

PATIENTS NEWS



July 2014

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In This Issue

[Featured Article](#)

[Training and Resources](#)

[Activities & Accomplishments](#)

News

- PATIENTS released a new website on June 15, 2014. [Read More](#)

- PATIENTS published its first manuscript in the June issue of Value in Health. [Read More](#)

- Researchers from University of Maryland and Westat visited our partner PatientsLikeMe for the program's first off-site experiential training. We will tell you more in our next issue.

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 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 our [website](#).

Dear Reader,

As we approach the end of our first year as partners in the PATIENTS program, I am pleased to announce a series of firsts:

- Researchers from University of Maryland and Westat visited our partner PatientsLikeMe for the program's first off-site experiential training.
- PATIENTS hosted our first visiting student trainees. One of them, Rose Kajih, wrote about her experience with the team. See the Featured Article in the current issue.
- We funded our first pilot studies, and launched the first version of our full-featured website to promote available training opportunities and resources.
- PATIENTS investigators collaborated to publish the first manuscript of the program. You can read more about this below.
- We sponsored our first poster presentation at this year's International Society for Pharmacoeconomics and Outcomes Research (ISPOR) conference in Montreal.

I look forward to building upon these successes as we go into PATIENTS' second year, which starts on September 30, 2014.

Sincerely,

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

Featured Article

Student's Training Experience With PATIENTS

My name is Rose Kajih and I am a 4th year doctor of pharmacy student at Howard University College of Pharmacy in Washington, DC. This summer, I completed a five-week research rotation with Dr. C. Daniel Mullins and his team within the Pharmaceutical Health Services Research (PHSR) Department. My experience in conducting qualitative and quantitative data analysis, critiquing journal articles that highlight the importance of patient engagement to public health outcomes, and answering patient-centered drug information questions allowed me to actively participate in the PATIENTS program.



My contributions to PATIENTS activities included developing a list of interview questions to help with the production of training videos for patient-centered outcomes research (PCOR) participants and identifying reputable online

videos that effectively summarize PCOR. Another aspect of my work was directed at finding reliable and accessible health information for people in the community. Working with Dr. Ebenezer Oloyede, I identified additional videos that provide information on research participation as well as the prevention, pathophysiology, treatment options, and follow-up care for breast cancer, cervical cancer, and lung cancer patients. Including such videos on the program's website is one step towards a trusting and sustainable relationship with patients and community partners.

I learned that involving patients at every step of the research process makes for better PCOR, which is why the PATIENTS program aims to provide researchers and patients with cultural competency training and other resources needed for successful collaboration. As a future pharmacist, I have more understanding on how important it is to practice patient engagement for better health outcomes. Thank you to Dr. Mullins and his team of researchers, students, and staff at the PHSR Department for an enlightening rotation experience!

Training and Resources

Take Two Brief Courses and Get a Certificate!

Ms. Cynthia Chauhan, MSW, is a cancer survivor and a patient representative serving on our External Advisory Committee. She has advocated on behalf of patients for more than a decade. In this month's issue, Ms. Chauhan shares two resources offered by the National Institute of Health (NIH).



The first resource is a brief [course on financial conflict of interest](#) in cancer research. People can take the course in about ten minutes and get a certificate of completion to print off.

The second resource is another [course on protecting human research participants](#), which takes an hour or less and also has a certificate of completion that can be printed.

Resource Links:

- <http://grants.nih.gov/archive/grants/policy/coi/tutorial/fcoi.htm>
- <http://phrp.nihtraining.com/users/login.php>

Join the CER/PCOR Work Group!

Are you interested in and/or currently working on research projects related to CER or PCOR? Are you looking for opportunities to collaborate or network with other researchers? Then join the [CER/PCOR Work group!](#)

The CER/PCOR Work group, co-chaired by Drs. [Eleanor Perfetto](#), [Linda Simoni-Wastila](#), and [Olivia Carter-Pokras](#), aims to promote interdisciplinary collaboration and a broader understanding of the nature, scope, methods, and implications of comparative effectiveness research and patient-centered outcomes research (CER/PCOR). As a member of this interdisciplinary group, you will have the opportunity to network on research projects and grant proposals, share information, and develop campus-wide strategies on CER/PCOR education, training, and research. In addition, you will also benefit from the diverse group of researchers' experience and expertise. For more information or if you would like to join, please send an email to Sara Higa at sara.higa@umaryland.edu. This group is open to researchers, including faculty, graduate students, and post-docs, across all campuses.

University's First Ever PROEM Center of Excellence

The University of Maryland Baltimore Patient-Centered Research for Outcomes, Effectiveness, and Measurement (PROEM) Center of Excellence in Comparative Effectiveness and Patient-Centered Outcomes Research Education is designed to expand and improve training in CER and PCOR research methods. Established in 2014, the center focuses on patient-centeredness, characterized as patient engagement, as the first step in any CER activity. PROEM is one of 5 centers funded by the PhRMA Foundation to expand graduate and training programs across the nation. The Center uses two approaches to enhance training programs in CER and PCOR research: expansion of the existing MS/PhD degree granting program to include a new CER/PCOR concentration, and interdisciplinary online and in-person continuing education programs, including the first ever CER/PCOR Summer Institute. For more information about PROEM please contact Dr. Eleanor Peretto at eperetto@rx.umaryland.edu.

Activities and Accomplishments

PATIENTS Released Its New Website

By Kaloyan Bikov
Monday, June 16, 2014



On Sunday, June 15, our web development team released the new website of the PATIENTS program ([link](#)). We will start working soon on our next major release. Meanwhile, we will continue making small improvements as we go. Use this [form](#) to give us your feedback and ideas.

Congratulations to Recent PILOT Fund Award Recipients!

By Joe Vandigo
Tuesday, June 24, 2014

The PATIENTS program awarded funds for the following work:

- *Mobile Health for Older Adults with Type 2 Diabetes* by Dr. Charlene Quinn (funds provided by University of Maryland, School of Pharmacy)
- *After Spinal Cord Injury: Empowering Patient Directed Care during Transition from Rehabilitation to Community* by Dr. Paula Geigle and Dr. Peter Gorman (funds provided through AHRQ grant # R24 HS22135-01)

As a reminder - these awards are designed for researchers to meaningfully engage patients and PATIENTS partners prior to beginning research activities. We hope to fund an **additional ten \$5,000 pilot fund awards by October, 24 2014**. The [application](#) has a rolling deadline and notice of award is typically made within eight weeks.

PATIENTS Published Its First Research Article Entitled "Patient-Centeredness in the Design of Clinical Trials"

By Malissa Carroll and Joseph Vandigo
Friday, March 21, 2014

In a new study published in Value in Health, the journal of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR), researchers from the University of Maryland School of Pharmacy and PatientsLikeMe - a patient network that allows people to share and learn from real-world, outcome-based health data - suggest patient participation in clinical

trials could be improved if trials were designed to be more patient-centered. [Link to Press Release](#) [Link to Article](#)

"Many people are reluctant to participate in clinical trials," says [C. Daniel Mullins, PhD](#), professor and chair of the Department of Pharmaceutical Health Services Research (PHSR) at the School of Pharmacy and lead author of the study. "This reluctance can stem from the perceived risks that people associate with participating in these trials, in addition to individuals not seeing any clear benefit to their participation. Oftentimes, the only exception is when a person has a condition for which there is no effective treatment. In this instance, he or she may feel that there is no other option but to participate in a clinical trial."



The study, titled "Patient-Centeredness in the Design of Clinical Trials", argues that, while individuals might initially feel comfortable with their participation in a clinical trial, they often become unsure of their involvement as the trial progresses. This hesitation can result from a number of factors, including participants' mistrust of medical research, perceived risk of harm, or inconvenience associated with the trial's protocol.



"Randomized controlled trials have traditionally been designed with the science in mind," says [Paul Wicks, PhD](#), vice president of innovation at PatientsLikeMe and co-author of the study. "But, as patients become increasingly empowered through digital information, and engaged in managing their own condition, the traditional trial models need to evolve, too."

Mullins and Wicks collaborated with other partners to launch the Patient-Centered Involvement in Evaluating the Effectiveness of Treatments (PATIENTS) program at the School of Pharmacy, which aims to reduce health disparities by leveraging relationships with patient communities and health care systems to ensure that patients, health care providers, and other partners are actively engaged in research. Both researchers are advocates for patient-centered outcomes research (PCOR), which looks at the benefits and harms of a wide range of treatment options to help patients, their families, and health care providers make better decisions about their care.

Although traditional trials typically recruit patients from a specialist environment following a rigorous screening process, Mullins and Wicks suggest three approaches - pragmatic, adaptive, and Bayesian trial designs - that could enhance patient-centeredness within the clinical trial setting if properly implemented.

Unlike traditional trials, pragmatic trials recruit participants from a wide range of clinical settings. They are designed to evaluate the effectiveness of certain treatments in real life situations. Adaptive trials allow researchers to alter certain features of the trial as it progresses as well as evaluate findings in real-time, instead of waiting for the trial to end. The results produced by Bayesian trials are more easily interpreted by patients and their health care providers than results produced by traditional trials.

"The way in which a clinical trial is designed can provide an opportunity to empower patients in the research process," says Mullins. "By applying different aspects of these trial designs to their research, investigators can improve the quality of care and safety for their participants as well as improve trial recruitment and retention."

Wicks adds, "Each of these approaches gives patients a higher chance of maximizing their outcomes and avoiding harms, as well as helps integrate trials into every day practice so that research becomes a part of care."

Though additional research is needed to help determine which trial design works best to actively involve participants in clinical trials, Mullins and Wicks emphasize that trial design is not the only barrier that prevents people from engaging in the research process.

"Making clinical trials more patient-centered extends beyond implementing more pragmatic, Bayesian, and adaptive trials," says Mullins. "Investigators need to involve informed participants and patient advocates in the study design, promote continuous engagement and feedback among participants, and better address the information needs of diverse populations to truly ensure the trial is patient-centered and improve recruitment and retention."

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