

2022 **Progress Report**



A voice for serious illness care in North Carolina.

Welcome...

As I look at the [NC Serious Illness Coalition](#) at the end of 2021, I'm struck by several observations.

First of all, it's been amazing to see how much growth this new entity has experienced in less than two years. We got started at the last scheduled meeting of the NC Institute of Medicine's (NCIOM) Task Force on Serious Illness Care in January 2020, where the Task Force's first recommendation was to create exactly this coalition. We took that seriously and around 40 people came together a month later (on Valentine's day) to take the step of establishing this group. We didn't imagine that we'd need to meet remotely, online for years, but here we are.

The truly unexpected thing was that people found this coalition something they wanted to be a part of, and so it grew. Today, those initial 40 folks have been joined by over 125 additional people, which increased the new entity's capacity and reach dramatically. And it's not just been individuals. Virtually every major healthcare organization across the state has joined in, as well as many other organizations representing the interests of vulnerable North Carolinians.

A distinct second observation is that so many of the hospitalizations and deaths from COVID-19 have been among those who are the most vulnerable – many of the very individuals on whose behalf this coalition came together to provide care and for whom we advocate. While the rapid and widespread impact of the pandemic has been a very unexpected situation, it seems that the NC SI Coalition joined together at a uniquely important time to engage the reality of this need. That's not to say that the many other causes of serious illness across the state and nation are, or should be, minimized or missed in this challenging time.

During the past two years we've had a number of 'learnings,' such as a better appreciation of the intense needs of parents with seriously ill children, - or the unique environment that gay or transgender individuals face as they work to 'plan for care in advance' for

themselves or loved ones without family necessarily understanding or accepting their distinct life condition. We've also seen and learned about the devastating impact of implicit racial bias and the effects of inequity throughout the structure of health and healthcare. I know I have certainly grown, and I believe we've all grown in understanding for why we need to be even more aware and more diligent to take on issues facing seriously ill people, and the individuals who care for them, so we can find the best environment for the lives in which we are entrusted.

I'm especially proud of how our many dedicated members have brought information, and passion, and determination to make a difference for people across NC using their unique perspectives and backgrounds and skills. You've especially done it through the Coalition's four working groups – Clinical Practice & Quality, Advance Care Planning, Caregiving & Patient Engagement, and Communications/ Advocacy/Education. These groups have initiated and fostered needed legislation, organized important forums on critical issues, built further alliances around caregiving, brought about crucial conversations, and provided necessary space for relationships to grow in order to further meet people's needs.

I could go on and on about how important this Coalition has become, and how much we've all learned along the way, but let me just conclude by saying that you are truly a coalition of amazing people who care about others in so many different ways. You are the indeed the oil that enables all this to work. It's been a privilege to be a part...

David Sevier, Co-Director of NC SI Coalition

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A vision for the ‘voice of serious illness care in North Carolina’.

As the North Carolina Serious Illness Coalition comes to the end of its second year of work, the North Carolina Institute of Medicine is grateful for the expertise, energy, and wisdom of the Coalition leadership and members, and for their dedication to moving forward the recommendations of the 2020 NCIOM Task Force on Serious Illness Care, as well as to helping our partners understand the impacts of the COVID-19 pandemic across serious illness care.

The NCIOM Task Force was convened in spring 2019, in partnership with many experts around the state that provide care and advocacy around palliative care, hospice, aging, and long-term supports and services. The Task Force was comprised of over 60 members across many sectors, including clinicians, social workers, spiritual leaders, community advocates, veterans' advocates, private and public payers, legal and financial planning experts, family and caregiver representatives, health educators, and academic researchers. The Task Force developed consensus-based, evidence-based, and actionable recommendations to achieve a common vision for serious illness care in the state: The Task Force vision for serious illness care in North Carolina is a system and culture that prioritizes quality of living for people with serious illness, their families, and communities.

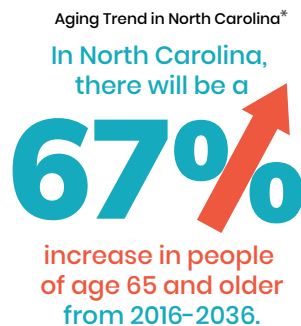
The work of the NC Serious Illness Coalition has been invaluable in ensuring that key stakeholders have the facilitated connection, support, and information they need to work toward this common vision. Especially during this time of increased focus on the health care needs of our state, the North Carolina Institute of Medicine looks forward to continued partnership with the Coalition to improve serious illness care and quality of living for all North Carolinians.

—**MICHELLE G. RIES, MPH**
Associate Director at North Carolina Institute of Medicine

NCIOM RECOMMENDATIONS FROM APRIL 2020 REPORT

There are 13 Priority Recommendations, each with very clear tasks.

- **RECOMMENDATION 2.1:** Establish coordinated statewide leadership to facilitate implementation of recommendations and ongoing work to achieve quality of living for individuals with serious illness (This has been accomplished with the establishment of the NC SI Coalition.)
- **RECOMMENDATION 2.3:** Prioritize health equity and the reduction of disparities as guiding principles throughout implementation of all recommendations of the Task Force on Serious Illness Care
- **RECOMMENDATION 3.1:** Deliver goal-concordant, coordinated, team-based care for individuals with serious illness
- **RECOMMENDATION 3.4:** Develop and apply new payment models to support palliative care delivery
- **RECOMMENDATION 3.5:** Convene a work group tasked with assessing and developing appropriate quality metrics for serious illness care
- **RECOMMENDATION 4.2:** Develop statewide initiative for improved awareness of, and support for, completion of advance care planning
- **RECOMMENDATION 4.6:** Revise signature and notary requirements for advance directives documents
- **RECOMMENDATION 4.7:** Ease administrative burden, increase participation in completing documents, and improve accuracy of Advance Directives
- **RECOMMENDATION 4.9:** Promote electronic completion and adequate integration of advance directives and portable medical orders
- **RECOMMENDATION 4.11:** Expand home- and community-based services to better support individuals with serious illness and their caregivers
- **RECOMMENDATION 4.12:** Establish Task Force on Caregiving for Those with Serious Illness and analyze additional legislative solutions and financing options to meet the needs of caregivers
- **RECOMMENDATION 5.2:** Promote models of interdisciplinary training for best practices in serious illness care, including palliative care
- **RECOMMENDATION 5.4:** Increase access to serious illness care through expanded implementation of innovative models of care delivery (including telehealth and community- and home-based care)



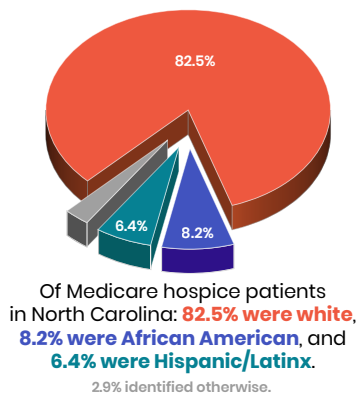


COVID's Exposure of Needs in Serious Illness Care

On February 14, 2020, when we had our founding NC SI Coalition meeting, who would have thought that in less than a month we would shut down the world as we knew it? At the time of the first meeting if you asked most of the forty plus attendees what the future had in store, we would have said regular face to face meetings, likely every 4-6 weeks, mostly in the center of the state. Beyond that, we would have aimed to grow and get started with in-person meetings focused on our thirteen priority initiatives outlined by the NCIOM Serious Illness Task Force.

So, here we are approaching our second anniversary with 160+ members representing more than 85 organizations, and still dealing with COVID. We are stronger than we could have imagined. While

Racial/Ethnic Diversity of Patients*



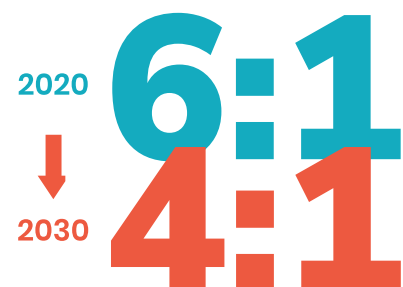
we can speculate on why that is - great timing for the serious illness cause, pent up desire on the part of leaders statewide to address legal barriers to advance care planning, or the passion of caregivers who are exhausted by the lack of concern for their wellbeing, among others. But whatever the reason(s), COVID has provided a backdrop for the NC Serious Illness Coalition to come together in force to address needed changes and opportunities for improving care.

The necessity for us to meet virtually cannot be understated and it has allowed people to show up and invest big blocks of time with colleagues - while not losing an entire day traveling. It has also given us the chance to hear from varied individuals who engage us with thinking about a coordinated approach - enhancing the quality of serious illness care regardless of location or provider site.

The arrival of COVID—a serious, infectious disease that has hospitalized and killed many, has also provided opportunities to speak out about the needs of people living with serious illness. A new urgency about advance care planning, the unique needs of the homebound and their caregivers, and the problems created by inequality in providing health care have all been magnified - and are now more apparent to us all. While not remedied, we have seen previously unappreciated issues take center stage and get some of the attention they deserve.

We do not know how COVID will impact 2022 or 2023, but we are certain that the work of the Coalition is crucial to serious illness care across the state, and the tasks we have identified will have an increasingly significant place in the work of our members and the larger community.

Number of Caregivers per Adult*



By 2030, there will only be 4 caregivers for every adult in North Carolina.

*Source: NCIOM Task Force Report April 2020

NORTH CAROLINA SERIOUS ILLNESS COALITION

WORK GROUP SUMMARIES

- **Clinical Practice & Quality**
- **Advance Care Planning**
- **Caregiver & Patient Engagement**
- **Communications, Advocacy
and Education**

Clinical Practice & Quality



The Clinical Practice Work Group is committed to improving the quality of care for seriously ill patients in North Carolina. The goal of the work group is to assure consistency in palliative and end-of-life care throughout the state.

OUR ACTION ON RECOMMENDATIONS

DURING 2021, the Clinical Practice & Quality Work Group hosted a series of continuing education programs focused on predictive analytics, financing care, spirituality, and roles and responsibilities of clinical providers. These recorded programs featured clinical and administrative experts who offered insights and opportunities for colleagues to examine current practice and ways to more effectively provide high quality care.

OUR NEXT STEPS

Following two years of the pandemic, the clinical practice work group, like many national experts, sees an even greater imperative to focus on the provision of goal concordant care to the seriously ill population. This year the work group plans to work with NCSI Coalition members to develop a directory of palliative care services in North Carolina. The work group will also actively examine the changing field of clinical care by focusing on the challenges of frailty and the importance initiating clinical conversations and documentation that result in goal-concordant care. Several programs will focus on these topics and will guide recommendations of the group.



Advance Care Planning

The purpose of the NC SI Coalition Advance Care Planning (ACP) Work Group is to make it easier for North Carolinians to learn about, complete, and access advance directives and portable medical orders (including the MOST form), so that each individual receives care aligned with their personal goals and wishes.

OUR ACTION ON RECOMMENDATIONS

- **DEVELOPED PLAN TO ALIGN NC MOST FORM WITH NATIONAL POLST AND SET THE STAGE FOR ELECTRONIC PORTABLE MEDICAL ORDERS**
A subcommittee has worked diligently to enhance portable medical orders in NC for the short and long term. Revisions have been drafted to the NC portable DNR order and to align the NC MOST with National POLST and have been reviewed with a number of stakeholders. Changes proposed to the portable DNR form do not require legislative change and are currently under review by the Ethics and Judicial Affairs Committee of the NC Medical Society, preparatory to acceptance by NC Office of Emergency Management Services (OEMS) – hopefully by mid-2022. Planning has begun related to legislative changes which would align the NC MOST with POLST and to adopt electronic documents.
- **INITIATED PLANNING FOR COMMUNICATION SKILLS TRAINING SPECIFIC TO NEEDS OF HISTORICALLY MARGINALIZED AND RURAL PATIENT POPULATIONS**
Recognizing that communications skills training is offered at major healthcare systems, a sub-committee has proposed provider trainings focused on serving historically marginalized and rural patient populations, including an outreach to engage local community influencers. Final plans will be shaped by the results of a research study, for which The Carolinas Center (TCC) is the fiscal agent, to test use of the Serious Illness Conversation Program from Ariadne Labs in communities of color.
- **SUPPORTED LEGISLATIVE EFFORT TO SIMPLIFY ADVANCE DIRECTIVE SIGNATURES**
The ACP workgroup took the lead in promoting legislation to simplify completion of a valid advance directive by replacing the need for BOTH two disinterested witnesses AND notarization with allowing EITHER two disinterested witnesses OR notarization. Senate Bill 666 passed unanimously in 2021 and its companion House bill is slated for consideration in the 2022 short session.
- **CREATED GLOSSARY OF TERMS RELATED TO ADVANCE CARE PLANNING**
In order to support consistent use of messaging and reduce confusion about the various elements of Advance Care Planning the work group created a draft glossary of terms. When finalized, this will be used as a companion piece to materials and education efforts produced by the Coalition.
- **PROVIDED WORKSHOPS ON ADVANCED CARE PLANNING**
Workshops were offered in the spring of 2022 to align with National Healthcare Decisions Day. The ACP and Clinical Practice work groups combined efforts to host a 2-part “lunch and learn” style educational offering in April 2022, focused on ACP and Goals of Care communication skills with the theme - “It’s a team sport”. This effort was supported by Area L AHEC, offering the opportunity for free education credits for various clinical disciplines, and both were well attended.

Making a Difference

“Completing my Advance Directives was very important to me, especially recently when I had a near miss car accident.

I come from a large family. Unfortunately my children are deceased so I have no one that would speak for me. I wanted to complete the AD now while I was in my right mind and speak for myself as to what my choices/preferences and wishes were. By doing this, it prevents my husband from going up against my family, and possibly going against what they think I should have versus what I actually want.”

—Certified Nursing Assistant



OUR NEXT STEPS

Finalize and advance interdisciplinary communications skills training plan

Learning from the results of the Serious Illness Conversation Program and working with The Carolinas Center, the work group will continue efforts to develop and offer programs to enhance support for historically marginalized and rural populations.

Promote changes, including specific legislative revisions, to enable alignment of the NC MOST with National POLST model, including electronic MOST/POLST

The subcommittee focused on enhancing the MOST form will continue to obtain stakeholder input on proposed changes to the MOST/POLST form and will work with representatives from the NC Health Information Exchange Authority to facilitate electronic versions of the form. Introduction of enabling legislation for both the new MOST/POLST form and electronic recognition will be targeted for the 2023 session.

Some changes recommended to the current North Carolina MOST and/or the Portable DNR form do NOT require legislative approval and would move North Carolina's practices towards greater alignment with National POLST.

Work group members have been working with the North Carolina Office of Emergency Medical Services and North Carolina Medical Society to try and secure the necessary buy-in to make these changes as soon as possible.

Improve tools for ACP

Finalize and achieve consensus on the glossary of Advance Care Planning terms and launch for use in conjunction with new materials.

Promote awareness of ACP

The work group is looking to host a consumer focused informational session in 2022, and will pursue this effort pending finalization of the Glossary of Terms to support the consistency and clarity of all Coalition presentations.

Improve professional education on ACP

Provide clinical practice forums specific to ACP. In addition to the March/April "It's a team sport" concept offered in the spring of 2022, the work group plans to host workshops focused on other ACP related topics in partnership with the Clinical Practice and/or Caregiver & Patient Experience work groups.

Caregiver & Patient Engagement

The purpose of the Caregiver and Patient Engagement Work Group is to develop action plans that address two priority recommendations from the NCIOM Serious Illness Task Force. These recommendations support patient, family, and caregiver engagement through efforts to revise/create policies and processes that address the financial burden and physical and mental well-being of family caregivers.

OUR ACTION ON RECOMMENDATIONS

• CAREGIVING COLLABORATIVE FORMATION

Members of the Caregiver & Patient Experience (CPE) work group, members of two other coalitions (the North Carolina Coalition on Aging and the Children's Complex Care Coalition of North Carolina) and other stakeholders formed the Caregiving Collaborative and began meeting in late 2021 to align efforts around support for caregivers of those with serious illness across the lifespan in North Carolina. The Caregiving Collaborative group plans to work together toward raising awareness of serious illness caregiving issues, advocating for better support for caregivers, and improving patient engagement in health care.

• NAC UNIFIED STATE STRATEGY INITIATIVE

North Carolina was one of 5 states invited to participate in this National Alliance for Caregiving initiative. CPE work group members attended educational webinars on topics related to task force establishment and coalition building for advocacy to help support caregivers across the lifespan. Mentoring sessions with other states that formed caregiving coalitions and/or established caregiving task forces were invaluable for helping our group clarify its mission and continue the momentum it had built.

• HOSTED CAREGIVING FORUMS

To better inform Serious Illness Coalition members on issues faced by caregivers, the work group hosted two forums in 2021. The first was a research presentation about the state of family support policies in the United States and how these may inform the work group's efforts. The other was a screening of the documentary *Caregiver: A Love Story*, followed by a short discussion about challenges faced by caregivers.

Making a Difference

"Patients and caregivers are invaluable experts on the health care team.

Being part of the Caregiver and Patient Engagement Workgroup continues to inspire me both professionally and personally. The group is refreshingly diverse and centers on lived experience.

It is the lived experience that drives our work to cultivate partnerships, advance policy and seek systematic solutions to create awareness and improve our systems of care. "

HEATHER
BURKHARDT, MSW
Executive Director,
NC Coalition on Aging



OUR NEXT STEPS

Caregiver Listening Sessions

CARES Act funds were secured through the North Carolina Department of Health and Human Services to study the effects of the Covid-19 pandemic on caregivers. A subgroup of the CPE work group is finalizing a proposal to use the funds to host up to 6 virtual listening sessions throughout North Carolina with small groups of diverse caregivers to learn more about existing needs, challenges, gaps, and barriers.

Additional Forums

The CPE work group plans to host at least two caregiver and patient engagement forums in 2022, to help Coalition members and other stakeholders understand the challenges, gaps, and barriers to support for caregivers of those with serious illness across the lifespan.

Additional Funding Opportunities

The CPE work group will consider additional potential funding opportunities for advocacy and awareness-raising purposes.

Task Force Establishment

Much of the work group's efforts will continue to focus on the establishment of a state-level task force. Documents completed by work group members to support this effort include:

- Return on investment report - compiled from existing research and reports with data on caregiving across the lifespan, and specific to North Carolina where possible.
- CPE work group charter updates – the charter identifies recommended tasks for the task force to undertake, once formed.
- Recommended task force member list

These documents can be provided for reference to the Task Force, when and if it is formed.

Communications / Advocacy / Education

The NC Serious Illness Coalition Communications, Advocacy and Education working group is a vital support mechanism to foster active collaboration and cooperation across all work groups that comprise the NCSI Coalition. The work group will accomplish this by providing communications expertise, gathering useful information and disseminating that information via various communications channels, advocacy best practices, and educational tools.

OUR ACTION ON RECOMMENDATIONS

- **DEVELOPED BRAND MATERIALS**

It's hard to be the "Voice of Serious Illness Care in North Carolina" without a voice, right? The team met and determined many different elements of a cohesive organizational brand strategy to best support the Coalition members and each of the different work groups.

- **DEVELOPED COMMUNICATIONS PLAN**

To get the Coalition's initiatives advanced, members and Work Groups shared their primary needs in advancing the recommendations of the North Carolina Institute of Medicine's Task Force on Serious Illness Care. One key to evolving serious illness care in North Carolina is to raise awareness of the options and opportunities that exist to own one's health and plan for care in advance as well as build sustainable solutions with industry leaders who recognize that collective action can have much needed impact on future legislation and practices.

- **SUPPORTED ACP ADVOCACY EFFORTS**

One of the many ways that the Coalition works to connect North Carolinians with their own serious illness care is through drawing attention to advance care planning (ACP) in collaboration with the ACP working group as well as encouraging increased adoption and utility of the ACP documents. The work group supported these efforts through various channels, and continue to collaborate in educating and motivating communities to make advance care planning part of their day-to-day health practices. Part of this collaboration includes the Coalition's close communication and coordination with The Association for Home & Hospice Care of North Carolina (AHHHC) along with the AHHHC Governmental Affairs staff and lobbying team regarding the Coalition's advocacy efforts, most notably SB 666.

- **BUILT MORE ROBUST WEBSITE**

The website is a core resource where Work Groups share information and the public can access content including our recorded Friday Facts interview series with industry leaders, healthcare professionals, and community organizers from North Carolina and beyond.

Making a Difference

"It's so fulfilling building community with others in the Communications, Education, and Advocacy work group.

Giving voice to serious illness care in North Carolina is a major responsibility as Coalition members share their experience, insights and passion. It's powerful.

Whether collaborating with health care stakeholders or connecting with patients, providers, and caregivers, our message connects to every North Carolinian: **Everyone must be able to own their health and plan for care in advance.**"

—Work Group Member



OUR NEXT STEPS

Advocate for Legislative Changes Consistent With North Carolina Institute of Medicine's Task Force on Serious Illness Care recommendations

This Work Group will continue its work advancing awareness and adoption of the recommendations through increased connection with media, Coalition members, and community leaders.

Support the Remote Online Notary bill

We will be taking steps to encourage increased awareness and comprehension of legislation that increases accessibility to advance care planning documentation.

Expand the North Carolina Serious Illness Coalition Website

Enhance our current website with increased resources for community leaders, caregivers, and individuals seeking more information about being able to own their health and plan for care in advance. The expanded site will also increase access to additional serious illness resources.

Introduce Opportunities to Collaborate with the Direct Care Workforce, Industry Leadership, and Elected Officials

Through targeted education and awareness live and virtual events such as Friday Facts as well as live forums, we will be expanding more opportunities to hear the many voices invested in the future of serious illness care.

Our Vision & Next Steps

As the Coalition makes strides in furthering its mission of supporting and advancing serious illness care across North Carolina, focus will remain on continuing the work of addressing the NCIOM task force recommendations. The Coalition's four working groups continue to diligently address the priority issues identified within their groups. The following are the major focus areas of the Coalition for 2022:

INCREASING AWARENESS OF ADVANCE CARE PLANNING

- Improving tools, professional education, and awareness
- Advocating for the electronic upload of ACP documents in the NC Health Information Exchange.
- Continuing efforts around eMOST and alignment with the National POLST

ADDRESSING THE NEEDS OF INDIVIDUALS LIVING WITH SERIOUS ILLNESS, AND THOSE CARING FOR THEM

- Providing educational sessions targeting caregiving to increase awareness of the challenges, gaps, and barriers to support caregivers of those with serious illness across the lifespan
- Establishing a state-level caregiving task force

PROVISIONING GOAL-CONCORDANT CARE TO THE SERIOUSLY ILL POPULATION

- Developing a directory of palliative care services in North Carolina
- Actively examine the changing field of clinical care by focusing on the challenges of frailty and the importance of initiating clinical conversations and documentation that result in goal-concordant care.

ADVOCATING FOR LEGISLATIVE CHANGES CONSISTENT WITH THE NCIOM'S TASK FORCE ON SERIOUS ILLNESS CARE RECOMMENDATIONS

- Supporting the Remote Online Notary Bill
- Expanding the Coalition's Website
- Introducing Opportunities to Collaborate with the Direct Care Workforce, Industry, and Elected Officials

PRIORITIZING HEALTH EQUITY & DIVERSITY AND REDUCING DISPARITIES

- Increasing diverse representation in organizational participation and leadership
- Responding through actions, initiatives, and programming to health disparities in serious illness care for minority and disabled communities

As always, the Coalition remains committed to empowering those living with serious illness, their families, and their communities by providing them with the resources they need to make appropriate decisions related to serious illness care.

—Virginia Slocum, Executive Director, NC SI Coalition





View the report online at
ncsicoalition.org/progress-report-2022

The North Carolina Serious Illness Coalition is a volunteer-led
group of health professionals, providers, and caregivers.

ncsicoalition.org • info@ncsicoalition.org