



TASK FORCE ON PATIENT AND FAMILY ENGAGEMENT

North Carolina Institute of Medicine
630 Davis Drive, Suite 100
Morrisville, NC 27560
June 19, 2014
10:00 – 3:00
Meeting Summary

Attendees

Members: Kimly Blanton, Eliane Brown, Heather Burkhardt, Sharon Elliot-Bynum, Hannah Klaus, Jill McArdle, Nidu Menon, Jo Morgan, John Owen, Belinda Pettiford, Kathryn Pollak, Matthew Potter, Parrish Ravelli, Sarelli Rossi, Anita Schambach, Bill Smith, Melissa Thomason, Margaret Toman, R.W. Watkins

Steering Committee and NCIOM Staff: Sue Collier, Andrea Phillips, Kimberly Alexander-Bratcher, Thalia Fuller, Kiah Gaskin, Michelle Ries, Elena Rivera, Pam Silberman, Adam Zolotor

Guests and Other Interested People: Brent Anthony, Megan Bolejack, Amy Jones, Maureen Mauer, Ben Money, Karla Siu

WELCOME, INTRODUCTIONS, & INPUT

Kimly Blanton

Patient Advocate

Co-chair

Melanie Bush, MPAff

Assistant Director, Policy and Regulatory Affairs

Division of Medical Assistance

North Carolina Department of Health and Human

Services

Co-Chair

Warren Newton, MD, MPH

Director, North Carolina AHEC Program

William B. Aycock Professor and Chair

Department of Family Medicine

University of North Carolina School of Medicine

Co-chair

Dr. Newton, Director of the North Carolina AHEC Program, called the meeting to order and welcomed the Task Force members. The group went around the room so that each attendee could introduce themselves.

OVERVIEW OF PAST AND UPCOMING MEETINGS

Kimberly Alexander-Bratcher, MPH

Project Director and Research Associate
North Carolina Institute of Medicine

Ms. Alexander-Bratcher, Project Director and Research Associate at the North Carolina Institute of Medicine, reminded the Task Force about what we covered in prior meetings, gave a brief overview of the day's meeting, and reminded the group what we will be covering in future meetings.

PATIENT AND FAMILY ADVISORY COUNCILS

FRAMING OVERVIEW

Sue Collier, MSN, RN, FABC

Performance Improvement Specialist
Patient-Family Engagement
North Carolina Quality Center/North Carolina Hospital Association

Dr. Newton introduced Sue Collier, Performance Improvement Specialist for North Carolina Quality Center and North Carolina Hospital Association. Ms. Collier presented an overview of Patient and Family Advisory Councils (PFACs) to frame the panel discussion. She began by giving a definition of patient and family advisors and patient and family advisory councils. A PFAC is a team of patients and families and healthcare members that provides an opportunity to engage patient perspectives in the planning, implementation, and evaluation of healthcare services and programs. PFACs assure the patient and family point of view, perspective, and experience are not only heard, but also integrated into the delivery of healthcare. There are many benefits of PFACs, including improved relationships between patients, families, and providers, increased knowledge and skills for patients and family advisors, and improved quality of health care services. Ms. Collier concluded her presentation by stating that there are unique opportunities and barriers to creating effective PFACs and asking the panelists to speak about this.

PANEL

Amy Jones

Administrator
Office of Patient and Family Experience
Vidant Health

Amy Jones introduced herself and her experience working with patients and their families to improve health care at Vidant Health. She helped build the model of PFACs at Vidant and spearheads work to include patients and families in operational decisions and policy making.

Kimly Blanton, MIS, MLS

Patient Advocate
Vidant Health

Kimly Blanton talked about her experience as a patient and a patient advisor engaging with providers and other health care professionals. As a patient advisor, she works from the bedside

to the boardroom: at the bedside, she talks to nurses primarily about her own experiences and in the boardroom she speaks as a representative for all patients about common issues that arise.

E. Benjamin Money, Jr. MPH

President & CEO

North Carolina Community Health Center Association

Ben Money introduced himself and spoke from the state perspective as the President and CEO of the North Carolina Community Health Center Association. He discussed the unique community health center (CHC) model of PFACs, known as patient-majority boards. Each CHC must have a governing board comprised of at least 51% patients being actively served. Community health centers have always been committed to giving the power and authority to the consumers of their health services, so patient advisors in this model have complete autonomy over governance and operations.

Discussion

After the panelists introduced themselves, there was a discussion amongst panelists and Task Force members. The group began by discussing barriers to creating effective PFACs, including the time and energy it takes to create and manage PFACs and to prepare patients to participate in a meaningful way. There is also an unfounded fear that patient advisors will only complain about the health care they receive and make unrealistic requests. Another issue is that some hospital and health care systems only invite patient advisors to participate in order to “check a box” and claim they value patient engagement. One Task Force member asked if there was a risk that patient and family advisors serve so long on PFACs that they become desensitized to the issues of patients and assimilated into the culture of the hospital or health care setting. Several other Task Force members responded that this can happen, and the solution is to keep patient and family advisors with a variety of experience on PFACs.

The Task Force also discussed the difference between involving patient and family advisors in policy-making and involving them in making decisions about operations. Panelists responded that patients are capable decision makers and even do their own research to be informed and prepared. There is opportunity for community empowerment and mobilization that comes with complete ownership of decisions (for operations and governance).

The Task Force agreed that its recommendations should highlight the benefits of PFACs rather than mandating PFACs. Members also suggested that the NCIOM recommend a model on how to select patient advisors and a guide for setting up the PFAC and running the PFAC. The Task Force could also recommend a system (such as a website) that facilitates communication between PFACs.

PATIENT AND FAMILY ENGAGEMENT: CULTURE CHANGE

SMALL GROUP DISCUSSION

Dr. Zolotor introduced the afternoon session on culture change. He gave a brief presentation. First he highlighted an article by Luxford et al. that studied healthcare organizations with a reputation for improving patient experience. There were several facilitators to improving patient experience: strong committed senior leadership, clear communication of strategic vision, active engagement of patients and families throughout the institution, sustained focus on staff satisfaction, active measurement and feedback reporting of patient experiences, and

culture strongly supportive of change and learning. Common barriers identified include: changing culture from “provider-focus” to “patient focus” and length of time for transition/change. Dr. Zolotor transitioned to talking about culture change in hospitals and health care settings. He reminded the Task Force that its goal for the afternoon is to think about how to change or transmit culture to encourage meaningful patient and family engagement.

The task force then broke into 3 groups for small group discussion: health professional education, administration/leadership, and patients and families. Each group met for 45 minutes to discuss the following questions and then all groups came back together to report back on their recommendations.

- Who is responsible for culture change?
- What are the barriers and facilitators?
- What steps are required?
- What can we recommend?

NEXT STEPS & FEEDBACK

Adam Zolotor, MD, DrPH

Vice President

North Carolina Institute of Medicine

The Task Force meeting concluded with a discussion of next steps. The Steering Committee will take the culture change recommendations from today to consider and revise, and will present them again at the July meeting. There was a final discussion on finding the “tipping point” for patient and family engagement. What are the places and systems to target to make the biggest difference and tip the scale in favor of increased engagement? This is something the Task Force wants to continue to think about in crafting recommendations.