

## **Serious Illness Care Task Force Meeting 4 Summary**

**North Carolina Institute of Medicine**

**630 Davis Drive, Suite 100**

**Morrisville, NC 27560**

**July 12, 2019**

**10:00am-3:00pm**

Co-Chairs in attendance: Jonathan Fischer

Members in attendance: Mary Bethel, Nathan Boucher, Vicky Bovavill, Christine Brown, Christie Burris, Sue Collier, David Cook, Linda Darden, Brad Drummond, Anne Elmore, Debbie Futrell, Beth Golding, Charles Hardy (phone), Mitch Heflin, Mark Hensley (phone), Lin Howell, Sue Kirkman (phone), Donna Lake, Kristen Lakis, Saberna Lea, Deb Love, Debi Nelson, Carla Obiol, Laura Patel, Melanie Phelps, Janna Pogers, Tim Rogers, Cherie Rosemond, David Sevier, John Smith, Keith Stirewalt, Charlotte Sweeny, Lynne Templeton, Betsy Vetter (phone), Stan Walters, Polly Welsh (phone), Donna White

Steering committee members in attendance: Steve Freedman, Cathy Sevier

Guests in attendance: Allison Crossman, Nikki Hamilton, Marrsette Hassan, Ryan Lavailey, Scott Lofland, Shane Lukas, Michael Olender, Marsha Vanhecke

Speakers: Christian Carr, Ken Deans, Brian Wood

NCIOM staff in attendance: James Coleman, Michelle Ries, Berkley Yorkery

### **Introductions and Framing Remarks for The Day**

#### **Jonathan Fischer, MD**

*Physician*

Duke Palliative Care

*Assistant Professor*

Duke University Department of Community  
and Family Medicine

#### **Michelle Ries, MPH**

*Project Director*

North Carolina Institute of Medicine

Task Force co-chair Dr. Jonathan Fischer brought the meeting to order and facilitated meeting introductions. After Dr. Fischer, Michelle Ries provided framing remarks, going over topics and activities for the day.

### **What Is the Role of Technological Solutions to Address Communication Challenges in Serious Illness Care?**

Facilitator:

**David Sevier, MS**

*Managing Director*

The Generations Study Group

Speakers:

**Christie Burris**

*Executive Director*

North Carolina Health Information Exchange Authority

**Christine M Carr, MD**

*Professor, Department of Emergency Medicine and Department of Public Health Sciences*

Medical University of South Carolina

*Sr. Clinical Advisor, South Carolina Hospital Association*

*Chief Clinical Officer, Health Sciences South Carolina (HSSC)*

**Kenneth Deans Jr., MBA**

*President & CEO*

Health Sciences South Carolina (HSSC)

**Brian Wood**

*Coordinator, Community Outreach and Research*

Mind My Health

David Sevier, Managing Director of The Generations Study Group, facilitated a presentation and Q&A session focused on developing a shared understanding of technological innovations designed to facilitate communication between patients and providers of serious illness care and the role of collaboration in implementing best practices to focus on capacity of Health Information Exchanges (HIE).

#### *Wood Presentation*

The first presentation from this session was from Brian Wood, Coordinator for Community Outreach and Research at Mind My Health. Mr. Wood presented on the work of Mind My Health: a non-profit program of the Carolina Centers dedicated to building an online platform that would facilitate advance care planning and make documents available whenever and wherever needed.

To begin, Mr. Wood reviewed the goals of Mind My Health, which are

- Develop an online platform that makes ACP documents available at the point of care
- Increase the number of people who discuss and complete an ACP document
- Work with Healthcare systems to transfer stored ACP documents in the electronic health record

After going over the goals of Mind My Health, he then provided a timeline of the progress of the Mind My Health project:

- Funded by the Duke Endowment in early 2017

- Received additional funding from NC License to Give Trust Fund Commission in 2018
- Online platform, which is free to use, began a soft launch in the Triad area in April of 2019
- Currently, Mind My Health is pursuing several approaches that would allow for the easy transfer of document into the EHR

To end his presentation, Mr. Wood talked about the next steps for Mind My Health

- Expanded sharing capacity and mobile upload capability are slated for development in coming months
- Continued collaboration with hospices, faith groups, and hospital systems is planned for Fall 2019
- Enhanced efforts to reach individual consumers and their communities will also become a growing focus

### *Deans and Carr Presentation*

Following Mr. Wood's presentation, Kenneth Deans, President & CEO of Health Sciences South Carolina (HSSC), and Dr. Christine Carr, HSSC's Chief Clinical Officer, talked about the work of HSSC's Carolina e-Health Alliance (CeHA) initiative, a South Carolina based HIE. CeHA is a partnership between hospitals and emergency departments in the Charleston, SC area dedicated to the timely sharing of vital patient information. CeHA houses and allows the sharing of the most critical data sets of patients on hospital admission & discharge, medications, allergies, diagnostics, and ED records. The sharing of this data helps providers:

- Avoid readmissions
- Avoid medications errors
- Improve diagnoses
- Decreases duplicate testing

Providers in participating systems have timely access to this data and are able to access their patient's information before they even see the patient. Deans and Carr also gave an overview of the impact and added value CeHA has had on its participating hospitals and EDs including:

- Improved quality
- Lower costs
- Improved efficiency
- Improve population health

According to Mr. Deans and Dr. Carr, CeHA supports advance care planning (ACP) by allowing patients to upload ACP documents, enabling patients and families to access them electronically. In addition, once ACP documents have been uploaded to the HIE, in cases of emergencies, EMS can access "smart 911" and see all the patient's information.

### *Burris Presentation*

The final presentation of this session was from Christie Burris, Executive Director of North Carolina's state-run HIE, NC HealthConnex. According to Ms. Burris. NC HealthConnex has more than 40,000 providers who can share their patients' health information securely and safely. Providers are able to

access patients' data in NC HealthConnex through a web-based portal or through electronic health records. Patient's data available through NC HealthConnex include:

- Demographic info
- Allergies
- Advance directives
- Medical encounters, history, and conditions
- Medications
- Medical documents/ clinical notes

Concluding her presentation, Ms. Burris talked about how NC HealthConnex is building upon its notification/alert system, using artificial intelligence and clinical intelligence engine technology.

Questions/Comments for all three presentations (select):

- Should state and non-profit HIEs partner with for-profit HIEs who have a broader reach?
  - Responses
    - For-profit HIEs have different priorities, mostly working with ACOs
    - In addition, their services are expensive
      - Not a problem for larger systems
    - Partnering with for-profit HIEs could be a short-term fix until state-run and non-profit HIEs catch up
- What is the process for patients to know information is being shared?
  - patients can opt-out of information to be shared
    - However; most patients opt-in
- In NC, home health and SNFs are exempt from integrating into the NC HIE
  - These industries are being left behind, with a lot of patient info skill kept solely on paper
  - Exemption status is decided each legislative session

### **Communication: How Are We Engaging In This Conversation and How Do We Improve?**

Facilitator:

**Cathy Sevier, DrPH, RN**

State President

NC AARP

The second session of the day was facilitated by Cathy Sevier, NC AARP State President. The goal of the second session of the day was to move the Task Force thinking toward actionable recommendations and inform the afternoon's exercise and discussion. The task force was broken up into small groups which were instructed to discuss current strengths, weaknesses, opportunities, and threats related to communication in serious illness care from one of the five following perspectives: Healthy Adult; Seriously Ill person; Family and caregiver ; Health provider community ; System communications/costs (among providers); Legal, regulatory. Below are the comments from each group (select):

### *Legal/Regulatory*

- Advance directive – simplify process, review language options, allow e-witnesses
  - Remove 2 sig requirement
  - Remove requirement for paper MOST
  - State repository needs to be improved to easily update to include latest versions
  - Remove time restrictions
  - Add organ donation to align decision-making
- Workforce: training for legal professionals, including requirement for licensure
- Training for health care providers on legal aspects
- Use NC Bar Association training modules
- Lack of elder law attorneys

### *Seriously ill caregivers*

- Four general problem areas
  - General knowledge of ACP
    - People should be aware of before they are seriously ill
  - Understanding the seriousness of the issue
  - Timing
    - When to bring the topic up of advance care planning
  - Lack of knowledge of resources needed for support

### *Healthy adult*

- Changing legislation
  - Remove 2 witness requirement
- Easier access to education is important
- Normalization conversation with adults
  - Integrate with routine visits with doctors
- Start conversations early (high school and college students)

### *Health provider community*

- Incentivize conversation through changed payment models
- Promote team-based models of identifying patient/family needs (look at Seattle Pediatric model)
- Incentivize collaboration
- Increase use of family advocates and navigators
- Assign CME requirements to ACP conversations
- Promote goals of care conversations across provider networks

### *System communications/costs*

- Intersystem collaboration
  - How do we incentivize health systems to collaborate?
- Have family advocates to serve as navigators for patients and their families

- Former patients, family caregivers, or community health workers
  - Would serve a similar role as Dulo
- Could even set the policy in place, that once someone reaches a certain level of illness care, they must be assigned a patient navigator

### **Discussion: Draft Recommendations and Next Steps**

Facilitator:

**Michelle Ries, MPH**

*Project Director*

North Carolina Institute of Medicine

The final session of the day was facilitated by Michelle Ries and was focused on small group discussion dedicated to the drafting of potential recommendations. Each small group was assigned 2 recommendation topic areas and was asked to identify and evaluate potential recommendations. Key discussions points for each topic are below:

#### Topic 1: Advance Care Planning

- Eliminate 2 signature requirement
- Promote the use of technology for sharing documents
  - Integrated across systems
  - Advance directives and MOST forms
  - Ensure portability and affordability
- Set standards for conversations across settings with consistent language
- Work with DHHS on a digital copy of MOST (HSR?) in order to address administrative barriers to MOST forms
- Value-based payments to incentivized ACP: MOST use – including for training and creation of documents
- Create central access points for providers and consumers
- Ensure that health systems will honor MOST forms regardless of origins (from other systems)
- ACP/MOST should be ongoing conversation/review – through annual wellness visits
- Normalize conversations
- Use existing technology systems in the state to increase the portability of documents
- Look at best practices for ACP portability in other states

#### *Topic 2: Language/Stigma/Semantics*

- Develop interprofessional training on illness progression – based on ELNEC training
- Train navigators on language
- Train on built-in decision support

### *Topic 3 – Care Delivery*

- Provide reimbursement for services
- Develop flexible models of care
- Train workforce on end of life care
- Develop training for community/navigators for individuals with serious illness
- Develop methods of flagging patients at substantial risk for serious illness – promote AI and predictive analytics
- Develop a paraprofessional workforce
- Replicate work of Centers of Excellence

### *Topic 4: Family Caregiver Support*

- Pass Bill 915
- Expand respite care through enhanced infrastructure
- Use Project CARE model to develop caregiver support systems for other illnesses
- Develop and promote Caregiver-Friendly communities
- Advocate for paid family leave
- Use NCCare360 to connect caregivers with resources for support
- Broadband access
- Promote geographic equity in caregiver support