

PATIENTS NEWS

April 2014

Join Our Mailing List

In This Issue

News

About PATIENTS

Featured Article

Activities & Accomplishments

Questions and Answers

News

The PATIENTS program congratulates [Dr. Richard Kronick](#) on being named the new director of our sponsoring organization, the Agency for Healthcare Research and Quality (AHRQ).

AHRQ has recently adopted a [new mission statement and priorities](#), which will directly impact research funding. Researchers are advised to review the following two Special Emphasis Notices as they prepare to submit grants to AHRQ:

- AHRQ Announces Interest in Research on Health Insurance Coverage, Access and Affordability [link](#)
- AHRQ Announces Interest in Research on Healthcare Delivery System Affordability, Efficiency, and Quality [link](#)

About PATIENTS

Launched in September 2013, the PATIENTS program aims to build the necessary infrastructure to empower patients to propose questions about their health care concerns and actively participate in studies to answer them. Funded through a grant from the Agency for Healthcare Research and Quality (grant # R24 HS22135-01), the

Welcome to the first newsletter of the PATIENTS program!

Our quarterly newsletter will share our success stories and research findings in the areas of patient-centered outcomes research (PCOR) and comparative effectiveness research (CER). In addition, it will provide information about upcoming events of interest to PATIENTS stakeholders, and relevant funding opportunities. In the future, these newsletters will include:

- a message from a member of the PATIENTS community
- a feature story highlighting an organization, event, or achievement
- one or more articles about recent program activities and accomplishments
- news and events from the PATIENTS program and its partners
- a section for questions and answers

The newsletter will be distributed via email and will be archived on our website, which is being redesigned to give patients, caregivers, and health care providers the knowledge and tools they need to make patient-centered treatment decisions. The official launch of the redesigned website is scheduled for June.

We hope that these new resources will unite us and remind us of our shared vision as we strive to develop and promote patient-centered research and health care.

Sincerely,

C. Daniel Mullins, PhD
PATIENTS Program Director
Interim Chair, Department of Pharmaceutical Health Services Research
University of Maryland School of Pharmacy

Featured Article

More than Two-Thirds of PATIENTS Contributors Weigh in on Priorities

Westat, a PATIENTS partner and one of the foremost research and statistical survey organizations in the United States, is responsible for our program's formative and impact evaluation. Occasionally, Westat staff will ask partners and participants in the program to take part in a survey or interview. They will evaluate the current and evolving status of our partnerships, document our preferences and ideas, summarize our achievements, and measure our impact on patient-centered outcomes research.

In November 2013, Westat conducted a baseline survey of the PATIENTS program. The survey assessed familiarity with PCOR and asked about immediate priorities for the PATIENTS program. Sixty-seven percent of our External Advisory

program contributes to the University System of Maryland's "MPowering the State" initiative by combining the expertise of leading researchers from the University of Maryland, Baltimore and the University of Maryland, College Park through innovative partnerships with patient communities and health care systems. Together, we work to ensure that patients, health care providers, and other partners are actively engaged in research. To learn more about us, check out [website](#).

Committee (EAC) members and 79 percent of our Internal Steering Committee (ISC) members responded to the survey. Thirty-five additional contributors also responded. We were thrilled to have such a high rate of participation. It truly shows that we are all very committed to our work in the program.

Following the survey, Westat interviewed the PATIENTS administrative core as well as the principal investigators of the program's four pilot projects. These interviews provided great insight into how people reacted to the initial findings from the survey and gave Westat the opportunity to ask more detailed questions about the partnership.

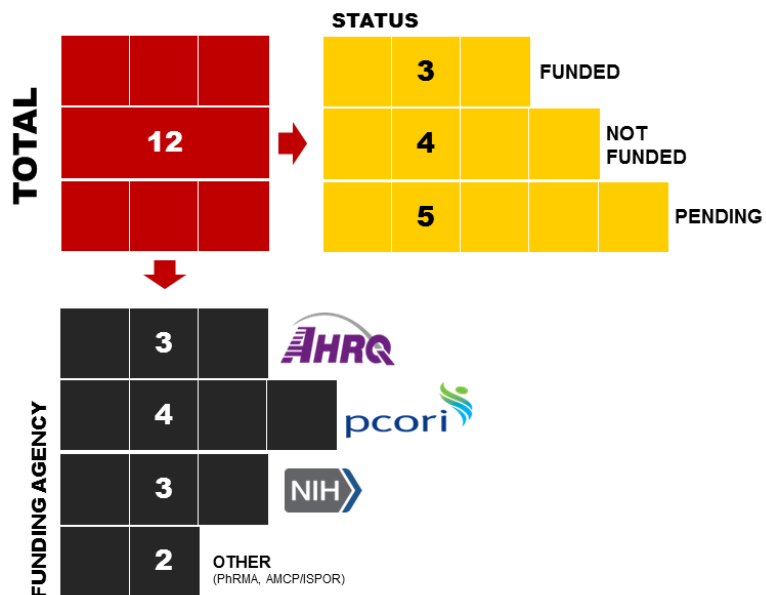
Here is a brief summary of the findings from the Baseline Needs Assessment survey:

- PATIENTS' first-year priorities should include: (1) developing and strengthening partnerships, (2) developing research capacity with community partners, and (3) preparing training and professional development modules for researchers.
- The three most critical areas for training topics should be (1) stakeholder engagement, (2) proposal development, and (3) the use of online platforms.
- The greatest need for training topics on patient engagement include (1) creating sustainable partnerships between researchers and patients, (2) identifying and prioritizing research topics with the help of patients, and (3) working with patients as collaborators on research proposals.
- The top three suggested PCOR tools or resources included (1) the PCORI website and training materials, (2) the AHRQ website and training tools, and (3) the Methodology Committee Translation Table IOM Methods meeting videos.

You can access the full Baseline Needs Assessment Report [here](#).

Activities and Accomplishments

PATIENTS-supported Grant Submissions in 2013



PATIENTS supported 12 CER/PCOR grant submissions in 2013. Six of these received help from the [CER/PCOR Work Group](#).

The following PATIENTS partners collaborated on one or more grant proposals during this period:

- Association of Black Cardiologists
- Bon Secours Baltimore Health System
- Center for Medical Technology Policy
- PatientsLikeMe
- Westat

Congratulations to Drs. Susan dosReis and Eleanor Perfetto, who received funding for the following proposals:

dosReis	Methods for Prioritizing Surrogate Desired Health Outcomes for Patients (PCORI) more
Perfetto	Comparative Effectiveness Research Certificate Program: A Project to Create an Enduring Blended Training Resource (CER Collaborative) A Center of Excellence in Comparative Effectiveness and Patient-Centered Outcomes Research Training (PhRMA)

PATIENTS Program Engages Community Members at Local Health Fair

The PATIENTS program partnered with Mt. Lebanon Baptist Church to host a community health fair on March 22. Held at the church, this health fair helped local residents access important services related to housing health, and fitness. [more](#)

Questions and Answers

Is a letter of intent (LOI) mandatory, and is it subject to peer review?

The answer to this questions is specific to the type of patient-centered outcomes research grant for which you are applying. Read the research funding announcement carefully to determine whether a LOI is mandatory and/or subject to peer review.

	LOI is required	LOI is peer-reviewed
AHRQ	Usually	NOT usually
PCORI	Usually	Often but not always