

# Assessing the Impact of Patient and Family Initiatives: The Evidence

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Our Mission

PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from **research** **guided by patients, caregivers, and the broader healthcare community.**



# Why Engage Patients and Stakeholders in Research?

To influence research to be patient-centered, relevant, and useful

To establish trust and a sense of legitimacy in research findings

To encourage successful uptake and use of research results



# Patient and Family Engagement in Patient-Centered Outcomes Research (PCOR)



Planning the Study



Conducting the Study



Disseminating the Study Results



PCOR Engagement Principles



# Patient-Centered Research into Outcomes Stroke Patients Prefer and Effectiveness Research (PROSPER)

## Engagement

- Focus groups and stakeholders assist in identifying which outcomes are most desired and prioritized by patients as well as evaluate treatment options

## Potential Impact

- Could change practice by making post-stroke treatment more personalized, based on the patient's personal preferences, values, and characteristics



Tests patients to see which of the common current therapies after a stroke are the most effective, including blood thinners, cholesterol-lowering regimens, and anti-depressants, and learns more about the therapies' benefits and risks.

*Adrian Felipe Hernandez, MD, MS,  
Duke University  
Durham, NC*

*Assessment of Prevention, Diagnosis, and Treatment Options, awarded September 2013*



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# Drug Prescription Helps Stroke Survivors Live at Home Longer



**Date:** September 4, 2015

**Topics:** [Research](#)

One of our core beliefs at PCORI is that if studies look at outcomes important to patients and those who care for them, the results will help those stakeholders make more-informed healthcare decisions. So I'm pleased to pass along a particularly strong example of that approach, from [a recently published paper](#) reporting results of such a PCORI-funded study.




# Comparative Effectiveness of Intravenous vs. Oral Antibiotic Therapy for Serious Bacterial Infections

## Engagement

- Advisory councils will be involved in formulating the research question, defining essential characteristics of the comparators and outcomes, monitoring study progress, and developing strategies to disseminate and implement the research findings

## Potential Impact

- Could change practice because no studies have been done to compare the impact of these two treatment options on the quality of life of the children and their caregivers



Compares effectiveness of oral vs. intravenous antibiotics in children who require at least one week of home antibiotic therapy following hospitalization for a serious bacterial infection. Spends 18 months surveying at least 1,000 patients (and their caregivers) who are discharged from four large children's hospitals.

*Ron Keren, MD, MPH,  
The Children's Hospital of Philadelphia  
Philadelphia, PA*

*Assessment of Prevention, Diagnosis, and Treatment  
Options, awarded December 2012*



# Information that Matters to Moms





# Patient-Centered Outcomes



Evidence Based Patient Information

Evidence Based Medicine

- Joint Decision Making Tools

Patient Engagement

Direct Care

Patient-centered care

Healthcare Services Improvement  
Hospitals, Ambulatory Care

Implementation

Policy Making

Guideline Developers, Quality Measures Developers, Accreditors, Prof. Societies, Regulators, Medical Education, Payers, Purchasers, Healthcare Systems

Evidence

## Patient-Centered Outcomes Research (PCOR)

Based on Research Questions and Outcomes that Matter to Patients  
In Partnership with other Relevant Stakeholders to Ensure Implementation



# Thank You

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