Getting the Word Out: Patient Engagement in Scholarly Publishing and Communication

Council of Science Editors Annual Meeting
Columbus, Ohio
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Patient-Centered Outcomes Research Institute

About PCORI

- Independent research institute authorized by Congress in 2010
- Overseen by 21-member Board of Governors representing US healthcare community
- Funds comparative clinical effectiveness research, studies that assess which healthcare options work best for whom, based on outcomes important to patients
- Engages patients and other stakeholders throughout the research process
Our Mandate

“... to assist patients, clinicians, purchasers, and policy makers in making informed health decisions by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis...

... and the dissemination of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services...”

—from PCORI's authorizing legislation

We Take Our Name Seriously

- We engage patients throughout our work and have from the beginning
- Patient-centeredness and engagement are required for funding
- Patients and patient groups are partners on research teams and receive other types of funding to advance research and dissemination of new evidence
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- An Advisory Panel on Patient Engagement provides ongoing input
- Patients are on the panels that review applications for research funding and among the peer reviewers of our completed projects
- Patients are on the Steering Committee for our Annual Meeting and serve as co-presenters and discussants for plenary and breakout sessions

A Mandate to Disseminate Research Findings

Our authorizing law requires that we:
- Peer-review our funded studies to ensure scientific integrity and adherence to methodology standards
- Make results available as quickly and widely as possible to clinicians, patients, and the general public
- Do so “in a manner that is comprehensible and useful to patients and providers in making healthcare decisions”
- Pursue journal publication as a key element, albeit only one piece
How We Do It

- We link to all journal articles resulting from funded studies
  - We fund open access where available
- We peer-review the final research reports all awardees submit when they complete their studies
- Our PCOR Translation Center develops professional and public summaries of study results, posted within 90 days of the completion of peer review
- Final research reports and peer review summaries posted within 12 months
- Information resources that go beyond individual results summaries

Focusing on Patients Throughout the Process

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
Examples

How Often Should Patients with Lung Cancer Have Imaging Tests after Surgery?

Project Summary

Lung cancer is the most common cancer in the United States, emerging in patients as an active population and a top cancer concern in older patients. The incidence of lung cancer is on the rise, and while screening for lung cancer remains controversial, older patients should be considered for these imaging tests because it may require a different approach when considering the future of lung cancer screening.

What were the results?

Comparative effectiveness research was conducted to determine the effectiveness of various lung cancer screening tests. The results showed that lung cancer screening is effective in identifying lung cancer early, but there is a need for further research to determine the best approach to lung cancer screening.

Why is this study important?

Understanding the effectiveness of lung cancer screening is important for identifying lung cancer early and improving patient outcomes.

Studied cancer types include:

- Lung cancer

Additional information:

- Lung cancer is the most common cancer in the United States.
- Screening for lung cancer is controversial.

What is the research about?

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