



PATIENTS NEWS

April 2015

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Approaches to Stakeholder Engagement

On April 2, 2015, Ellen Tambor, Senior Research Manager at the Center for Medical Technology Policy, delivered a seminar presentation about stakeholder engagement throughout the comparative effectiveness research process. You can watch the recorded lecture [here](#).

Video Highlights from The PATIENTS Program Site Visit

On Jan. 12, 2015, The PATIENTS Program hosted its second annual site visit. Researchers, clinicians, and community health advocates came together to celebrate accomplishments made in the program's first year, discuss some of the most important issues in PCOR, and to chart a course for PATIENTS' year two. Enjoy some of the highlights of that visit through this video recap.

Dear Subscriber,

The PATIENTS Program aims to help people make more informed decisions about their health and health care. We do this by meeting people at health fairs and talking to them about diseases and treatment options; collaborating with researchers who want to make their work more patient-centered; and connecting researchers with patient communities. Our mission is one of teaching, research, and service, and that call to service has only grown stronger in recent days.

In this issue, you'll read about some of the amazing work our colleagues are doing to help make health care research and processes more useful for all kinds of patients. Our university remains committed to the idea of accessible health care as a cornerstone of equality. I had the honor of collaborating with our campus president, Jay A. Perman, MD, and Robin Newhouse, PhD, on an article called, "Population Health and the Patient." This article, which appears in [The Transformation of Academic Health Centers: Meeting the Challenges of Healthcare's Changing Landscape](#), encourages academic health centers to consider all of the factors - especially the social and economic factors - that impact their patients' health and wellness. We write, "Research results can have more impact and be more meaningful for patients if they are engaged to assure that 'the patient's voice' is heard throughout the research process. A patient-centered emphasis throughout the research process helps to ensure that it remains focused on problems that people care about and that the research questions, design, comparators, and outcomes are more applicable to real-world patients."

The devastation and destruction in West Baltimore, which is one of the communities where The PATIENTS Program works, gives us a sense of what can happen when people feel that they have no resources. I believe that PATIENTS can, in our own way, offer something positive and powerful against that disenfranchisement: We can give people the information they need to be healthier and to spread the message of wellness and health advocacy to their friends and neighbors. We can also provide a platform that gives patients and all people a voice, and a way to disseminate information. This is a large reason why we're shifting the focus of this newsletter toward more community and patient-centered material. I hope you will be moved and inspired by the stories we'll share, and that you will keep our communities in your thoughts.

Sincerely,

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

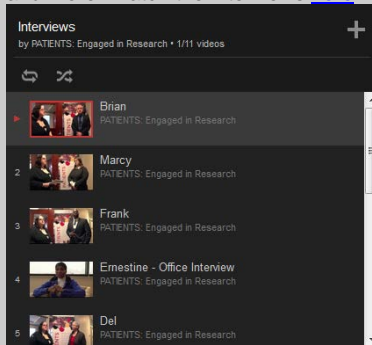
[PATIENTS-Supported Grant Submissions](#)



2015 Annual EAC/PO Site Visit

"Red Carpet" Interviews

During The PATIENTS Program's second site visit, we asked partners and guests to stand in front of the camera and answer questions about patient-centered research, partnering for research, health care in the community, and more. Watch the interviews [here](#).



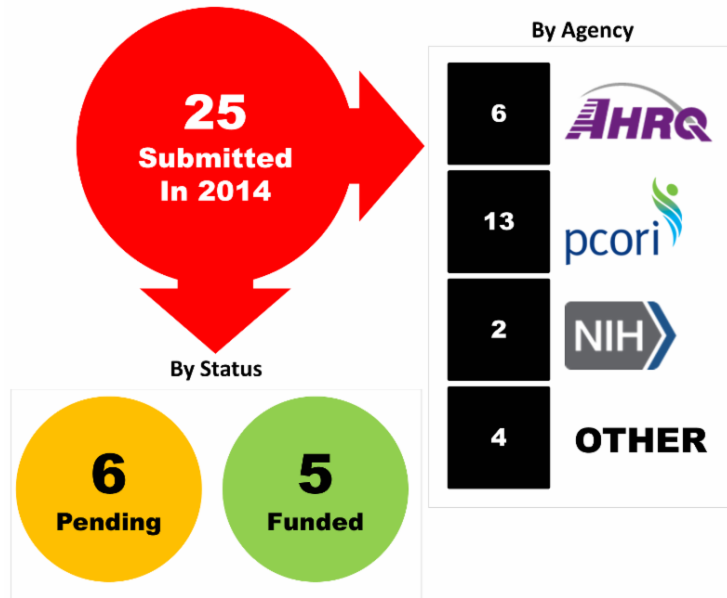
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About PATIENTS

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), the 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



PATIENTS-Supported Proposals in 2014 (as of April 1, 2015)

To date, The PATIENTS Program has supported 43 CER/PCOR grant proposals. In 2014, we supported 25 proposals, which is a 56% increase over 2013.

Sixteen submissions also took advantage of the [CER/PCOR Work Group](#), which is an informal group of researchers and partners at the University of Maryland chaired by Drs. Eleanor Perfetto, Linda Simoni-Wastila, and Olivia Carter-Pokras. The group aims to promote interprofessional collaboration and a broader understanding of the nature, scope, methods, and implications of comparative effectiveness research and patient-centered outcomes research.

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

- Association of Black Cardiologists
- Bon Secours Baltimore Health System
- PatientsLikeMe
- Westat

Congratulations to Drs. dosReis and Perfetto, who received funding for the following proposals in 2014:

dosReis	Methods for Prioritizing Surrogate Desired Health Outcomes for Patients (PCORI)
Perfetto	Comparative Effectiveness Research Certificate Program: A Project to Create an Enduring Blended Training Resource (CER Collaborative)
Perfetto	A Center of Excellence in Comparative Effectiveness and Patient-Centered Outcomes Research Training (PhRMA Foundation)
Perfetto	Patient Focused Drug Development (M-CERSI)
Perfetto	Leveraging Big Data II -- What Does it Mean for Improving Product Development and Healthcare? (M-CERSI)

Bon Secours Baltimore Health System submits an Application for a PCORI Tier 1 Pipeline to Proposal Award

research. To learn more about us, check out our [website](#).



Aurelia Laird, director of clinical and community research at PATIENTS Partner Bon Secours Baltimore Health System, was invited to submit an application for a PCORI Tier 1 [Pipeline to Proposal](#) Award. Fewer than half of the individuals who submit letters of intent (LOI) for Tier I awards are invited to submit a full proposal and her LOI made it through on the first attempt!

The ultimate goal of a Tier I Award is to form a team of patients and researchers/non-researcher stakeholders who are focused on a common health issue and demonstrate a commitment to developing a patient-centered research proposal. Laird proposes to engage patients, providers, and researchers in a Community Work Group to gain insight on the use of primary care by individuals managing their chronic conditions. The PATIENTS team was able to support her proposal with information on resource and budget requirements. While the proposal did not receive funding this round, Laird received favorable feedback from PCORI and intends to resubmit during the next cycle.

PCOR Training for "Non-usual Suspects": A Program for Rare Disease Patient Advocates



Over 6,800 rare diseases have been identified around the world, and many of these diseases are still without treatments or cures. Researchers work tirelessly to develop these life-saving treatments; however, there are often critical voices missing in the research process - those of the patients who are most directly impacted by these diseases. The aim of patient-centered outcomes research (PCOR) is to ensure that patients are involved in the conception, design, implementation, and dissemination of research. And, thanks to a proposal recently funded by the Patient-Centered Outcomes Research Institute (PCORI), teams at The University of Maryland and The

National Organization for Rare Disorders (NORD) will come together to make the research process more patient-focused and patient-driven.

This proposal, which was drafted by Eleanor Perfetto, PhD, MS, professor of Pharmaceutical Health Services Research at the University of Maryland, seeks to create and evaluate an educational program that will teach PCOR best practices to staff and patients or caregiver involved with NORD-member organizations. NORD is a federation of health care organizations dedicated to offering advocacy and care to people who are afflicted with these diseases.

Videos on PCOR Grant Writing

The PATIENTS Program is committed to providing its partners and researchers with training resources. Below are three training videos that we recorded in the past year:



[Federal-wide Assurance for the Protection of Human Subjects](#)



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