

TASK FORCE ON PATIENT AND FAMILY ENGAGEMENT

North Carolina Institute of Medicine 630 Davis Drive, Suite 100 Morrisville, NC 27560 March 20, 2014 10:00 – 3:00 Meeting Summary

Attendees

Members: Val Atkinson, Bonnie Britton, Eliane Brown, Heather Burkhardt, Brian Caveney, Lucy Dorsey, Nancy Henley, Lin Hollowell, Peter Lichstein, Helen Marie Mack, Jill McArdle, Barbara McNeill, Nidu Menon, Jo Morgan, John Owen, Belinda Pettiford, Melanie Phelps, Joanne Pierce, Matthew Potter, Parrish Ravelli, Sarelli Rossi, Anita Schambach, Bill Smith, Melissa Thomason, Margaret Toman, Karen Woomer, Joan Wynn

Steering Committee and NCIOM Staff: Sue Collier, Michael Lancaster, Ruth Petersen, Andrea Phillips, William Schwartz, Kimberly Alexander-Bratcher, Thalia Fuller, Michelle Ries, Micha'le Simmons, Adam Zolotor

Guests and Other Interested People: Brent Anthony, Jennifer Lord, Hannah Klaus, Maureen Maurer, Jhana Parikh, Melissa Riffe-Guyer

WELCOME, INTRODUCTIONS, & INPUT

Kimly Blanton Patient Advocate *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*

PATIENT AND FAMILY ENGAGEMENT: A MODEL FRAMEWORK

Maureen Maurer Senior Researcher Health and Social Development Program American Institutes for Research Maureen Maurer, Principal Researcher at the American Institutes for Research, presented on the PFE framework, how it was developed, and how it can be used. PFE should include patients and families at all levels of care including operations and governance. The task force discussed that PFE requires a significant paradigm shift in order to provide patients and families with equal power; shared responsibility should be emphasized and providers should understand that following this framework requires increased flexibility as patient expectations are fluid and vary from person to person. The task force also emphasized the need to think about care outside of the hospital, including how to involve e-advisors.

PATIENT AND FAMILY ENGAGEMENT: DEFINITION, FRAMEWORK, AND SHARED OUTCOMES DISCUSSION

Sue Collier, MSN, RN, FABC

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

Sue Collier, Patient and Family Engagement Specialist at the North Carolina Quality Center, shared several of the nationally recognized conceptual frameworks for PFE and identified the challenges in determining PFE best practices. Seeing that PFE is patient-driven, there has to be a focus on patient preferences and the best practices should be defined in terms of the patient. The group also commented that PFE cannot be overly focused on best practices as the higher levels of scientific rigor may not be possible to meet. The task force also discussed the importance of tying outcome and process measures to PFE; consensus should be met on how to measure how PFE practices influence cost and quality. Appropriate distinction must be made between patient engagement and patient experience (patient satisfaction) in order to make progress toward patient centered care.

OVERVIEW OF THE AFFORDABLE CARE ACT: OPPORTUNITIES FOR PATIENT AND FAMILY ENGAGEMENT

Adam Zolotor, MD, DrPH Vice President

North Carolina Institute of Medicine

Adam Zolotor, Vice President of the North Carolina Institute of Medicine, presented on the Affordable Care Act and its implications for PFE. These patient-centered strategies include a \$75 million appropriation to HHS to develop quality measures, quality based reimbursement for providers, and community transformation grants. One task force member touched on the success of a care transitions program where nurses work with complex patients post-discharge and go to their home and their first doctor's appointment; this effort resulted in a significant decrease in readmissions. The group agreed that discharging from the hospital should really be seen as admitting the patient back into the community. Post-discharge is where there is an opportunity to improve patient engagement. Concerns were raised that based on privacy laws, hospitals are not always able or willing to share pertinent information with necessary parties such as families and social workers, who are looking to help the patient make the safest care transition. The group also discussed the need to expand the idea of advance directives beyond just end of life care, and to see these conversations as dynamic and constantly changing.

NEXT STEPS & FEEDBACK

Moving forward the Task Force wants to think more about how PFE practices can be integrated into care that patients receive at the community level; the group acknowledges that there are challenges in physicians being able to provide the time necessary to engage in these practice with their patients. Further discussion will include determining what metrics should be used for tracking PFE related outcomes and how to engage patients in their daily self-care processes.