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# PATIENTS' Voices

a newsletter from the PATIENTS Program at the  
University of Maryland School of Pharmacy



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## Message from the PATIENTS Program Team

Happy holidays from the PATIENTS team! Even though we're slowing down for the next couple of weeks to relax and spend time with family and friends, there's plenty of work ahead of us. In this issue of PATIENTS Voices, we've included a snapshot of some of the projects we focused on in 2017 and are slated to continue in 2018.

This issue also includes an introduction to a member of the PATIENTS Program Management & Evaluation team, Olayinka (Yinka) Ladeji. Her dedication to our staff, partners, and the community has already had a significant impact on the work that we do. In her spare time, she continues her health advocacy work through writing, and is the author of a book that explores how religion and integrative medicine can be leveraged towards the health of the individual and community.

Lastly, we've highlighted just a few of the community events we had the pleasure of participating in and community groups we've worked with in 2017. Be sure to take a look at those videos and subscribe to the PATIENTS YouTube channel to receive updates on new content as it becomes available.

As always, we welcome your feedback on how to make this newsletter a better resource for you. Feel free to email us at [patients@rx.umaryland.edu](mailto:patients@rx.umaryland.edu) to submit your comments, suggestions, and ideas.

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## Meet the PATIENTS Team

E. Olayinka (Yinka) Ladeji, MPH  
Program Specialist, The PATIENTS Program, University of Maryland,  
School of Pharmacy



Olayinka (Yinka) Ladeji joined The PATIENTS Program in February 2017 as a Program Specialist on the Program Management & Evaluation team. In her role, she works with PATIENTS and its partners to ensure efficient and compliant execution of various projects, along with ensuring the quality and sustainability of the PATIENTS Program.

Before joining the PATIENTS team, Yinka served as a Sr. Business Analyst at the Centers for Disease Control and Prevention, Center for Global Health in Atlanta on the Informatics and Information Resources team. She also worked as a program manager (and later as a consultant) at AOAC INTERNATIONAL, a Maryland-based not-for-profit scientific organization that publishes standardized, chemical analysis methods designed to increase confidence in results of chemical and microbiologic analyses.

In addition to her work as a program manager, Yinka is the author of *Spirituality, Complementary & Alternative Health Practices...and their Promise for Public Health*, published in January 2015. The book explores how religion and integrative medicine can be leveraged towards the health of the individual and community. It's available on Amazon.

[read more](#)



## Year in Review: PATIENTS Project Round-Up

It's been a busy year for The PATIENTS Program and its partners, and we plan to keep the momentum going in the New Year! We're excited to support projects that will help answer real-world, patient-centered questions, and lead to lasting changes for everything from early cancer detection through specialized community engagement, to the best ways to reduce surgical site infections after surgery for broken or fractured bones.

Be sure to visit the PATIENTS YouTube channel for updates on these and other projects run and/or supported by The PATIENTS Program.

### **The 10-Step Project**

Principal Investigator: Daniel C. Mullins, PhD (University of Maryland, Baltimore)

In a PCORI-funded report, "Patient Engagement in Research: A Systematic Review", the authors concluded that "research dedicated to identifying the best methods to achieve engagement is lacking and clearly needed." A subsequent study reiterated that fact stating "the most effective approaches to engagement have not been well defined." Principal investigator, Daniel Mullins, PhD, and the PATIENTS team along with the project's stakeholder advisory board, are conducting a research project, funded by PCORI. In it, they examine different ways of engaging patients at each of the 10 steps of

the research process.

The project, which began in September 2015 and slated to end late 2018, aims to identify evidence-based engagement strategies, emerging methods, and develop methodological guidance for selecting the most appropriate, meaningful, and impactful engagement method for each step of PCOR and the relevant resources required. The project put considerable effort into advancing patient and stakeholder engagement methods that aim to expand rather than duplicate prior work.

[Learn more about the 10-Step Project](#)

### **RadComp: A study at the heart of breast cancer treatment**

Principal Investigator: Justin E. Bekelman, MD (University of Pennsylvania)

Nearly 3 million women are living with breast cancer in the United States and radiotherapy plays a major role in the treatment of this disease. Because of incidental radiation to the heart, radiotherapy carries increased risks of cardiovascular morbidity and mortality; survivors who receive radiotherapy have at least a two-fold increased risk of cardiovascular death. Thus, success of cancer therapy has led to survivorship burden. Patients live longer, but suffer from toxic consequences of treatment.

RadComp (short for Radiotherapy Comparative Effectiveness) is a group of radiotherapy sites that have come together for this new study of radiation therapy for breast cancer. The consortium has engaged a collaborative stakeholder effort to partner with patients to design the studies, and to build support for proton therapy comparative effectiveness research responsive to the information needs of stakeholders, decision makers, and policy makers. To better understand the patient perspective and the outcomes most meaningful to patients, RadComp leveraged the patient engagement expertise at The PATIENTS Program, conducting interviews with more than a dozen patient advisors individually and in small groups. The study aims to answer four key questions:

- Does proton therapy reduce major cardiovascular events compared to photon therapy?
- Is proton therapy not-inferior to photon therapy in reducing breast cancer recurrence?
- Does proton therapy improve patient-reported quality of life compared to photon therapy?
- Based on radiation dose distributions in real-world practice, can we develop predictive models of cardiovascular toxicity and quality of life to help patients make informed radiation treatment decisions?

Visit the [PATIENTS YouTube channel](#) to learn more about the RadComp trial, or visit the study's [website](#) for more details.

### **Project HEAL**

Principal Investigator: Cheryl L. Holt, PhD (University of Maryland, College Park)

The Health through Early Awareness and Learning (HEAL) Project works with community partners, largely in faith-based communities, to increase early detection of breast, prostate, and colorectal screening. With the support of agencies such as the National Cancer Institute and the American Cancer Society, the project team employs a community

based participatory research approach to engage African-American churches and health ministries to educate, empower, and connect people with resources they need to get screened. The PATIENTS Program outreach and community engagement team members worked closely with the project HEAL leadership and stakeholders to train church leadership in health ministry development, including training manuals and other resources. [Visit the Project HEAL website](#) to hear testimonials from program participants and to download resource guides and community health advisor training modules.

## **Learning Health Care Community**

Principal Investigator: Daniel C. Mullins, PhD (University of Maryland, Baltimore)

Minorities comprise more than a third of all Americans and more than half of American children under age five, according to Census figures. However, their prominence in the U.S. population also comes with greater health disparities. In Baltimore, where minorities make up 72 percent of the city, a similar picture exists. Traditionally, poor communication by healthcare providers and lack of trust in the medical system have resulted in negative healthcare experiences in medically underserved communities. In particular, within African-American communities, such experiences are aggravated by years of distrust of medical research.

Supported by a two-year, \$250,000 grant from Merck, the University of Maryland School of Pharmacy is developing a new approach - a Learning Health Care Community, focused on continuous patient engagement and establishing partnerships with churches, organizations, providers, caregivers, healthcare facilities, and other area stakeholders. The project involves community leaders in facilitating patient engagement and collecting information with the community itself from the outset, in an environment centered on comfort and trust.

The framework of the Learning Health Care Community will be developed over 18 months, utilizing the PATIENTS Program's resources, partners, and stakeholders. Team members will collect a full range of community perspectives to guide best practices and incorporate lessons learned from patient engagement. "The community can help us address disparities and create health equity," says the study's principal investigator, C. Daniel Mullins, PhD, professor and chair of the Pharmaceutical Health Services Research Department at the University of Maryland in Baltimore.

Visit the [PATIENTS YouTube channel](#) to hear members of the project's advisory committee describe the goals and benefits of the learning health care community model.

## **The PREPARE Trial**

Principal Investigator: Gerard P. Slobogean, MD, MPH (University of Maryland, Baltimore)

Surgical site infection (SSI) after surgery to mend a broken bone is an avoidable adverse patient-centered outcome with significant patient and healthcare system burden. More than one million Americans suffer an extremity fracture (broken bone in the arm, leg, or pelvis) that requires surgery each year. Approximately 5% (or 50,000) of surgical fracture patients develop an SSI, which is twice the rate among most surgical patients, and nearly five times the rate among patients undergoing elective orthopaedic surgeries (e.g. joint replacement).

In collaboration with The PATIENTS Program and other stakeholders, the PREPARE trial will enroll 8,680 fracture patients to determine the most effective preoperative skin cleansing (antiseptic) solution to reduce the risk of SSI. To ensure a diverse patient population, a systematic process was used to carefully select 10 hospitals from the trial team's network of over 100 trauma centers across the US and Canada to participate in the PREPARE trial.

The PREPARE trial will compare two antiseptic solutions (Iodine- versus CHG-containing antiseptic surgical prep solutions) that are ubiquitously used in US hospitals, inexpensive, and universally considered effective. Since the interventions are similar in appearance, application, and cost, the results of our trial are poised for immediate implementation to reduce SSIs for one million fracture surgery patients a year. This potential for overnight practice changing results reflects our goal to find simple, inexpensive means to reduce SSI. This approach aligns with one of PCORI's strategic goals to "speed the implementation and use of patient-centered outcomes research evidence."

The PREPARE team held its kick-off meeting on November 29th and is slated to run for a five-year period.

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## Partner Spotlight: Westat

Location: Rockville, MD

Website: [www.westat.com](http://www.westat.com)

Facebook: <https://www.facebook.com/westat.hq>

Twitter: @westat



Westat is a full-service research corporation with an established reputation for quality research and a broad range of capabilities in statistical surveys, program evaluation, technical assistance, epidemiologic studies, clinical trials, and information technology.

Drawing on its evaluation expertise and experience in patient-centered research, health IT, and community health, Westat serves on the PATIENTS internal steering committee. They support PATIENTS by guiding the process for collecting, analyzing, and disseminating actionable information, tools, and resources that are useful to researchers and partners.

Westat's Paula Darby Lipman, Ph.D. and Jennifer Huang, along with PATIENTS Program Director C. Daniel Mullins, PhD recently co-authored an article published in *Transactional Behavioral Medicine*, an official journal of the Society of Behavioral Medicine. The article, "Bridging the divide: building infrastructure to support community-academic partnerships and improve capacity to conduct patient-centered outcomes research", focuses on the importance of training and mentoring academic researchers to meaningfully engage community members in patient-centered outcomes research (PCOR). It also emphasizes the need for research institutions to strengthen their underlying infrastructure to support PCOR.

[Read the full article](#) or visit the [PATIENT YouTube channel](#) to learn more about the topics

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## In the Community

### 2017 Community Engagement Highlights

St. Matthew's Community Long-Term Outreach Center sets the example of how the church can play an important role in healthcare. This year, the PATIENTS Program had the pleasure of adding Barbarajean Shaneman, LPN (Miss BJ) to the team as part of the community engagement team. Miss BJ is the executive clinical director of the center that gives hope for the neighborhood. [In a short video about the center](#), Miss BJ and the community members she serves describe the importance of the work that they do at St. Matthews.

Join the PATIENTS team as we participate in one final event for the year, to support Miss BJ as she hosts the center's annual Christmas and New Year celebration. Attendees can enjoy music, Christmas stories, along with gift exchanges and light refreshments. There may even be a visit from Santa!

Date and Time: Saturday, December 23, 2017, 4:00 p.m. - 6:00 pm  
Location: 3003 W. North Ave., Baltimore, MD 21216

For details or questions about the PATIENTS Program's involvement in these events, call 410.706.3839.

#### Video Highlights



**United Way of Central Maryland** helps to eliminate the barriers for families and individuals struggling with homelessness. PATIENTS Program team members volunteered at the organization's sixth annual Project Homeless Connect, which provides a path to stability for attendees. Guests who attend the event can access services from medical exams, legal advice, and even a haircut.

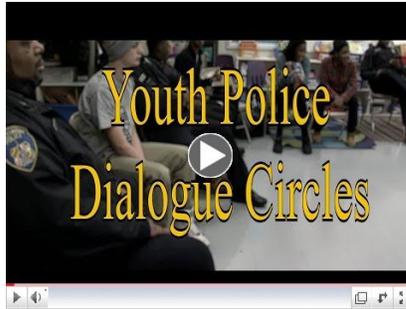
The PATIENTS Program's Tracy Rice and BJ Shaneman were invited to the **Enoch Pratt Free Library's Orleans Street Branch**. They had the opportunity to present at the Harry and Jeanette Weinberg Seniors Program to many seniors in the community. This program has been reaching out to Baltimore's patriarchs for several years, keeping them informed and connected.



The relationship between police officers and youth have been broken in many Baltimore communities. Leaders from the city, police, and school are mending the bond



between law enforcement and youth with the help of community mediation. The PATIENTS Program gives insight to the next step in rebuilding the relationship.



The PATIENTS Program helped the Senior Companion Advisory Council Steering Committee acquire funds from the Patient Centered Outcomes Research Institute. The grant will assist seniors to stay in their homes while managing their diseases. You will hear from city health leaders, stakeholders, and volunteers about the success and needs of the program.



Project Pneuma helps teen-aged boys in Baltimore shed negative behaviors and gain empowering life skills by using exercise, meditation, and group support to develop focus and structure. Damion Cooper the founder of project, and member of The PATIENTS Program's Learning Health Care Community project advisory board, molds these young men into leaders. The PATIENTS Program gives a look inside a life changing program.

## Stay Connected

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## Our Vision

Patients and stakeholders are heard, inspired, and empowered to co-develop patient-centered outcomes research.