

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

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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



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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



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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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We Take Our Name Seriously



- 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

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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

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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

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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

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Examples



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

This project has results

Public Abstract | Professional Abstract

Download this abstract: [English \(pdf\)](#) | [Español \(pdf\)](#) | [Audio Recording \(mp3\)](#)

What was the research about?
Lung cancer is the second most common cancer in the United States. Among lung cancers, 80 are of the type called non-small cell lung cancer, or NSCLC. When doctors find NSCLC early, they removing all or part of the lung. Imaging tests then look for signs of the cancer coming back or cancer forming. These tests include chest CT scan or X-ray. Guidelines vary in their advice to how often patients should get these imaging tests. Guidelines may recommend imaging tests months after surgery.

What were the results?
Compared with getting an imaging test for NSCLC every 12 months, getting an imaging test every 3 or 6 months—didn't make it more likely the patients would live longer after their surg. Frequent imaging tests also didn't improve how early doctors detected returning or new cancer.

Who was in the study?
The research team looked at medical records for 6,350 patients with NSCLC who had lung surgery. Of these, 68 percent had an early stage of NSCLC. The average patient age was 68 years old. The study was funded by the National Cancer Institute.

Read More

This project's final research report is expected to be available by May 2019.

Patient-Centered, Risk-Stratified Surveillance After Curative Resection of Colorectal Cancer

This research project is in progress. PCORI will post its findings here within 90 days after our In the meantime, results have been published in peer-reviewed journals, as listed below.

Project Summary
Nearly 14 million Americans are alive today having survived their battle with cancer. Cancer survivors make up the second largest group of cancer survivors, and the current population of colorectal cancer survivors is expected to grow nearly 25 percent by 2022. To these survivors and caregivers, as well as their physicians, the most pressing issue is determining how to monitor the survivor in the future. Cancer surveillance has been identified as a top priority by the Institute of Medicine and the Agency for Healthcare Research and Quality. However, current surveillance guidelines are a one-size-fits-all approach. As a result, the quality of care, patient experience, and resources are compromised, and research to generate evidence and tools for improved surveillance is greatly needed.

This proposal will address the critical question: "Based on my individual tumor characteristics and preferences, what is the best way to monitor for recurrence?" We hypothesize that by tailoring surveillance to the individual CRC survivor—taking into account their risk for recurrence, tumor characteristics, and personal preferences—the effectiveness of cancer monitoring the burden on patients and the healthcare system would be reduced.

We specifically will

1. determine how effective CRC surveillance is and measure the risk and time to recurrence by taking into account different patient and tumor characteristics—through detailed data from CRC clinical trials conducted by the ALLIANCE network, as well as from

Comparing a Smartphone Program with a Peer-Led Program to Help People with Serious Mental Illness Manage Their Symptoms

This project has results

Public Abstract | Professional Abstract

Download this abstract: [English \(pdf\)](#) | [Español \(pdf\)](#) | [Audio Recording \(mp3\)](#)

What was the research about?
People with a serious mental illness, or SMI, may have difficulty with daily activities like working or taking care of themselves. Programs at mental health clinics can help people with SMI manage their symptoms and improve their health. But it can be hard for people with SMI to get to the clinic to use these programs, and some may not feel comfortable at a clinic.

What were the results?
Using the programs. The research team studied how often people used the programs. To do this, the team looked at whether people used FOCUS at least once a day for five days every week. For WRAP, the team looked at whether people went to at least 60 minutes of a 90-minute session every week. More people in FOCUS started the program than people in WRAP. After eight weeks, more people in FOCUS used their assigned program than those in WRAP. When the programs ended after 12 weeks, the team found no difference between people's use of the two programs.

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Examples



pcori PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
EVIDENCE UPDATE
OCTOBER 2018

Choosing an Antibiotic for Your Child's Ear, Nose, or Throat Infection



New research findings can help you and your child's clinician figure out the best option for treating your child's infection.

When bacteria cause your child's ear, nose, or throat infection, your clinician will suggest one of two kinds of antibiotics. One kind is **narrow-spectrum antibiotics**. These medicines fight just the bacteria that are most likely causing your child's ear, nose, or throat infection. Examples are amoxicillin or Amoxil®. The other kind is **broad-spectrum antibiotics**. These medicines fight many kinds of bacteria at the same time. Examples are azithromycin or Z-Pak®.

pcori | Urology Care FOUNDATION | MN Men's Health Network | ASTRO TARGETING CANCER CARE

How Will Treating My Early-Stage Prostate Cancer Affect My Quality of Life?

Early-stage prostate cancer can be treated in different ways. The three main ways are active surveillance, surgery, and radiotherapy. Active surveillance means having your prostate checked every few months to make sure the cancer is not spreading. Surgery would take out the prostate, and radiotherapy uses high-energy rays to kill cancer cells in the prostate.

Two recent PCORI-funded studies compare the effects of these choices on the quality of life for men with early stage prostate cancer. These studies looked at three effects treatment might have on a man's quality of life. These are problems having sex, urinary problems, and bowel problems.



Prostate cancer grows very slowly, making the risk of dying from the cancer very low.

That gives you a chance to think about quality of life issues that matter most to you.

Here's what the new research says:
The different ways of treating early-stage prostate cancer (active surveillance, radiotherapy, or surgery)

Thank You!

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