

PATIENTS' Voices

a newsletter from

The PATIENTS Program

at the University of Maryland
School of Pharmacy



2019

Message from the PATIENTS Program Team

This has been an amazing year for The PATIENTS Program team! From the launch of the Learning Health Care Community project, to the success of our second-ever PATIENTS Day community health fair, we couldn't be happier with the relationships we've made--and the ones we've had the privilege to deepen--on our journey to bring together individuals, researchers, and healthcare professionals for authentic interactions that lead to more understanding, collaboration, and healthier communities.

We're also excited that PATIENTS supporters can now make a donation to help us realize our vision of ensuring that patients and stakeholders are heard, inspired, and empowered to co-develop patient-centered outcomes research (PCOR). You can [visit the PATIENTS website](#) and click the "Donate" button at the top of the page to make a donation of any amount.

Be sure to take a look at one of our newest videos, ["The Why Behind Medical Research"](#), on the PATIENTS YouTube channel. In the video, researchers, community members, and PATIENTS Program partners [dispel common myths about medical research](#) and explain [why health research is important for people in underserved communities](#).

As always, we welcome your feedback on how to make this newsletter serve you better. Feel free to email us at patients@rx.umaryland.edu to submit your comments, suggestions, and ideas.

Meet the PATIENTS Team

PATIENTS Program's Hillary Edwards Wins October's UMB Employee of the Month

On October 23rd, University of Maryland, Baltimore's (UMB) President Perman stopped by The PATIENTS Program's offices to personally present Hillary Edwards with the UMB Employee of the Month award. Edwards, the program's associate director of program management and evaluation, has worked with PATIENTS for three years and has been at UMB since 2010.



"With leadership and enthusiasm, Hillary has served as a role model for the PATIENTS Program's peers and colleagues, inspiring them to initiate sincere and genuine interactions with the community. The feedback we received from the community about PATIENTS Day demonstrated the positive impact it had," said C. Daniel Mullins, PhD, PATIENTS director, and professor and chair of the school's Department of Pharmaceutical Health Services Research.

[Visit the School of Pharmacy website to read the full article.](#)



Projects and Publications Update

PATIENTS Begins Research Project to Help U.S. Food and Drug Administration Learn How to Better Communicate with Women
Principal Investigator: Daniel C. Mullins, PhD
(University of Maryland, Baltimore)

Researchers for The PATIENTS Program have begun the first phase of a study to learn how the U.S. Food and Drug Administration (FDA) can improve health communications about the products (food, drugs, devices, vaccines) they regulate to women aged 38 and over. The FDA Health Communication Project, "Improving FDA Health Communications with Older Women Regarding FDA Regulated Products", is a collaborative project under the umbrella of University of Maryland Center of Excellence in Regulatory Science and Innovation (M-CERSI) which is funded by the FDA.



In phase one of this project, PATIENTS researchers along with the program's partner organization, [Westat](#), conducted 13 focus groups with 109 women from different age groups. The focus groups were held across the Baltimore-Washington metropolitan area including West and North Baltimore, Towson, Owings Mills, Hyattsville, and Rockville.

Preliminary results identified the participants' health information-seeking behaviors in addition to their perceptions and preferences for FDA health communication materials. In phase two, researchers will incorporate the results of phase one to develop a large-scale survey aimed at learning more about study participants' views on:

- what they consider trusted health information sources,
- their awareness and perceptions of FDA regulated products,
- preferred patient engagement strategies, and
- how they prefer to receive health information about drugs, vaccines, medical devices, and food products.

For more information on the project, email patients@rx.umaryland.edu or call 410.706.3839.

The Learning Health Care Community Study Continues Its Final Phase, Prepares to Share Findings

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

The Learning Health Care Community (LHCC) study, which began with pilot focus groups this past June, has entered its final phase. Having finished the focus groups and interviews in early August, PATIENTS Program researchers completed the final analysis of the data (comments from interviewees) and are now preparing to share (disseminate) study findings with the community and additional stakeholder groups via community gatherings, conferences, and other media.

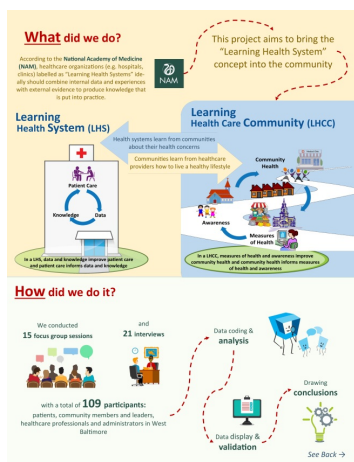
Recap: LHCC Study Milestones

- assembled a Stakeholder Advisory Board to help guide our activities
- co-developed interview guides to use during interviews and focus groups with patients, community members and healthcare providers
- conducted focus groups and interviews



LHCC: Innovating Health Care Through the Community's Voice

As part of the dissemination process, LHCC researchers shared preliminary results with 15% of study participants. The participants' feedback will be incorporated into the final communication materials. One of the first dissemination pieces, an infographic which provides a non-technical summary of the findings, is now available for download. [Click here to download the infographic.](#)



The team will now devote its energies to phase four, the final part of the LHCC study, which is to co-develop and co-implement recommendations. This will include seeking funding to implement some of the findings as well as continued dissemination.

Thank You!

The PATIENTS Program would like to extend a **special thank you** to the LHCC board members, who provided engaged and insightful input throughout the duration of the project. We couldn't have done this without such a dedicated board!

LHCC Project Board Members

Jennifer Baldwin, RN, MPA

Jacqueline (Jackie) Caldwell

Damion J. Cooper, M.Th.

Marcia Cort, MD, MBA, FACEP, FAAEM

Gail Graham

Karen Kippen, MSA

About the Learning Health Care Community Study

Funded by Merck & Co. Inc. Investigator Studies Program, "Co-developing Sustainable Learning Health Care Communities (LHCC) using Community-Based Participatory Research", aims to increase collaboration between patients and health care systems and promote greater health equity across the local area. The Learning Health Care Community model shifts from relying on natural outgrowths of patient interactions with providers and health systems at large, to a deliberate, proactive focus on co-learning practices based on trust and engagement by all community stakeholders.

The RADCOMP Study Provides New Resources to Help Breast Cancer Patients Find the Information They Need

The PATIENTS Program continues to develop blog post content in collaboration with its advocacy partners in order to provide patient resources to RADCOMP study participants.

The following posts were developed in collaboration with PATIENTS advocacy partners:



[Finding Your Online Community](#)

Arin Hanson from LBBC (Living Beyond Breast Cancer) and Carol Baas from YSC (Young Survival Coalition) provide insight on the benefits of online support communities, and highlight notable online support communities to visit.

[What to Consider When Joining an Online Support Community](#)

Arin Hanson from LBBC and Carole Bass from YSC discuss potential privacy concerns of online communities and offer tips to protect private information.

Physical Activities for throughout Radiation Treatment

YSC advocacy partners Stacy Gagas, Mary Ajango, and Carole Baas discuss options for physical activities to participate in while in radiation treatment, as well as physical activities to avoid in order to reduce harm.

For more information about the RADCOMP study, visit the [PATIENTS website](#) or [YouTube channel](#).

The PREP-IT Trial Continues Engaging Study Participants to Determine the Best Approach for Preventing Infection During Surgery

The prevention of infection is the single most important goal influencing peri-operative care of patients with open fractures. Currently, standard practice in the management of open fractures includes two techniques: the sterile technique and pre-operative skin preparation with an antiseptic solution.



PATIENTS Program director,
Daniel C. Mullins, PhD,
addresses attendees

Now in its eight month, the PREP-IT trial, with support from the PATIENTS Program, continues working to learn more about which of the two standard methods for preventing infection during surgery on open fractures.

Recently, the PREP-IT team met with stakeholders to develop a text messaging script and system to contact individuals in the study at different follow-up checkpoints.

In addition, PREP-IT patient advisors, principal investigator, and clinical coordinators were interviewed about their experience being a part of a Patient Centered Outcomes Research (PCOR) trial, and their thoughts on how they defined PCOR. This video will be used to inform others as well as those entering the PREP-IT study about PCOR.



The PREP-IT team also supported the submission of two patient advisor write-ups to [The BMJ](#), an international publishing journal.

For more information, visit the [PREP-IT website](#).

The IGNITE Network and The Patients Program Host a Focus Group to Engage Community Members about the Importance of Genomics in Today's Healthcare Landscape

IGNITE, a National Institutes of Health (NIH) funded network dedicated to supporting the implementation of genomics in healthcare, along with the PATIENTS team, brought together Baltimore community members and IGNITE researchers from across the country

to discuss genomic medicine and healthcare. Topics included an overview of genetics, genomics research, and how to disseminate information properly within minority communities.

During the October 4th event held at the Orleans Street branch of the Enoch Pratt Library, IGNITE members and the PATIENTS team hosted a focus group surrounding these topics and offered an opportunity for community members to provide feedback. Medical professionals and researchers were able to explain genomic medicine and how it can be used to improve an individual's health, as well as dispel some of the myths behind this important medical research.

Watch as researchers and community members discuss genomics and why it matters to individual healthcare issues.



IGNITE Implementing GeNomics
In pracTicE

In this video, Ebony Madden, MS, Ph.D., NIH Program Director, Division of Genomic Medicine, talks to the attendees about NIH's mission and the important of genomic research and testing to improve healthcare for everyone.



National Institute of Health's
Ebony Madden talks Genomics

Visit the [IGNITE website](#) for more information about this network.



Press Play: Featured Video on the PATIENTS YouTube Channel



The Why Behind Health Research

Feature: The Why Behind Medical Research

In this video, researchers, patient advocates, and community members discuss why medical research is important

to healthcare, and what makes The PATIENTS Program a unique and trusted partner in that process.

[Watch the full video](#) or [watch the clip](#) about dispelling myths.

Feature: Patient-Driven Values in Healthcare

Evaluation (PAVE)

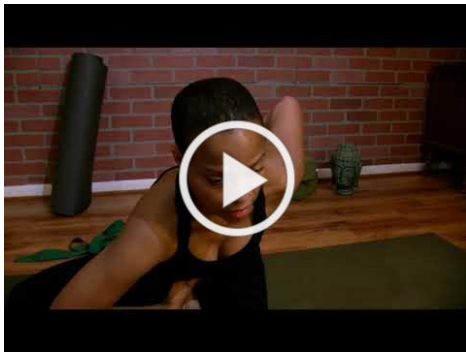
PAVE is a Center of Excellence in Patient-Driven Value assessment that brings a diverse group of clinicians, researchers, and patients to the table in an effort to learn what the elements of value are when considering drug treatments or other health services. In this video, members of PAVE talk about what makes the center unique and valuable to community health. [Watch Now](#)



Patient-Driven Values in Healthcare Evaluation (PAVE)

Feature: Yoga to Improve Digestion and to Open Tight Hips

PATIENTS partner and certified yoga instructor, Jaqueline Williams, shares two short yoga sequences: one to aid with digestion and another to open tight hips (which helps reduce lower back strain.)



Yoga To Improve Digestion



Yoga for Tight Hips

Feature: Chronic Renal Insufficiency Cohort (CRIC) Study at UMB Site Provides Insights on Kidney Disease in African-American Patients



In this video, researchers at the UMB site of the CRIC Study thank participants and share findings on genetic diagnostics and risk factors for kidney disease among African-American patients. [Watch Now](#)



NIH CRIC Study

Stay Connected

View our videos on YouTube

Our Vision

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

