Task Force on Serious Illness Care

North Carolina Institute of Medicine

630 Davis Drive, Suite 100

Morrisville, NC 27560

May 17, 2019

10:00amm-3:00pm

Meeting Summary

Co-chairs in attendance: Paulette Dillard**,** Jonathan Fischer

Members in attendance: Tom Akins, Mary Bethel, Victoria Boviall, Christine Brown, Ken Burgess, Christie Burris, Melanie Bush, David Cook, Representation Carla Cunningham, Wendee Cutler, Linda Darden, M. Bradley Drummond(phone), Bridget Earle, Stacey Ellis-Antisdel, Anne Elmore, Debby Futrell, Elizabeth Golding, Michell Heflin, Sheila Helms, Jay Kennedy, Sue Kirkman(Phone), Donna Lake, Deborah Love, Kristen Lakis, Laura Marx, SaraJane Melton(phone), Adrienne Mims, Christopher Morrisette, Ellie McConnell, Susan Nestor, Laura Patel, John Perry, Melanie Phelps, Janna Pogers, Urusla Robinson(Phone), Larry Rocamora, Timothy Rogers, Cherie Rosemond, David Sevier, John Smith, Lynn Spragens, Apollo Stevens, Keith Sitrewait, Pam Strader, Betsy Vetter, Stan Walters, Ellie Ward, Christine Weason, Polly Welsh(Phone), Senator Mike Woodard

Steering committee members in attendance: Steve Freedman, Cindy mORGAN Cathy Sevier

Guests in attendance: Sheila Bell, Nathan Boucher, Vicki Daughtry, Melissa Mahaney, Corey Remailer (phone), Brittany Schwartz, Brian Wood

Speakers: Nadine Barrett, Holly Sienkiewicz, Debbie Taylor

NCIOM staff in attendance: James Coleman, Michelle Ries, Berkeley Yorkery, Adam Zolotor

Welcome and Introductions

Paulette Dillard, PhD
President
Shaw University

Task Force co-chair Paulette Dillard brought the meeting to order and facilitated introductions. During introductions, every meeting attendee introduced him/herself by sharing their name, title, and organization.

Scope of Task Force---Guard Rails

Adam Zolotor, MD, DrPH
President and CEO
North Carolina Institute of Medicine

Dr. Zolotor talked about the Task Force charge and started a discussion on setting guardrails/limits for the task force scope and trajectory. Dr. Zolotor explained the setting limits on the scope early is needed to keep the Task Force on track.

Limits outlined by Dr. Zolotor:

- Patient we are talking about in regard to the work of the task force is one that a health care provider would not be surprised if she/he dies in the next year
- We are not talking about prevention of serious diseases
- Topics and areas of the task force should be ones where there is room for compromise and consensus
- We need to avoid political poison pills (ex: medical marijuana)
    - It is ok to talk about them during the work of the task force, and we can even mention potential poison pills in the report. However, we should avoid making recommendations concerning political poison pills
    - Avoid discussion areas and topic that are solely regulated by federal policy

After Dr. Zolotor went over proposed limitations, he opened the floor for task force member to suggest what topics should be include in the scope of work and what should be avoided.

Task Force members suggestions included (Select):

- Need to include in scope/areas of discussion
    - mental and whole health
    - aging population quality of life issues
    - medical marijuana (discussion)
    - Telehealth
    - Uninsured/underinsured
    - Pediatrics in palliative and hospice care
- Poison pill to avoid
    - Medical aid in dying

Zolotor Presentation

Advancing Health Equity: Framing the Conversation for Greatest Impact

Nadine Barrett, PhD, MA., MS
Assistant Professor
Duke University School of Medicine
Department of Community and Family Medicine

Following Dr. Zolotor, Dr. Nadine Barrett talked to the task force about health equity and health disparities. The purpose of her presentation was to help the task force frame its future work with health equity in mind. During her presentation Dr Barret talked about:

- Definitions of healthy equity and health disparities
- Why health equity and addressing health disparities is important
- How social determinants of health determine health outcomes and drive health disparities
- Health equity and disparities within the realm of advance care planning and serious illness care

Barrett Presentation

Refugee Health Challenges: Healthcare Experiences in the U.S.

Holly Sienkiewicz, DrPH
Director / Research Scientist
UNCG Center for New North Carolinians

Pam Strader, M.Div., Ordained UMC Pastor
Pastor of Congregational Care & Discipleship Ministry
West Market Church

Debbie Taylor, RN, BSN, MPH
Director of Outreach
West Market Church

Holly Sienkiwicz, Pam Strader, and Debbie Taylor talked to the task force about the refugee healthcare experience. During their presentation, topics they covered included:

- Definitions of refugee, asylum-seekers, and immigrant
- Global data on number of internally displaced people, refugees, asylum-seekers, and stateless peoples
- Reasons for resettlement
    - Medical needs are 1-2% of reasons
- Federal and state resources offered to refugees
- Resettle process in NC
- 2 case studies of immigrants in Greensboro area and issues they faced in seeking treatment for serious illness care
- Common obstacles and barriers that refugees face in medical system

Strader, Sienkiewicz & Taylor Presentation

Advance Health Care Directive

Ann Elmore, JD
Agency Legal Specialist
NC Secretary of State

Before lunch, Ann Elmore talked to the task force about the advance care directives and the advance care directives registry system in NC. Topics touched upon by Ms. Elmore included:

- What advance care planning is and what it is not?
- Why people should have an advance care plan in place
- Data on advance care planning utilization and reasons people do not plan
- Remedies and barriers to advance care planning
- Why advance care planning is important
    - Talked about possibilities of what can happen when one does not plan in advance
- History and overview of the NC advance care directive directory
    - Scope of registry

Questions/comments (Select)

- Is there any mechanism to make sure directory is current with the deceased?
    - Answer: not at this time
- Any plans to integrate registry with Nc Health Information Exchange system?
    - Answer: not at this time

Elmore Presentation

Role of Advance Directives in Advance Care Planning: Benefits and Challenges

Melanie Phelps, JD
Senior Vice President, Health System Innovation
Deputy General Counsel
North Carolina Medical Society

After lunch, Melanie Phelps talked about the purpose and effect of advance care directives and their role in the advance care planning process. Topics she touched upon include:

- Why advance care planning is simply just not about forms
- Types of advance care directive forms
- Similarities and differences between advance directives and portable medical orders
- Benefits and limitations of advance care directive forms
- Overview of where ACS forms fit in the advance care planning process
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Questions/Comments (Select)

- Blue Cross Blue Shield NC can be billed for advance care and medical order documents
    - There is a CPT billings code and procedure code
- NC is one of 5 states that still requires the 2 qualified witnesses and notary requirement for advance care planning documents
    - Great support in the state to change this
    - In the past, certain interests were considered that removing these requirements would lead to people forging advance care planning documents

- There are other advance care documents out there, even some for pediatrics
    - Most of these must be purchased
- Financial planners and churches need to engage and educated on advance care planning process
- on your NC driver's license that you can designate that you are an organ donor. Why cannot we do the same for having advance care documents?
- Nc Medicaid and other NC insurers should start billing for advance care documents

Phelps Presentation

Challenges health systems face in accessing AD documents, providing training, and communicating with patients and families

Ellie Ward, RN
Program Coordinator, Community Education and Outreach
Vidant Health
After Ms. Phelps, Ellie Ward talked to the task force about Vidant's work on provider engagement around advance care planning and culture change around communication between providers and families. Topics discussed included:

- Vidant Health's framework for advance care planning
    - Gave an overview of Vidant Health's 2019 work plan for advance care planning
        - Can be found on slide 4 of Ms. Ward's presentation
- What a desired state of advance care planning looks
- Challenges related to accessing ACP documents
- What if we had a designation of advance directive symbol on driver licenses like we do for organ donation
- Challenges related to ACP training
    - In medical school, there is not much discussion, if any about advance care directives
- System training and resources
- Role of doctors, nurses, and community members

Ward Presentation

All's Well That Ends Well: A Comprehensive Advance Care Planning Strategy

Elizabeth Golding, DO
Medical Director of Palliative Care Services
Cone Health

The last presentation of the day was from Elizabeth Golding. During her presentation she gave an overview of Cone Health's strategy for advance care planning. She touched upon:

- Background of Cone's advance care planning strategy
- Its financial impact
- Digital platform used within Cone' advance care planning system
- Strategic targeting within Cone's system for advance care planning
- Educational initiative and work to improve communication around advance care planning within Cone Health

Golding Presentation

Bridging the Gaps Between Law, Health Systems, and Families: Challenges and Solutions

Facilitator:

Jonathan Fischer, MD
Assistant Professor
Duke University Department of Community and Family Medicine

Task force Co-Chair Dr. Jonathan Fischer facilitated the last session of the day. The facilitated discussion was aimed at identifying aspects of care delivery the task force would like to "keep" and aspects the Task Force would like to "change".

Comments/Questions (Select):

- Need to simplify or eliminate 2 sig rules
- Needs to be uniformity in understanding of DNR between medical institutions
- Potential push back of certain faith groups who feel these conversations around end of life planning is inappropriate
- Physicians can have a role in training pastors, and attorneys on medical language in orders
- ROI for medical institutions is key for building buy in
- In Canada everyone is automatically a DNR unless there is a good reason
    - Non default DNR has no ethical or evidence behind it.
- People do not know that the default is to restitute.
    - Most people think it free as well.