

## Give a Gift that Keeps on Giving



The man who stood up to speak offered a dynamic and effective argument as to why the assembly should vote for him. As I watched from the audience, I thought about what he wasn't sharing. He didn't talk about how he had faced a childhood of debilitating kidney disease. How he spent years in and out of the hospital, plagued by pain and fatigue, watching his seven siblings live healthy lives. How finally, as he approached adulthood his Mom had saved his life by giving him one of her kidneys. I know this because his Mom is a friend and fellow patient advocate.

In this season of giving, I often think of the many friends I have who are my friends because they were here. "Here" meaning still alive due to the incredible gift of organ donation. Chrissie Blackburn's daughter, Lily, just celebrated one year with a new kidney. Patricia Pooley's donated kidney is hanging in there after thirty years. My friend Russ never thought when his brother married his sister-in-law that one day, she would save his life with a kidney donation.

I found that, "Transplantation restores not only organ function but also quality of life. For children, transplantation also leads to improvement in development, growth, education and mental health in the recipient and in quality of life for the carer."<sup>1</sup>

Many advances have been made in the field of organ donation quality and safety. Just keeping the organ to be donated at the appropriate temperature during transport is very important. "Cold ischemia time is an important modifiable risk factor for poor transplant outcomes, and it is imperative that transplantation logistics are constantly reviewed and improved to keep cold ischemia time as short as possible."<sup>2</sup>

Unfortunately, transplant is another area where health inequity results in uneven outcomes for those waiting for transplant – and most likely for potential donors. "Disparities in access to transplantation among under-represented communities can also arise from a (perception of) lower awareness of donation and transplantation processes, religious or cultural distrust of local medical professionals, fear of racism, linguistic obstacles, a lack of awareness of service availability, financial constraints, and a lack of perception of mainly asymptomatic chronic illnesses, such as kidney failure."<sup>3</sup>

Also, unfortunately the number of transplants that happened during the COVID-19 pandemic significantly declined. While rates are beginning to rebound, the drop in 2020 has resulted in an increase in the number of persons awaiting the gift of a new kidney, liver, heart or lung or other tissue. Even blood donation levels have dropped. In some cases, post-COVID patients in need of lung transplantation have moved ahead on the transplant list of others who need a new lung.

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I reached out to our colleague, Donna Cryer, JD, at the Global Liver Institute, who shared the following about the state of transplant medicine:

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*As a transplant recipient, patient advocate, and as the leader of the only global liver health organization I speak with patients and families needing a transplant, researchers, and heads of transplant centers every day. More than 1100 people die every year on the waiting list for a liver transplant in the United States. We are only starting to be able to accurately estimate how many people die without ever making it to the waiting list, why patients of color are more likely to die even in the hospital while waiting, and how many families are deprived of the opportunity to donate because of stacked inequities in access to health insurance, primary care, and specialists; discrimination and bias in candidate evaluation and willingness to donate. Equity matters, ethically, scientifically and by law. People of color are 1.5 - 4 times more likely to have conditions leading to kidney and liver failure but less likely to receive transplants. Changes in liver allocation policy can only shift who dies and when. Only bold changes such as creating an Office of Organ Policy at HHS, ensuring organ procurement organization performance through transparent, verifiable standards, and continuing to research and resolve center-level disparities in listing, transplantation, and outcomes will make an equitable liver transplant system.*

*Donna Cryer, JD, President and CEO, Global Liver Institute.*

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Whether a living, deceased, or chain donor, an organ represents the gift of not just life, but often quality of life. The impact of your or your loved one's donation can mean more holidays together and more memories made for the recipient and their family. I'm including a few links for you and potential donors you may have around you.

To sign up in the United States, check out <https://www.organdonor.gov/sign-up>. Note, that while generic organ donor forms may be found on the internet, each state in the USA has different requirements for declaring your intent to donate. By clicking the link above, you will be directed to your state specific information.

For our members in the United Kingdom, click on <https://www.organdonation.nhs.uk> and find information about registering to donate and information about organ transplant from the NHS.

The variance in donation and transplant regulation by location can be confusing and represents a potential barrier to matching recipients and donors. Be sure to find out what regulations and laws are in effect in your area.

Let's get organ donation back on track. Consider a donor registration drive in your community. Evaluate how your transplant programs can improve your community's equitable treatment of donors and recipients. What can you do to facilitate gift giving during this holiday season?

Happy Holidays! -Lisa Morrise

1, 2 & 3: National Review Nephrology. 2021 May 5: 1–15.

doi: [10.1038/s41581-021-00425-3](https://doi.org/10.1038/s41581-021-00425-3) [Epub ahead of print]

PMCID: PMC8097678

PMID: [33953367](https://pubmed.ncbi.nlm.nih.gov/33953367/)

Resources shared by Donna Cryer:

<https://www.news-medical.net/news/20210111/Study-highlights-racial-disparities-in-liver-transplantation-listing.aspx>

<https://www.dayoneproject.org/post/addressingorgandonorcrisis>

<https://oversight.house.gov/legislation/hearings/the-urgent-need-to-reform-the-organ-transplantation-system-to-secure-more>

**Consumers Advancing Patient Safety is a 501c3 not-for-profit organization that envisions a partnership between consumers and providers to create global healthcare systems that are safe, compassionate, and just. CAPS champions patient safety led by consumers in partnership and collaboration with providers.** To support CAPS's work, please consider donating through your VENMO account to @CAPS-PatientSafety. If you prefer to use PayPal, our account is under Consumers Advancing Patient Safety or go to [www.paypal.me/patientsafety](https://www.paypal.me/patientsafety).

## CAPS Consumer Advisory Panel Profile



**Sarah Sampsel, MPH**, is a self-employed healthcare quality and public health consultant. Through a variety of professional engagements, Sarah works with clients to identify needs for translation into the development and implementation of a sound, comprehensive quality strategy. Sarah leads and manages a variety of health quality related projects, providing insight and subject matter expertise on quality measurement, health policy, and strategic initiatives. Sarah has a wide range of interests in improving quality and is currently engaged in projects exploring strategies to improve the kidney transplant system, disseminating learnings on Long-COVID, in addition to projects focusing on quality improvement in obesity, diabetes management, telehealth, sickle cell disease, hypertension and osteoporosis.

Sarah has over 20 years' experience in a variety of health care settings, including health care delivery systems and health insurance plans (CO-OP, Exchange, Medicare Advantage, Medicaid and Commercial, Behavioral Health). She has extensive knowledge of quality measurement, accreditation, compliance, and stakeholder engagement through her past professional roles including consulting firms, the National Quality Forum, and the National Committee for Quality Assurance (NCQA). She enjoys Hot Air Balloon Festivals, her two rescue dogs and her rescue Meercat.

### CAPS: When did you start your advocacy?

**Sarah:** I've had a long-standing interest in patient advocacy, dating back to helping my grandparents understand their Medicare explanation of benefits. But then, eleven years ago, I was working in the healthcare industry where my job was to track performance on quality measures and certain health indices. Over a nine month period, I was traveling a lot and often with a colleague who became pregnant during this time. This was someone I respected as a single, professional woman who had a dream of wanting to be a mom. She had to stop traveling as her pregnancy proceeded and with the discovery that she was carrying twins and in a high-risk pregnancy. Ultimately, this colleague delivered

early and unfortunately led to [HELLP syndrome](#). HELLP (Hemolysis, Elevated Liver enzymes and Low Platelets) syndrome is a life-threatening pregnancy complication usually considered to be a variant of preeclampsia. As a result, she needed multiple transfusions. Her kidneys failed and she was faced with caring for twin newborns while receiving dialysis three times a week. When she decided to pursue a kidney transplant and was waitlisted, she did what a lot of people in a similar situation do – put out a call for a living kidney donor. During this time, there had also been a number of news articles or stories about people in need of living organ donors and I just felt it was serendipity and a call for me to examine if organ donation was something I could do to help. So, I tested. They did a type and cross match, and we were a match. About nine months later, I donated my left kidney. Through this process, from pre-donor evaluation, through the surgery and onto post-donation – I’ve learned a lot about our health system, the transplant process, insurance coverage and patient needs.

From a patient perspective the donation experience changes your thoughts on healthcare and self-care.

## **CAPS: How has your advocacy evolved over the years?**

**Sarah:** In the beginning, I advocated for myself and people similar to myself. Over time, I began to think about population health and where there are better opportunities for engagement. Whether you are a donor or a recipient, this really is a journey. Patients should have a better voice and have their views represented in the health system. Often, the system operates from the perspective of improving clinical goals that are important to physicians/health professionals but may not align with those of patients.

They need to take into account patient goals, beyond clinical goals. Patient goals may include quality of life, return to a semblance of normality and just enjoying time with friends and family. Clinicians need to think beyond just a successful procedure or achieving a specific blood pressure or glucose target. I feel like there is a disconnect between patient goals and clinical goals. We really need patient-centered care. And for that to happen, patients have to be engaged and part of the process.

## **CAPS: What projects have you been involved in?**

**Sarah:** Most of the projects I’ve been involved in focus on encouraging patient-centered care and patient engagement. One example was one in which the Council of Medical Specialty Societies (CMSS) was awarded a Patient-Centered Outcomes Research Institute (PCORI) Engagement Award focused on Engaging Patients in Clinical Registries. Our goal was to identify innovative approaches to capturing the patient voice and develop best practices for organizations to effectively incorporate the patient voice into clinical data registries. ([Engaging Patients in Clinical Registries](#))

We developed toolkits for healthcare organizations and for patient advocacy organizations, in collaboration with the National Health Council, that included how patients want to be involved from conceptualization to implementation and evaluation. Patient engagement requires organizations to go well beyond including perspectives from one patient on a panel and we were able to identify success stories and examples that are included in the toolkits. We looked at what it means for a patient to be engaged and involved.

Currently, I’m involved in a couple initiatives where the organizations I’m working with are prioritizing the patient perspective and being inclusive in the clinical work we are pursuing.

## **CAPS: What would you recommend to persons who want to advocate for quality and safety?**

**Sarah:** I would recommend they have an understanding and appreciation of the complexities of patient journeys. Everyone experiences things differently, including surgery and interactions with health care professionals.

Now that we are getting patient input for our work, we need to realize that patients' ability to communicate differs also. Clinicians and health care professionals also should learn how to communicate with persons with various communication styles and expertise levels. Patients also would be well served to learn how to communicate with health care professionals and clinical teams. Patients can help physicians and clinicians understand what people have in common and how to meet the most needs. But appreciation should go both ways.

Similarly, population needs can't be generalized from just one person. Each patient journey is in some ways unique but can contribute to the bigger picture.

**CAPS: What would you recommend to health care systems to improve quality and safety?**

**Sarah:** Health care professionals may also need training to understand and appreciate patient perspectives as an essential component to improving quality of care. With the right mindset, patients can be considered experts. We also need more training on patient led research for both patients and clinicians. Start with including patients in operational and structural issues. There are some great systems to learn from that are doing this.

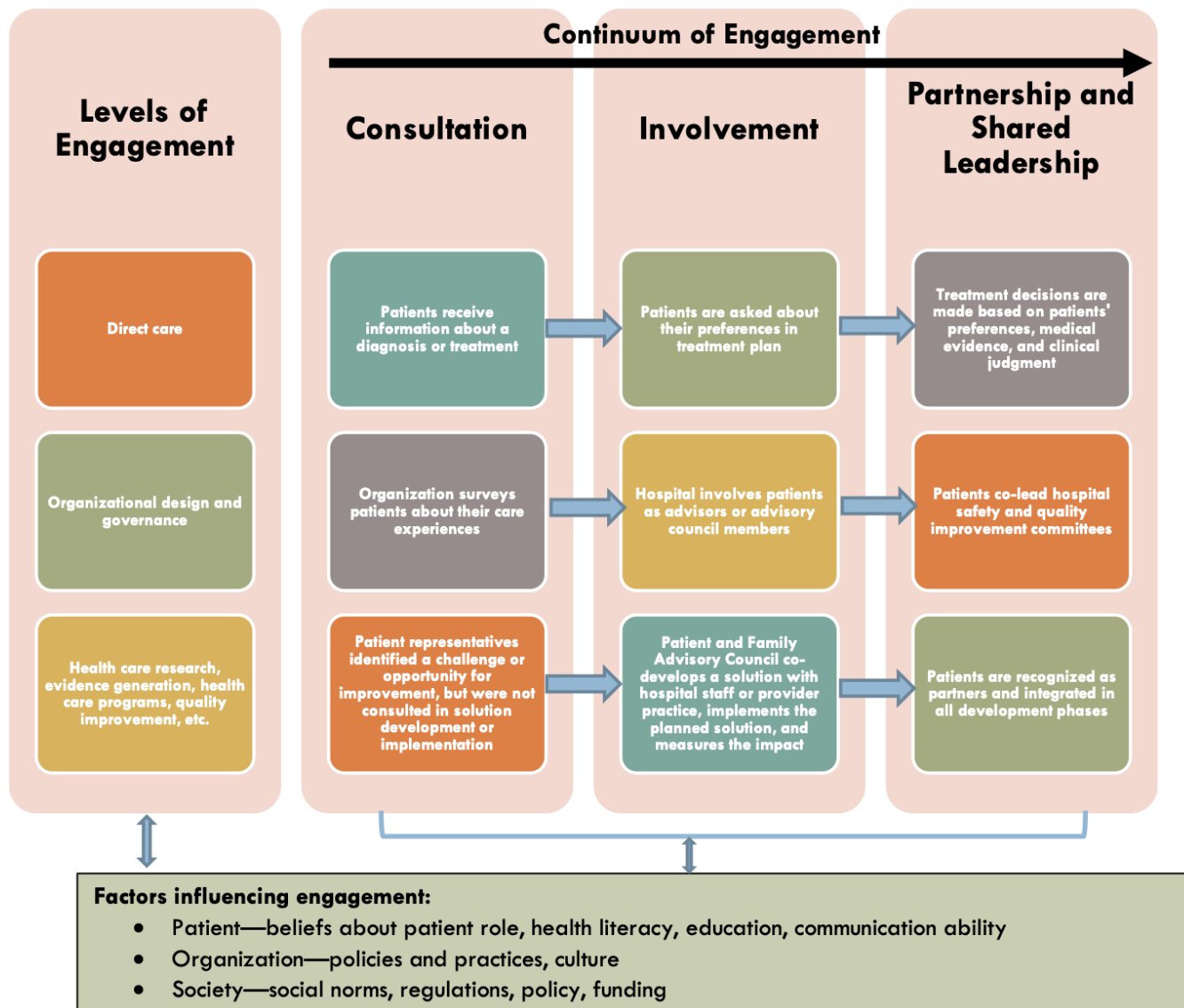
**CAPS: What are your future plans?**

**Sarah:** I really want to pull together my professional experience on the quality side and contribute to breaking down barriers in recognizing the full patient journey in a more holistic way. Our health system, and specifically our quality tools, are very siloed. While it's conceivable that a patient may have one primary health issue, the reality is that as we age, we have multiple inputs on our health and quality of life. Some are disease or organ system oriented, but we don't live in isolation. There are a multitude of inputs on our health, disparities based on race, gender, age, social determinants of health, etc. There has to be a way to allow for impacting the multitude of inputs in a patient journey versus chipping away at low hanging fruit. For example, if a patient has diabetes and depression, we should see the whole patient at one time, not in silos for endocrinology and mental health. I want to put hallways between the silos, so we recognize a whole journey, not just a point in time.

**CAPS: Thank you Sarah!** Reach Sarah Sampsel at [SLSampsel@ssampselqlty.com](mailto:SLSampsel@ssampselqlty.com)

Patient Engagement Framework from the November 2019 Council of Medical Specialty Societies Report: [Engaging Patients in Clinical Registries](#): CMSS Primer for Specialty Societies and Organizations Developing and Advancing Clinical Data Registries.

**Figure 1: Framework for Patient Engagement in Health and Health Care<sup>xiii,xiv</sup>**





## **ZOOMING for you in JANUARY: Restarting and Energizing PFACs - Easy to Implement How-To Lists**

Brought to you by:

*Consumers Advancing Patient Safety (CAPS) and Healthcare and Patient Partnership Institute (H2Pi).*

### ***“Recruiting patients for your PFAC”***

**You are invited to a Zoom meeting.**

**When: Jan 11, 2022, 02:00 PM Mountain Time and 4:00 PM Eastern Time**

**Register in advance for this meeting:**

**<https://us02web.zoom.us/join/tZAqd-urrjooGd1nzTLB3IHazy64s3WaSRLb>**

**After registering, you will receive a confirmation email containing information about joining the meeting.**

This series has been very well received. At just one-half hour per tutorial, the information is compact but powerful. CAPS member experts join Lisa Morrise in offering succinct and helpful real-world guidance on each topic. Remember to register and attend so that you may receive a .pdf summary of the information discussed.

- The second Tuesday of each month continuing with the meeting on **January 11** and coming months
- Each meeting will be held at 4:00pm Eastern / 3:00pm Central / 2:00pm Mountain / 1:00pm Pacific time
- **The Zoom meeting link is above. Please register in advance to reserve your space.**
- Topics covered will include:

- **Recruiting patients for your PFAC, January 11, 2022**
- Recruiting staff for your PFAC – February 8, 2022
- Diversity and inclusion – March 8, 2022
- Training in patient safety terminology for PFACs
- Choosing PFAC discussion topics

**Previously Recorded available now on the CAPS YouTube Channel:**

- Meeting remotely
- Building and using an agenda
- **Facilitating the meeting**
- Celebrating / recognizing and honoring PFAC members



## Consumers Advancing Patient Safety often partners with other organizations seeking to improve Quality and Safety. When possible, we support their efforts here:

### National Quality Forum Releases a Roadmap Providing Guidance on Developing Digital Patient-Reported Outcome Performance Measures

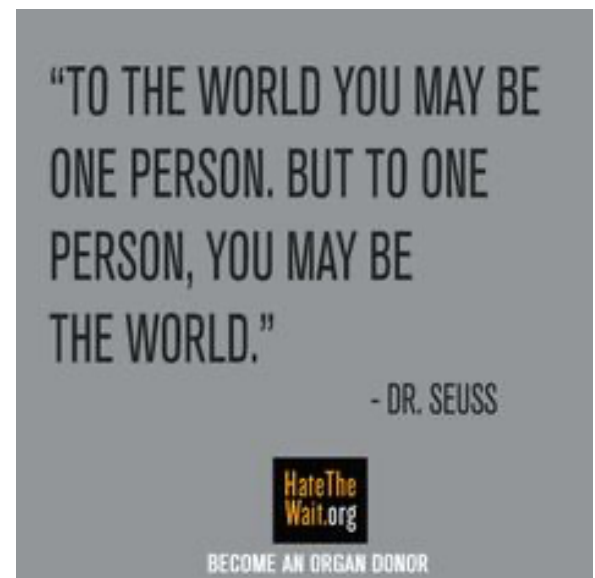
*Technical Guidance Report provides a valuable resource to help elevate the patient voice in performance measurement*

**WASHINGTON, DC** – In response to the expressed need for additional guidance in developing high impact patient-reported outcome performance measures (PRO-PMs), National Quality Forum has published a **Technical Guidance Report**.

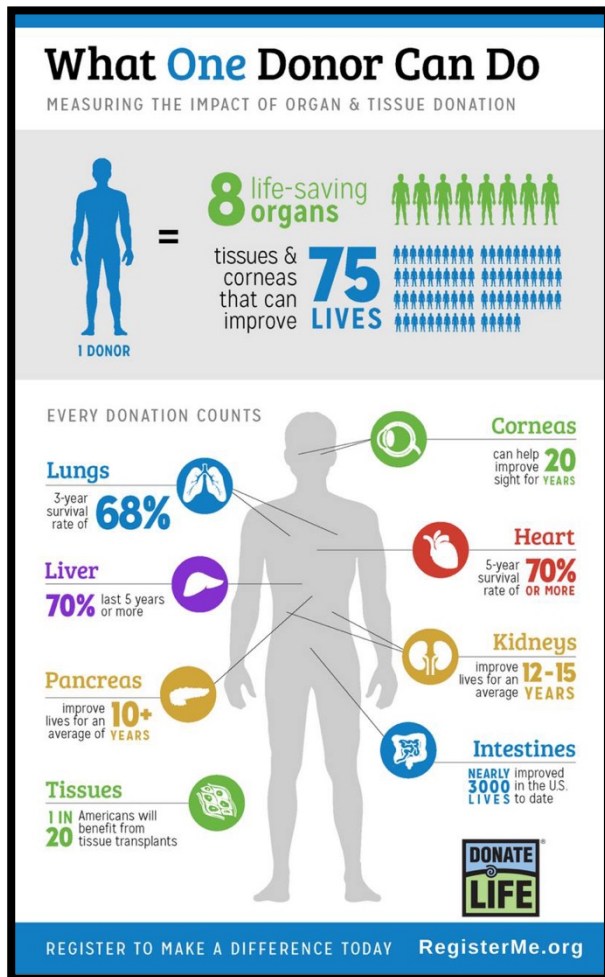
Elevating the patient voice through patient-reported outcomes (PROs) is critical to achieving equity, strengthening the care experience, and improving health outcomes for all. PROs represent the measurement of a patient's health directly from the patient – asking about dimensions of care that are best assessed by asking patients directly (e.g., pain, functional limitations, energy, emotional distress). Patient-reported outcome measures (PROMs) represent the tools and instruments that are used to collect the data (e.g., the Patient Health Questionnaire 9 [PHQ-9]). PROMs can be used to collect data over time, thereby measuring changes that are occurring for patients and populations. These longitudinal uses of PROMs can form the basis for performance measures (PRO-PMs), where the information is used to hold providers and payers accountable for the outcomes they achieve for their populations.

Read more: [https://www.qualityforum.org/Publications/2021/11/Building\\_a\\_Roadmap\\_From\\_Patient-Reported\\_Outcome\\_Measures\\_to\\_Patient-Reported\\_Outcome\\_Performance\\_Measures\\_-\\_Final\\_Technical\\_Guidance\\_Report.aspx](https://www.qualityforum.org/Publications/2021/11/Building_a_Roadmap_From_Patient-Reported_Outcome_Measures_to_Patient-Reported_Outcome_Performance_Measures_-_Final_Technical_Guidance_Report.aspx)

## Graphics Garden







### SHARE YOUR HEALTH

As coronavirus concerns intensify, we need healthy blood donors more than ever.

**Is it safe to give right now?**

Donating is a safe process and healthy individuals should schedule a blood or platelet donation to help maintain the nation's blood supply.

#### Safety at Blood Drives

Red Cross employees implemented added precautions to ensure blood drives and donation centers are safe for donors and staff.


- Using Sterile Collection Sets
- Spacing Beds 6 Feet Apart Where Possible
- Having Hand Sanitizer Available
- Using Aseptic Scrubs on Arms
- Donor and Staff Temperature Checks Before Entering Drives
- Wiping Down Donor-Touched Areas

**What if a donor becomes sick after donating?**

We provide a call back number donors should call if they become sick with any illnesses days after their donation.

**If you're healthy and well, we're urging you to make a blood appointment.**

Visit [www.RedCrossBlood.org](https://www.RedCrossBlood.org)



## Please Visit:

Our web page at [www.patientsafety.org](https://www.patientsafety.org). Find resources, archived recordings, and a form to share your story or sign up for this newsletter!

And, please like our Facebook Page:

<https://www.facebook.com/patientsafety.org/?ref=bookmarks>

## To Donate to CAPS:

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## Do you have information for the CAPS Newsletter?

Please send us information about what you are doing to advance patient safety. Send it to [capspatientsafety@gmail.com](mailto:capspatientsafety@gmail.com)

□

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