot between the needs and desires of researchers, scientific and lay publishers, and the diverse end users of patient-centered outcomes research.

The statutes call for:

- A process for peer review of primary research to assess scientific integrity and adherence to methodological standards
- Making research findings available to clinicians, patients, and the general public:

- "Not later than 90 days after the conduct or receipt of research findings"
- Ensuring that the findings are conveyed:
  - "In a manner that is comprehensible and useful to patients and providers in making health care decisions"
  - Discusses "considerations specific to certain sub-populations, risk factors, and comorbidities, as appropriate"
  - Includes limitations of the research
- Making "available to the public and disclos[ing] through the official public Internet website of the Institute":
  - Information contained in research findings
  - The process and methods for the conduct of research, including the identity of the entity and the investigators and any conflicts of interests
 The final process seems likely to involve:
- Registration of PCORI studies with the appropriate registry or public database
- Submission of a final report that PCORI will peer review according to its methodological standards. The report will include a 500-word abstract for medical professionals, a standalone results table, an ancillary information section that lists the identity of investigators, and any conflicts of interest / links to industry
- Posting of the peer-reviewed report and a lay audience summary
- Working to coordinate with traditional academic publication outlets and other dissemination vehicles and processes

There will be challenges with the PCORI process and its implementation, as the medical research and publication worlds lurch toward more timely and inclusive processes that balance the benefits of scientific peer review with the need for rapid accessibility and interactive interpretation of credible findings. The challenges include: synchronizing the time frames of research, review, and scientific and lay publication processes that may not always match PCORI statutory requirements, and managing the dissemination of continuing discoveries after the PCORI final reports have been processed. To the extent that PCORI and its funded research is successful in fostering a truly participatory research community of relevant stakeholders, however, the needs and desires of researchers,

scientific and lay publishers, and research end users will begin to come together.

Whatever the final form of the PCORI process, *Annals of Family Medicine* is committed to the principles of patient-centered outcomes research, the involvement of relevant stakeholders in all phases of the process from the generation of the question to the conduct of the research, and the participatory, evolving implementation and dissemination of the findings. We look forward to working with authors, diverse stakeholders, and with PCORI on being part of a larger process to make patient-centered outcomes research easily, credibly, and interactively accessible.

A number of features of *Annals* are already designed to make research accessible, credible, and interactive. *Annals* makes the full text of articles, brief lay-language article summaries, and interactive online discussion available free of charge to anyone with Internet access. *Annals* peer reviews and accepts articles without publication fees, and publishes without commercial sponsorship. Upon acceptance, we work with authors to identify diverse stakeholders potentially affected by the research and ask the stakeholders to join an online discussion that is part of the permanent record of the journal. We also work directly with the lay, professional, and social media to assure that the content of articles published in *Annals* is shared in diverse venues that reach audiences who don't regularly read scientific journals.

*Annals* publishes not only original research articles, but also high-impact research briefs, systematic reviews, methodology, theory, essays, and special articles that provide timely outlets to convey different ways of knowing. We will continue to develop our publication processes to meet to the evolving needs of the diverse communities who care about patient-centered outcomes research, and to help foster the participatory implementation and dissemination of that research to people and communities who will benefit from its use.

**To read or post commentaries in response to this article, see it online at <http://www.annfammed.org/content/12/6/503>.**

**Key words:** patient outcome assessment; quality of health care; primary health care; patient-centered care, PCORI

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