

Project Patient Care Newsletter - July 2019

Project Patient Care: Bringing the voice of the patient, family, and caregiver to improve health and healthcare locally, nationally, and globally.

Greetings!

This has been a very busy July with the Centers for Medicare and Medicaid Services (CMS) addressing many areas of concern raised by consumers, patients, and health advocates. Some of the CMS changes include:

- Chronic Kidney and End Stage Renal Disease
- Cost and Quality Transparency
- Release of a List on All Nursing Home Special Focus Facilities
- Several CMS Technical Expert Panels Seeking Patients and Consumers

As we look to address many man-made challenges and some with differing solutions, let us not forget that we recently celebrated the 50th Anniversary of having a person on the moon – which was and still is such an audacious challenge! Somehow the saying of ‘where there’s a will, there’s a way’ should be remembered as we tackle some of these health care issues which are challenges, not barriers, to improving healthcare and health for all.

There is a saying, ‘where there is a will, there is a way.’ Hopefully we can muster the will and implement the dramatic changes to CKD and ESRD services and support; make available the cost of care information to the public; share meaningful quality and safety information for consumer and patient decision-making; undertake interventions to address Antimicrobial Resistance; and continue to engage patients from co-creation through co-evaluation in healthcare developments.

We believe that everyone has a story and we will continue to highlight the Champion Change Agents in our newsletters and podcasts. The Champion Change Agents are making a difference in the lives of so many people through their selfless service and are changing how we define healthcare and health.

In this edition, we will share innovative approaches to giving voice to those that have witnessed violence or have been victims of violence. The survivors of violence are seeking a more peaceful life and community and many are sharing their experiences through artistic expression. Their artistic expression is connecting people and communities within cities by creating a space for understanding and having ‘crucial conversations.’

"We choose to go to the moon in this decade and do the other things. Not because they are easy, but because they are hard." *Past President John F. Kennedy*

"It's not that I'm so smart, it's just that I stay with problems longer." *Albert Einstein*

**CHAMPION CHANGE
AGENTS**

Our July 2019 Champion
Change Agents are TehRay
'Phenom' Hale, Sr. and Marcus



TEHRAY "PHENOM" HALE, SR.
Emcee Skool, L.Y.R.I.C., POETREE



MARCUS ROBINSON, Ph.D.
Collaboration

Champion Change Agents
July 2019

Robinson, Ph.D.. Both Phenom and Marcus are having a positive impact on youth and young adults as they spread peacebuilding initiatives and skills throughout Chicago with a focus on the communities that have experienced the highest incidence of violence now and in the past.

Teh Ray 'Phenom' Hale, Sr. has dedicated his life to bringing

peace building and restorative justice programs to youth through his artistic talent. As a well known and celebrated hip-hop artist, Phenom has performed across the US and abroad. Phenom started POETREE and also L.Y.R.I.C (Let Your Rhymes Inspire Creativity). The L.Y.R.I.C. program serves Chicago-based high school students and offers them opportunity to write and perform poetry as a non-violent means to stopping the violence in their neighborhoods. As a main member of HIP-HOP DETOXX, PHENOM has also hosted major events such as Ritual Sundays, Neo Soul Explosion, and Lyricist Loft, and while doing so this incredible artist has mentored over 6500 plus youth throughout the US. His goal is to inspire change in the urban neighborhoods of Chicago and abroad.

Phenom started the EmceeSkool with a vision to develop young artists in to community organizers and youth ambassadors for peace and as a mission to provide self-motivated artists with the proper tools and training to deliver highly impactful projects that can be used as peace making and humanity building strategies worldwide. The objective of *EmceeSkool* is to 'develop a social-creative-arts initiative designed to strengthen young teaching artists in the fundamentals of becoming a sustainable and impactful asset to their community and family via organizing through the arts. This will serve as a restorative justice and violence prevention strategy.'

Marcus Robinson, Ph.D., is the Managing Director of Collaboration, a theater arts program with a vision "to incite empathy, thought, dialogue and action through original devised theatre and live experiences made in collaboration with our audience and cultivating measurable change in attitude and behavior." Collaboration has a goal to increase their impact around Chicago's most critical social issues, including racism and violence.

Marcus has lead organizations in several communities and is a transformational leader of non-profit management, talent development, corporate culture, and diversity with inclusion. His extensive education compliments his years of experience as president and CEO of multiple corporations, including the Consortium of Community Development, Citizens for Progressive Change, Inc. and wetWare Inc. He also was founder and principal consultant of his own firm, Social Innovation Group, which worked with clients to create inclusive cultures that drive sustainable high performance.

Marcus has served as a hospital board member in Michigan and currently serves on a Patient and Family Advisory Council (PFAC) of a Chicago safety-net hospital in Englewood. Marcus has a passion for helping families and youth living in low resource communities, and he firmly believes that with Collaboration by his side, sustainable change is possible.'

Editor's Note: Every community has opportunities for anyone to get involved and to share their talent to help create peaceful communities. Many communities have programs to help youth and young adults exposed to violence to heal and help them move forward while at the same time educating communities about the harm of ongoing violence. Pat has partnered with Phenom on L.Y.R.I.C. and EmceeSkool programs and serves as a board member of Collaboration.

You can learn more about Teh Ray 'Phenom' Hale, Sr. and Marcus Robinson on the importance of peacebuilding through youth and young adult arts by listening to their upcoming podcast to be available August 15 on the [PPC Web Site](#).

CHRONIC KIDNEY AND END STAGE RENAL DISEASE

On July 10, Department of Health and Human Services Secretary Alex Azar announced a series of sweeping proposals to transform Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD).

The changes include:

- Early Detection of CKD with additional attention to patients with diabetes or hypertension
- Interventions early on to try and delay CKD patients advancing to Stage 5 CKD
- Support to dramatically increase dialysis at home
- Increasing live kidney transplants through proactive outreach and measurable results along with supportive services for the live donors
- Addressing the cost of post transplant medications
- Payment models to drive improvements in detection, management, and health outcomes

The National Kidney Foundation (NKF) estimates that 30,000,000 people in the U.S. have chronic kidney disease and most do not know they have CKD. Often times referred to as a silent disease, CKD symptoms do not appear until Stage 3. There are tests that can detect CKD in every person; however, very few patients understand or receive the results.

In addition to the challenges of being on dialysis, it is also a costly disease with approximately 7% to 8% of the Medicare budget going for treatment of patients with CKD. The National Kidney Foundation estimates that 726,000 people have irreversible kidney failure or ESRD. Of the 726,000 patients, over 100,000 ESRD patients are on the kidney transplant list awaiting a kidney donation.

President Trump signed an [Executive Order](#) directing federal agencies to educate and treat people with early forms of kidney disease, to make kidney transplants easier to get, and to shift the financial incentives for clinics and doctors away from the existing system that relies heavily on dialysis.

At the announcement in Washington, D.C. on July 10, two of the PPC Champion Change Agents from March 2019, Mary Baliker and Bobbie Reed, were at the meeting with Secretary Azar. Our third Champion of Change Agent, Precious McCowan was not able to attend as she was recovering from her recent kidney transplant.

To learn about the prevalence of CKD and ESRD, go to [PPC March Newsletter](#) To hear the background and stories of these three remarkable patient and family advocates for CKD and ESRD, go to [PPC March Podcast](#)



MARY BALIKER
National Kidney Foundation Advocate
LIVE LAUGH LOVE



PRECIOUS McCOWAN
BS, MS, ESRD Network of Texas



BOBBIE REED
National Kidney Foundation Advocate

Champion Change Agents

Proposed rules on hospital cost transparency were recently released in response to the [June 24 Executive Order on Improving Price and Quality Transparency in American Healthcare to Put Patients First](#).

Cost. The proposed cost transparency rules were embedded in the [Hospital Outpatient Prospective Payment System Proposed Rule](#) with comments due to CMS by September 27, 2019. The proposed cost transparency rule includes:

Hospitals would need to make public their standard charges – both 'gross charges' such as those in a chargemaster, and 'payer-negotiated rates' – in two ways:

1. A comprehensive, machine-readable file that makes public all standard charge information for all hospital items and services, and
2. A consumer-friendly display of common “shoppable” services derived from the machine-readable file. CMS is requiring that these charges be made public and updated at least once annually.

CMS seeks comment on technologies or standards that could facilitate public access to real-time updates to make this information readily available to consumers by applications – such as through an open Application Programming Interface (API).

Quality. Within the June 24 Executive Order there were several directives on quality, including:

- Streamlining the numerous different measurements the federal government uses to track healthcare quality
- Reviewing a number of HHS quality programs that were initially developed nearly 20 years ago to strengthen organizational capacity to improve outcomes for beneficiaries. These quality programs administered by the Centers for Medicare & Medicaid Services (CMS), Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control (CDC), Health Resources and Services Administration (HRSA) and Indian Health Service (IHS), have not undergone a systematic objective review to ensure they are serving their stated purpose of improving processes and enhancing communication to improve beneficiary outcomes.

Additionally, a Quality Summit is being organized that will bring together key industry stakeholders and government leaders to discuss how current quality programs administered by HHS can be further evaluated, adapted, and streamlined to deliver better outcomes for American patients. The Quality Summit will be chaired by Deputy Secretary Eric Hargan and Peter Pronovost, M.D., Ph.D., a renowned international expert on healthcare quality and patient safety.

Project Patient Care has been writing about the critical importance of health care costs to consumers including hospital, ambulatory, and surprise bills. The [February 2019 PPC Newsletter](#) had a deeper dive into the cost issues.

NURSING HOME SPECIAL FOCUS FACILITIES

As the result of some Senate inquiries into a 'non-public list', another 400 special focus facilities were identified in addition to the current public list of approximately 88 special focus facilities. To view the entire list of Nursing Home Special Focus Facilities - click [Here](#)

According to CMS, Nursing Home Special Focus Facilities have:

- More problems than other nursing homes (about twice the average number of deficiencies),
- More serious problems than most other nursing homes (including harm or injury experienced by residents), and
- A pattern of serious problems that has persisted over a long period of time (as measured over the three years before the date the nursing home was first put on the SFF list).

Per CMS, "Although such nursing homes may periodically institute enough improvements to correct problems identified on one inspection, significant problems would often re-surface by the time of the next inspection. Such facilities with a “yo-yo” or “in and out” compliance history rarely address underlying systemic problems that give rise to repeated cycles of serious deficiencies, which pose risks to residents’ health and safety. To address this problem CMS created the “Special Focus Facility” (SFF) program."

Several Opportunities for Patients, Families, Caregivers and Consumers to be Involved

PPC often hears about opportunities for patients, families, and caregivers to get involved in research, measurement development, or sharing their story. We would like to make you aware of these opportunities as they become available.

CMS Technical Expert Panel. CMS has several Technical Expert Panels (TEPs) they are recruiting for and are interested in having patient, family, or caregiver participants on the TEPs. The TEPs and the self-nomination deadlines are listed below:

- Patient Safety Measure Development and Maintenance - Deadline September 4, 2019
- Focus Group for Hospice Patient Assessment Instrument - Deadline August 26, 2019
- Behavioral Health Measures: Development, Reevaluation, & Maintenance - September 27, 2019
- Hospital Quality Star Ratings on Hospital Compare - Deadline August 19, 2019

To find out more about the CMS TEPs and how to apply to be a patient representative, Click [Here](#)

Sharing the Value of Patient and Family Engagement in Current, Emerging, and Innovative Programs



Insightful and energetic discussion at American Association of Colleges of Pharmacy focused on patient centered care through patient engagement. Discussions on patient and pharmacist partnerships included co-production models (co-design through co-evaluation); bi-directional teach back for improved listening and understanding by both pharmacists and patients; design models to increase patient engagement; open notes; highlighting of initiatives that engage patients as partners in governing bodies and patient and family advisory roles; the Pharmacists' Patient Care Process model; and the research and innovative approaches on the horizon. Special thanks and appreciation to Lourdes Planas, Moderator and panelists University of Oklahoma; Jamie Barner, University of Texas at Austin; Jon Schommer, University of Minnesota; Anandi Law, Western University of Health Sciences, and Pat Merryweather-Arges, PPC.



Lively and informative interactive discussion at MATTER in Chicago as we engaged in discussions on patient empowerment and the technological and innovative tools empowered patients, families, and caregivers may want - some of which were co-created by patients. Panel discussion was on "The Convergence of Patient, Technology & Innovation" moderated by Stephen Lieber, CAE, Executive Advisor at NextWave Connect; with panelists - Patrick Flavin, President of ARCHES; Andy Shin, JD, MPH, Chief Operating Officer at American Hospital Association, and Pat Merryweather, PPC. The Association Forum is the 'Association of Associations' with over 4,000 members - Chicago is the second largest home to associations outside of Washington, D.C. MATTER is a healthcare startup incubator, community nexus and corporate innovation

accelerator - mobilizing a community of entrepreneurs, industry innovators, scientists and clinicians committed to improving health and care for every patient.

PROJECT PATIENT CARE PODCASTS

Project Patient Care Podcasts are publicly available to you and everyone you wish to share them with.....We feature monthly podcasts with our Champion Change Agents that are available by clicking [here](#).

Featured Podcasts include:

- Sue Sheridan - *Driving Change Through the Patient Story and 'What Ifs'* - June 2019
- Beth Daley Ullem - *Advancing Quality Improvement and Safety through Improved Performance of Governing Boards* - May 2019
- Project Achieve - *Driving Quality Improvement and Health Outcomes Through Improvements in Care Transition* - April 2019

A series of 3 Podcasts:

- *Part 1 - Care Transitions: Project Achieve's Research and Findings* featuring Suzanne Mitchell, M.D., M.S. and Terry Davis, Ph.D. and Patient
- *Part 2 - Project Achieve Care Transitions: Importance of Strong and Effective Partnerships* featuring Jane Brock, M.D., M.S.P.H.; Paul Cantrell, Area Agency on Aging Consultant; and Christine Larocca, M.D.
- *Part 3 - Project Achieve's Findings from Surveys of Patients, Families, and Caregivers* featuring Carol Levine, Caregiver Advocate; Kathy Rust, Caregiver; and Joann Sorra, Ph.D.
- Mary Baliker, Precious McCowan, M.S., and Boobie Reed - *Chronic Kidney, End Stage Renal, and Transplant Advocates - Driving Changes in Chronic Kidney Disease and End Stage Renal Disease*

We know you will be inspired by these featured podcast programs and learn from the stories and experiences the presenters share - www.projectpatientcare.org



We Love to Hear From You!

We are always happy to hear from you - please feel free to contact us at any time.

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Thank you