

**PROJECT
PATIENT
CARE**·ORG

USING THE VOICE OF THE PATIENT TO IMPROVE CARE IN CHICAGO AND BEYOND



Project Patient Care Newsletter - October 2019

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

November is a time when people reflect and give thanks for all they have – family, friends, good health, and joy in living and helping others.

It is also a time when we give thanks and appreciation to those that have served us and our country, our veterans. There are many opportunities within our communities to give back and get involved in serving our veterans through local VA and veteran organizations. As a mother and daughter of veterans, I have found opportunities to give back through local VA and veteran Stand Down Days and serving on VA Community Partner Committees. If you are unsure of how to get involved and want to volunteer your time, go to <https://www.volunteer.va.gov/>

During this past week, we have seen several studies that have challenged our way of thinking about research and the impact of their findings --- both good and bad. In this newsletter, we will explore:

- Recent Studies Causing Us to Pause and Think
 - Measures Do Matter– Types of Measures for Quality and Performance Improvement
 - New Updates on Hospital and Nursing Home Compare
 - Still wondering about how to help local veterans? Some more ideas...
 - Technical Expert Panels in Need of Patients, Families, and Caregivers
 - Updates to Project Patient Care Web Site and New Podcasts
 - PPC Receives Local Award

Recent Studies Causing Us to Pause and Think

During this past week, both quantitative and qualitative studies have caused us to pause and think about the unintended consequences of the studies - which can be positive or negative. There are three studies that demonstrate the value and importance of assessing methodologies, statistical analysis, and potential unintended consequences.

Methodology and 'expected outcomes.' Researchers at the University of California, Berkeley, the University of Chicago Booth School of Business and Partners HealthCare in Boston found that a commonly used algorithm used by a healthcare management company and health plan in working with hospitals had flaws. The published study, "Dissecting racial bias in an algorithm used to manage the health of populations," by Ziad Obermeyer, Brian Powers, Christine Vogeli, Sendhill Mullainathan SCIENCE25 OCT 2019 : 447-453 has raised many questions on racial disparities and the importance of transparent methodology.

The flaws in the algorithm were based upon a biased set of data and assumptions that predicted which patients will benefit from extra medical care and significantly underestimated the health needs of the sickest black patients, leading to continuous racial disparities in healthcare. The full study can be viewed in the Science journal by clicking [here](#) As noted by the Kaiser Foundation, news of the **flawed algorithm spread quickly** and now the issue remains, how will this be quickly addressed.

The findings of the flawed algorithm raise issues for all of us on how we continuously assessing biases in methodology; usage and validity of proxy measures; and the use of expected performance. One of the most 'aha moments' that patients working on research studies find is that expected is not what they expectedmeaning they equate expected based upon best performance and not based upon average. So when we use expected performance it is for all intended purposes the average performance (with some minor statistical variation). This then leads to a discussion with patients on performance goals rather than expected performance and how PDSA (Plan-Do-Study-Act) utilizes AIMs and goals for performance improvement.

Reacting to Data without a Plan for Improvement. There have been many studies that showed an increase in fatal and harmful falls among the elderly. In 2016, 25,189 people 75 years and older died from falls, compared with 8,613 in 2000. The rate of fatal falls for adults 75 and older more than doubled during this period, from 51.6 per 100,000 people in 2000 to 122.2 per 100,000 people in 2016. **The report found** an increase in falls between 2000 and 2016 as noted by the authors in the JAMA Study - Hartholt KA, Lee R, Burns ER, van Beeck EF. Mortality From Falls Among US Adults Aged 75 Years or Older, 2000-2016. JAMA. 2019;321(21):2131–2133. doi:10.1001/jama.2019.4185

Melissa Bailey of the Kaiser Health News [recently reported](#) on the challenges patients and hospitals face in working to prevent falls among the elderly while at the same time helping patients to maintain their mobility. It is an interesting discussion on some findings that suggest the fear of a patient falling has resulted in less falls in hospitals, but not necessarily improved health and outcomes.

As a result of the findings on reducing falls and need to maintain and improve the mobility of elderly people, some hospitals are undertaking small tests of changes on approaches and interventions to do both - reduce falls and maintain and increase the mobility of elderly patients.

Unintended Findings. Recently researchers at Johns Hopkins Bloomberg School of Public Health have found that patients being treated by fraud and abuse providers had a risk-adjusted mortality 13% to 23% higher, and rates of emergency hospitalization in 2013 were 11% to 30% higher than found in providers not associated with fraud and abuse.

While often times fraud is detected on financial issues through claims analysis; whistleblowers; and other means, this study was able to also associate fraud and abuse with harmful health and outcomes to patients, The full study can be found by clicking [Here](#) Nicholas LH, Hanson C, Segal JB, Eisenberg MD. Association Between Treatment by Fraud and Abuse Perpetrators and Health Outcomes Among Medicare Beneficiaries. JAMA

Measures Do Matter—Types of Measures for Quality and Performance Improvement

Taking a methodical approach to the development, usage, and analysis of measures, is key to improving health and health outcomes. Patients have found that by explaining the reasoning behind different types of measures helps them, as patients, to better understand the value and intention of measures. As patients are increasingly involved in research studies and technical expert panels, the patients want to better understand measures so they can be effective contributors.

When undertaking a PDSA improvement initiative, one sets an aim or goal to achieve an improved outcome. As one sets a goal, the work on developing a measure to assess the effectiveness of an intervention begins. Rather than use just one type of measure, there are often times several measures involved in health and healthcare improvement initiatives, including:

- Structural - health care provider's capacity, systems, and processes to provide high-quality care including staffing
- Process - the interventions undertaken to maintain or improve health and healthcare
- Outcome - the impact of the health care service or intervention on the health status of patients, including patient reported health outcomes
- Balance - Assessing changes designed to improve one part of the system causing new problems or other improvements
- Proxy - An indirect measure of the desired outcome that is strongly correlated to the outcome; commonly used when direct measures of the outcome are unobservable or unavailable.
- Satisfaction and Experience - The satisfaction and experience of the intended audience for improvement needs to be assessed along with the providers of the improvement to determine their satisfaction and identify any unintended consequences
- Cost of Care - most difficult to obtain but is starting to become available through hospital charge masters on hospital web sites; state agencies; and health plans

New Updates on Hospital and Nursing Home Compare

There have been many recent changes on the Centers for Medicare and Medicaid Services **Hospital Compare** and **Nursing Home Compare**. These changes include process, outcomes, structural, and satisfaction measures.

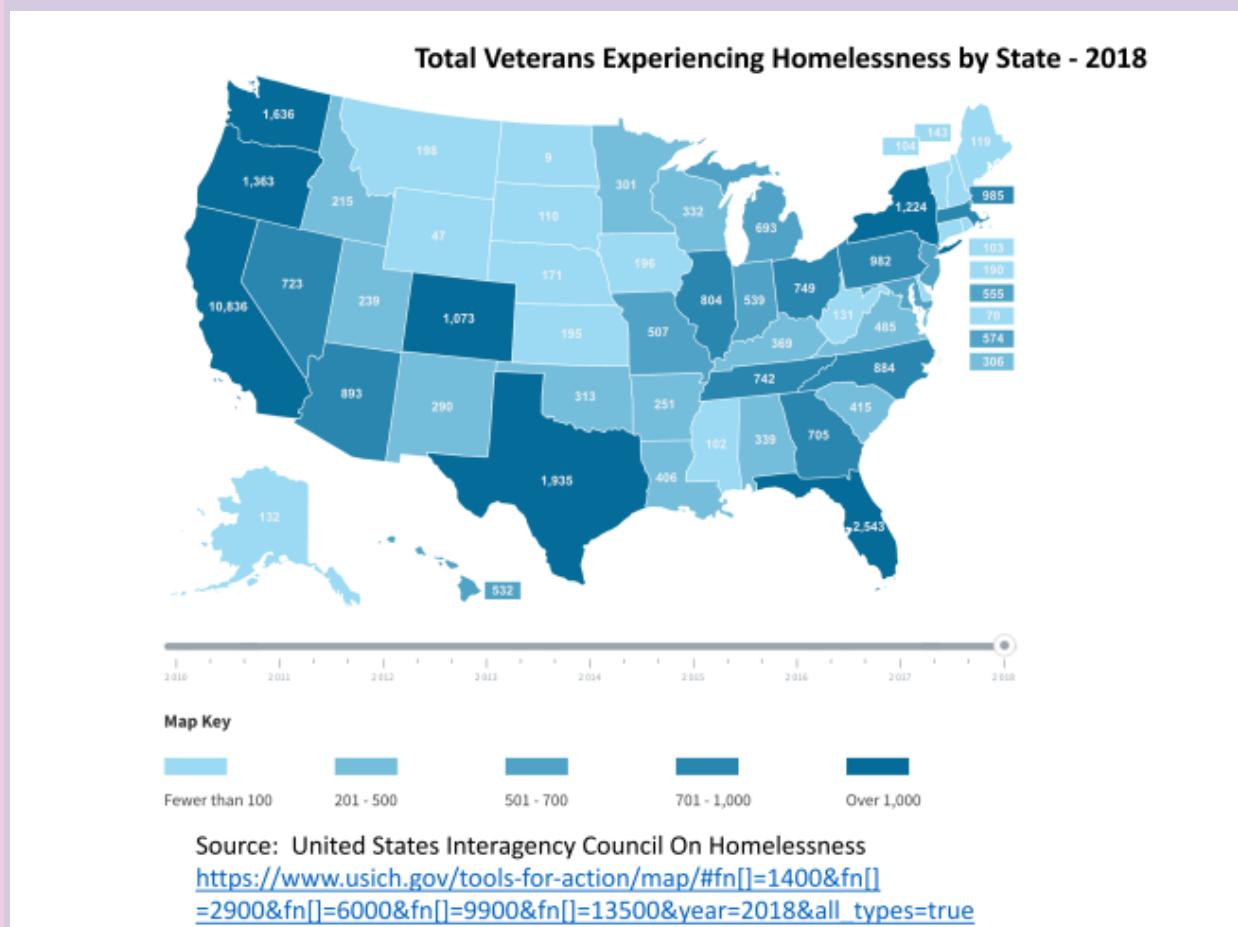
Hospital Compare new information includes:

- More hospital provider types including - Veteran Hospitals, PPS Exempt Cancer Hospitals, ambulatory surgical information from Hospital Outpatient Surgical Services and Ambulatory Surgical Centers
- Process, outcome, and satisfaction information from inpatient psychiatric hospital and inpatient psychiatric unit services
- Hospital payment measures for common types of clinical episodes including heart attack, heart failure, pneumonia, and hip/knee replacement

Nursing Home Compare new information includes:

- Alerts to consumers about abuse. Nursing homes that have been cited for potential issues related to abuse have a **red circle with a hand** in the circle that is next to the nursing home name to signify to the consumer that they should be alerted to the nursing home.
- Special Focus Facilities (SFF) are flagged for nursing homes. SFF program is for nursing homes that have a history of poor performance and care and may need increased oversight and enforcement. They are flagged with a yellow triangle and exclamation point in the center of the triangle.

**Still wondering about how to help local veterans?
Some more ideas...**



There are many opportunities to get involved in thanking our veterans by giving of your time and talents. As most states and urban settings have a Veterans Administration service office nearby, it is a good place to start as well as with local veteran organizations. The local VA hospitals are always in need of volunteers with locations throughout the United States by clicking [Here](#) If you would prefer volunteering in other settings, click [Here](#)

All of us can provide help to a veteran or someone experiencing PTSD by recognizing the symptoms and being aware of available resources. It has been estimated that 30% of all Vietnam veterans have experienced PTSD at some time and 10% of all Gulf War veterans and 11%-20% of all Iraq and Afghanistan War veterans have experienced PTSD.

Additional PTSD information for veterans and non-veterans is available by clicking [Here](#)

WHAT IS PTSD?

Posttraumatic stress disorder, or PTSD, is a mental health concern that some people develop after they see or experience a traumatic event.



7 to 8%

of the U.S. population will have PTSD at some point in their lives.



Reliving or re-experiencing the event

- Nightmares
- Flashbacks
- Triggers



Hyperarousal or being on guard

- Being jittery or overly alert
- Difficulty sleeping or concentrating
- Feeling angry or irritable



What it's like to have PTSD may be different for everyone. There are four types of PTSD symptoms.



Avoidance

- Avoiding crowds
- Avoiding certain smells, sights, or sounds
- Avoiding talking or thinking about the event



Negative changes in beliefs and feelings

- Losing interest in things you used to enjoy
- Feeling guilty or ashamed
- Unable to trust others

Do you have PTSD Symptoms?

- Hear Veterans share their experiences with PTSD and PTSD treatment at [AboutFace](#)
- Learn about and compare effective treatment options using the [PTSD Treatment Decision Aid](#)
- Explore the National Center for PTSD website for information, videos, and tools to help manage PTSD: www.ptsd.va.gov



U.S. Department of Veterans Affairs

CMS Technical Expert Panels In Need of Patients Deadlines Approaching

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. Please note these TEPs have specific patient, family, caregiver needs.

The TEPs and the self-nomination deadlines are listed below:

- 2020 Merit-based Incentive Payment System (MIPS) Improvement Activities Validation Criteria Technical Expert Panel - Deadline November 29, 2019. CMS is specifically seeking Consumer, Patient, Family (Non-Medical) Nominees
- Patient Safety Measure Development and Maintenance: Sepsis Outcome Measure - Deadline is November 9, 2019. CMS is specifically seeking patients and caregivers of patients that have had sepsis within a hospital setting.

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

Updates to Project Patient Care Web Site and New Podcast

At the beginning of November, you will see a new Project Patient Care web site. Web site address will remain the same - www.projectpatientcare.org



Coming soon with our new web site - Our Champion Change Agents - TehRay 'Phenom' Hale, Sr. and Marcus Robinson, Ph.D. 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.



Project Patient Care recently received the Best of Chicago Non-Profit Organization in 2019. Each year, the Chicago Award program identifies companies that they believe have achieved exceptional success in their local community and business category. These are local companies that enhance the positive image of small business through service to their customers and the Chicago community. These exceptional companies help make the Chicago area a great place to live, work and play.



Pat Merryweather-Arges joined with fellow Collaboration Board Member, Darlene Jackson, to co-chair the Collaboration Utopian Ball with a focus on raising funds for youth theatre empowerment programs. Darlene Jackson is the Creative Community Liaison for Columbia College and is known as the "Chicago's House Music Queen."



We Love to Hear From You!

Various sources of information were gathered and analyzed to choose the winners in each category. The 2019 Chicago Award Program focuses on quality, not quantity. Winners are determined based on the information gathered both internally by the Chicago Award program and data provided by third parties.

We are always happy to hear from you - please feel free to contact us at any time.
Contact us at:
Telephone: 312-445-6477
E-mail: Pat Merryweather-Arges
pmerryweather@projectpatientcare.org

Thank you