

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



#### Greetings!

I hope you are all enjoying some nice spring weather - it does seem like it has been a long winter! As we transition from winter to spring, we also recognize the importance of transitions in healthcare that occur every day and how difficult they can be for patients, caregivers, and providers.

Project Patient Care (PPC) will be highlighting Care Transitions in this newsletter as we all reflect on the importance of Care Transitions and the National Care Transitions Awareness Day.

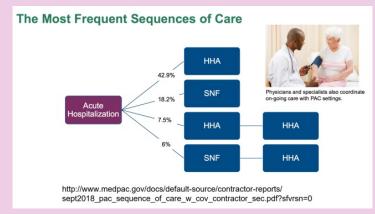
The Centers for Medicare and Medicaid Services (CMS) put a spotlight on the critical importance of Care Transitions as they hosted the National Care Transitions Awareness Day Summit on April 16. Patients, families, caregivers, healthcare providers, researchers, social workers, and other non-clinical providers shared their best experiences with each other and made offers and commitments to continue their work to improve care transitions.

Articles in this newsletter include:

- The importance of Care Transitions on the health and well-being of patients
- Recognizing Project Achieve for their role as a Champion Change Agent
- Empowering the Patient and Caregiver to ask the right questions from providers and understand the provider's answer
- CMS 2019 Priorities
- Identifying more opportunities for patients, families, and caregivers to have a voice and influence on research, policy, and care delivery CMS TEP, Academy Health, PATIENTS Day at University of Maryland in Baltimore

"Alone we can do so little; together we can do so much." Helen Keller

"None of us, including me, ever do great things. But we can all do small things, with great love, and together we can do something wonderful." Mother Teresa



## IMPORTANCE OF CARE TRANSITIONS

Every person that leaves a hospital will have a joint patient and healthcare provider designed care plan and will either be transitioned to another care provider setting or have a follow up appointment to see their healthcare provider. Care Transitions can occur in many settings, including

between hospitals; hospitals and post acute care providers; post acute care providers and other post acute care providers and hospitals; hospital to practice or clinic; observation or emergency care to another level of care or setting; and among specialty clinics and providers for patients with chronic disease or patients transitioning from pediatric care to adult care.

According to CMS, 45% of Medicare beneficiaries that were hospitalized in 2014 were transitioned to a post acute care (PAC) provider. The 33,000 post acute care providers include Long Term Care Hospitals (LTCH), Skilled Nursing Facilities (SNF - Nursing Homes), Home Health Agency (HHA), Inpatient Rehab Facilities (IRF), and Hospices. There are over 5,262 community hospitals defined as all non-federal, short-term general, and other special hospitals including academic, teaching, non-academic, and non-teaching hospitals.

CMS cited several studies highlighting the following facts in an **infographic** for National Care Transition Awareness Day:

- Inadequate care coordination and care transitions are responsible for \$40-\$54 billion in wasteful spending
- 57% of providers report things fall between the cracks when transferring patients from one facility to another
- 50% of hospital-related errors are attributed to poor communication during transitions of care

Due to the majority of admissions coming through the hospital emegency department, patients and caregivers do not know who their post acute care provider will be when they first enter a hospital. If post acute care services are needed, the patients and caregivers will be provided with a list of providers for their selection. Many patients will use CMS Compare to try and determine the best facility and most often caregivers will make a visit to the post acute care provider setting.

Not all hospitals have relationships with all of the post acute care providers. If you select a post acute care provider that the hospital does not have a relationship with, it is critically important that the hospital provider establish a relationship to ensure the post acute care provider has the trained staff and resources to support a patient's particular needs. There is a requirement for a patient to be assessed and a patient care plan to be prepared by the proposed acute care provider so the post acute care provider can determine whether they are able to properly care for the patient. At least, this is the way it is expected to happen. In reality, it does not always work this way (more to come later on how patients can be empoweed to raise questions to ensure care transitions go smoothly).

Given the large volume of patients that will require post acute care services following a hospitalization, it is important to start the care planning process as early as possible during a patient's stay. If proper planning and warm handoffs (provider to provider and provider to patient interactions) do not occur, the patient is at risk for not receiving the proper care which could result in serious harm.



<u>A</u>chieving Patient-Centered <u>C</u>are and Optimized <u>H</u>ealth <u>I</u>n Care Transitions by <u>E</u>valuating the <u>V</u>alue of <u>E</u>vidence

Funded by Patient Centered Outcome Research Institute (PCORI), nationally recognized leaders in health care and research methods are partnering with patients and caregivers to evaluate the effectiveness of current efforts at improving care transitions and develop recommendations on best practices for patient-centered care transitions and guidance for spreading them across the U.S.

Champion Change Agents

# **PROJECT ACHIEVE - CHAMPION CHANGE AGENTS**

This month we are celebrating Project ACHIEVE as a Champion Change Agent. Project Achieve is a multi-year Patient Centered Outcome Research Institute focused on improving care transitions. The project includes patients, families, caregivers, healthcare providers, researchers, and other organizations. Project ACHIEVE is an important example of co-production as patients and caregivers have been involved with researchers and clinicians in the co-creation of the project all the way through co-evaluation.

The project is lead by Dr. Mark V. Williams, MD, FACP, MHM—Principal Investigator and Dr. Jing Li, MD, MS—Co-Investigator of the University of Kentucky Center for Health Services Research. Paticipating organizations include Westat, University of Pennsylvania, Boston Medical Center, Telligen, Kaiser Permanente Southern California, Health Research & Educational Trust, Joint Commission Resources, Essential Hospitals Institute, National Association of Area Agencies on Aging, Caregiver Action Network, United Hospital Fund, Project Patient Care, Louisiana State University Health Sciences Center, University of Illinois at Chicago, 42 hospitals, and thousands of patients, families, and caregivers that participate in committees, focus groups, or surveys.

Project ACHIEVE Specific Aims:

- Identify the transitional care outcomes and components that matter most to patients and caregivers.
- Determine which evidence-based transitional care components (TCCs) or combinations of components most effectively yield patient and caregiver desired outcomes overall and among diverse patient and caregiver populations in different types of care settings and communities.
- Identify barriers and facilitators to the implementation of specific TCCs or combinations of TCCs for different types of care settings and communities.
- Develop recommendations for dissemination and implementation of the findings on the best evidence regarding how to achieve optimal TC services and outcomes for patients, caregivers and providers.

Project ACHIEVE Outcomes and Impact:

Through rigorous study and evaluation, Project ACHIEVE will:

- Identify best practices in care transitions that matter most to patients and their caregivers, and reduce excess emergency department and hospital utilization.
- Develop a toolkit to guide informed decisions and spread these best practices across the U.S.
- Develop Care Transitions Surveys that can standardize evaluation of patients' and caregivers' experience with care transitions.

We will be providing you with a series of Podcasts on Project ACHIEVE with the voice of

the patient and caregiver combined with physicians and researchers as they share findings of patient and caregiver focus groups and some interesting results. The link to the podcasts will be sent to you during the week of April 21.

# CLOSING THE GAPS IN CARE TRANSITIONS: PROJECT ACHIEVE FINDINGS





Jing Li, M.D., M.S.

Project ACHIEVE

Jing Li, M.D., M.S. and Glen Mays, Ph.D., M.P.H. share the most recent findings of Project ACHIEVE in this recorded webinar.

To learn more about what matters most to patients and caregivers and successful interventions to close the transition gaps, **click here** to listen and view the recorded webinar.

### EMPOWERING THE PATIENT AND CAREGIVER TO ASK THE RIGHT QUESTIONS AND UNDERSTAND THE PROVIDER'S RESPONSE

As you listen to the recorded webinar of Project ACHIEVE, the concern over handoffs and accountability were best illustrated in a caregiver's quote. *"It's like being thrown out in the middle of a lake and...[you're] frantically searching for somebody on the other side of the lake to help you."* 

Providers are working on initiatives to improve care coordination and make care transitions seamless for patients and their caregivers. CMS issued a "A Guide to Care Transitions: Navigating a Complex System" for a targeted audience of hospital systems and providers, community partners, and health plans and other business entities. The Guide includes information and resources on care coordination, care transitions between settings, hospital readmissions, and health information technology.

There are many patient advocate and disease based organizations that can provide guidance for patients and caregivers with questions to ask on care transitions. Several of the care transition programs, such as Bridge Model, Project BOOST, Project ACHIEVE, and Project RED, prepare patients, caergivers, and providers to address the questions. Many providers are developing programs and information in anticipation of questions posed by patients and caregivers such as the questions below.

For patients and caregivers - some questions to consider asking in advance of a care transition between settings of care:

Starting with WHY Questions might be the first step:

- Why does the patient need follow up care? Make sure you are satisfied with the response and if not, ask more why questions
- Why are you suggesting XXXX as the next level of care? Are there other alternatives?

WHERE should the patient get the follow up care?

- What are the options for selecting a high quality provider?
- Can you help explain CMS Compare information so it is understandable based upon the patient's situation?
- Where does the source of information come from in determining that the next provider has the trained staff and resources to care for the patient?

WHAT information can you share about this next level of care?

- What is their success rate in taking care of patients with this condition?
- What is their plan of care rehab, maintenance, improvement? What specific plans do they have?
- What do you see as the caregiver responsibilities in this process?
- Does the next provider have an electronic patient and caregiver portal? If not, what is the plan for initial and ongoing communication with the patient and caregiver?

HOW does this all work?

- How does this transfer occur ambulance, car?
- How does this all get paid for? Is it covered under insurance? If one is not able to pay the bill, can you make connections to organizations with resources to help cover the bill?
- How and when will you share medical records and history with each provider?
- How will I know all the necessary information is given to the next level of care? Will a copy of the information be provided to the patient and caregiver?
- How will you ensure the transition to another provider has gone well? Will you be contacting the caregiver? When?

WHO will be taking care of the patient at the next level of care?

- Who will their doctor be at their next level of care?
- If going to a nursing home or long term care hospital, will the doctor see the patient within 36 hours? Who will be responsible for ensuring the doctor will visit within 36 hours?
- How will the doctors all communicate? Who arranges the communication?
- If nursing home, how can the soon-to-be resident and caregiver participate in the Resident and Family Council?
- Who is in charge of the patient's medication? Who will consult with the patient and caregiver on the medication?
- Who does the caregiver contact to find out the progress the patient is making?
- Who decides if there is additional care or treatment needed?
- Who is in charge of creating the bill? Who does the patient or caregiver talk to about questions on billing?
- Who does the patient or caregiver talk to if one can't make the payments?
- Who will contact the caregiver in an emergency situation? Who does the patient or caregiver contact in an emergency situation?
- Who does the caregiver or patient contact if the patient or caregiver are not satisfied with the care?
- Who is responsible for arranging the transition of care from the current setting? Who will be the contact be for the transition and their back up person if they are not available (names, phone number, e-mail)?

There are many more questions to be asked pending the patient situation and their next provider. However, it is important to raise these questions if they are not answered in any written or oral communication by the health care providers.

# 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 Panels.** CMS has a Technical Expert Panels (TEP) they are recruiting for and are interested in having patient, family, or caregiver participants on the TEP. The TEP and the nomination deadline is listed below:

• 2019 Merit-based Incentive Payment System (MIPS) Improvement Activities (IA) Technical Expert Panel (TEP) - April 26, 2019 nomination deadline

To find out more about CMS TEPS and how to apply to be a patient participant, **Click** 

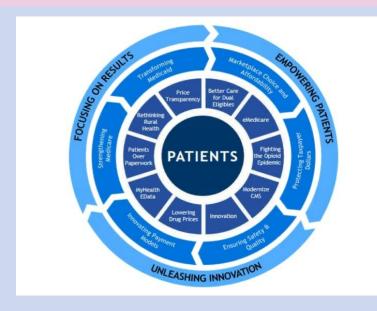
#### Here

Academy Health Annual Research Meeting - June 2-4 in Washington, D.C. Patient Full Scholarships and Patient Complimentary Registrations. Through support from PCORI, the Academy Health is providing two types of Patient Scholarships. The first scholarship is a full scholarship that includes registration, travel, and meals for patients that could not otherwise attend the meeting without the scholarship. The second scholarship for patients is for a complementary registration.

The Application and additional information are available by **Clicking here** *Deadline for applying is April 24 at 5:00 p.m. eastern time.* 

**PATIENTS and Patients Day in West Baltimore at University of Maryland -May 31 - Open to Patients and Community Members** The University of Maryland is one of seven health services research institutions funded through a five-year infrastructure development grant from the Agency for Healthcare Research and Quality to develop capacity for patient-centered outcomes research. On May 31, the PATIENTS program will be open to all patients, community residents, University of Maryland researchers and trainees, advocates, and health care providers to learn from each other about the most important needs in the community. PATIENTS Day seeks to improve the way research is understood and talked about by community residents, patients, and University of Maryland researchers and trainees.

The event will be held on May 31 from 12:30 - 5:00 p.m. with a lunch available at 12:30 at the University of Maryland, Baltimore (UMB) BioPark. Registration is required and the event and lunch are free of charge. To register, **Click Here** 



## CMS 2019 STRATEGIC PRIORITIES

During the National Care Transitions Awareness Day on April 16, Kate Goodrich, M.D., M.H.S., Director and CMS Chief Medical Officer, CMS Center for Clinical Standards and Quality, highlighted the CMS Strategic

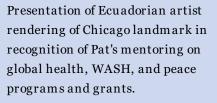
Priorities for 2019. Patients are at the center of CMS work and she noted that every educational and shared learning meeting opens with a message from a patient, family, or caregiver. Key strategic priority areas are Empowering Patients, Unleashing Innovation, and Focusing on Results.

### PPC STAFF COMMUNITY ENGAGEMENT - MAKING A DIFFERENCE





Meeting on Europe and Eurasia humanitarian projects with Pat and USAID Assistant Administrator, Brock Bierman, and staff.





## We Love to Hear From You!

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