

An introduction to the Serious Illness Care sustained area of focus.

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WHY SERIOUS ILLNESS CARE

We understand serious illness to mean any health condition with poor survival outcomes that makes daily life difficult for a patient and/or their caregiver.

Serious illness care has long been an area in need of improved care and reformed payment models. **As end-of-life costs escalate, both North Carolina and South Carolina routinely fall behind the nation and neighboring states on measures indicating how patient choice and quality of life are prioritized.**

Care that focuses on eliciting patient needs reveals a preference for care at home among the seriously ill, however, **both Carolinas rank below the state average for the share of Medicaid long-term supportive services expenditures in a home or in a community-based setting.**

Providers and case managers have little latitude to activate flexible, goal-concordant care options for patients and caregivers based on patient input. Payors have few choices when it comes to reimbursing for expensive treatment interventions that patients potentially don't want or need to enhance their quality of life but are intended as measures to help, yet have even fewer options to support alternative assistance measures that may be more meaningful. Outcomes for both patients and caregivers can be costly and painful in the name of prolonging a fragile life, but often go against a patient's wishes or best interests, ultimately.

Currently, there is no comprehensive payment model that allows a care manager to appropriately and compassionately select interventions from a variety of services to support a patient who is approaching the end of life. Care that is driven by traditional fee-for-service models often leads to avoidable or excessive treatments that don't accomplish patient goals and affect not just the individual, but family and caregivers, as well. Payors and providers need more flexibility to help identify and provide innovative interventions to patients and caregivers for better outcomes and satisfaction at a most important time.

THE CURRENT LANDSCAPE

The on-the-ground reality is one of disparate services that often don't match patients' medical needs or personal preferences, with few positive outcomes for key demographics. In response to this realization, there have been numerous advocacy groups and initiatives launched in recent years to improve access to high quality, equitable serious illness programs across the Carolinas. Additionally, in the last decade alone, there have been tens of millions of dollars in private philanthropy investment directed towards this topic in the Carolinas, as well. However, the diverse group of stakeholders are each engaged in programs targeting local communities or hospitals, or specific gaps in care.

As the number of people living longer with progressive illnesses and disabilities grows across the Carolinas, there is additional need for coordinated services, programs and policies. Patients with serious illnesses receive a range of treatments but face a common risk for poor quality of life, expensive care, and poor treatment outcomes. Serious Illness is a complex topic area. Many stakeholders are and want to be part of future innovation – and a real solution – but do not have a common forum in which to collaborate or affect systemic change.

IDENTIFYING THE CHALLENGES

Beginning in early 2020, CaroNova (formally the Carolinas Health Innovation Institute) conducted a discovery period to better understand the problems facing serious illness care. The team, led by staff from NCHA and SCHA, met with more than 150 stakeholders including patients with a serious illness, providers, subject matter experts, caregivers, healthcare workers and advocates. Some of the key outcomes accomplished were the identification of critical stakeholders, completion of an environmental scan, development of a logic model, drafted problem statements, a co-designed patient journey map with patients and caregivers, and the creation of a serious illness framework to inform the next steps of program development.

The learnings from this period were synthesized into four problem statements that provide focus and grounding for desired solutions to work towards:

1. **The needs of serious illness patients extend beyond the traditional healthcare delivery system.** The number of people living longer and with serious illness is growing, creating additional necessity for services, programs, and policies to meet the needs of these individuals and their caregivers.
2. A **lack of upstream education and training for providers is a barrier** to high quality, cost-effective, patient-centered serious illness care. Patient voices must be at the center of serious illness innovation; training and support for providers to have these critical conversations is a must.
3. Many **existing programs do not share a common language, vision, metrics, or focus**, creating gaps and a lack of continuity and consistency among comprehensive services for serious illness patients and caregivers.
4. There is a **lack of coordinated comprehensive and equitable access to serious illness services across settings and transitions of care.** There is an opportunity to increase awareness and collaboration among all the serious illness stakeholders.

OUR APPROACH TO FINDING SOLUTIONS

To reach a future in serious illness care where we can measure improved outcomes for patients and caregivers, lower costs for families and payors, and reduce disparities in access, will require a complex approach.

CaroNova adheres to a rigorous 7-step process to identify and guide solution development. Through the earlier discovery stages of this process, we determined that to truly and systemically address the challenges around serious illness care we cannot rely on one program model or one policy change, but will build a portfolio of potential solutions that can provide evidence-based serious illness care to 100% of patients who meet a pre-determined clinical criterion. This suite of interventions should involve both upstream strategies like provider training, and immediate clinical care solutions.

Solutions should focus on developing new payment strategies that support coordination across a continuum of care for goal-concordant services to patients and caregivers, and advocate for policy opportunities that eliminate barriers to this care.

The care model should include these four components:

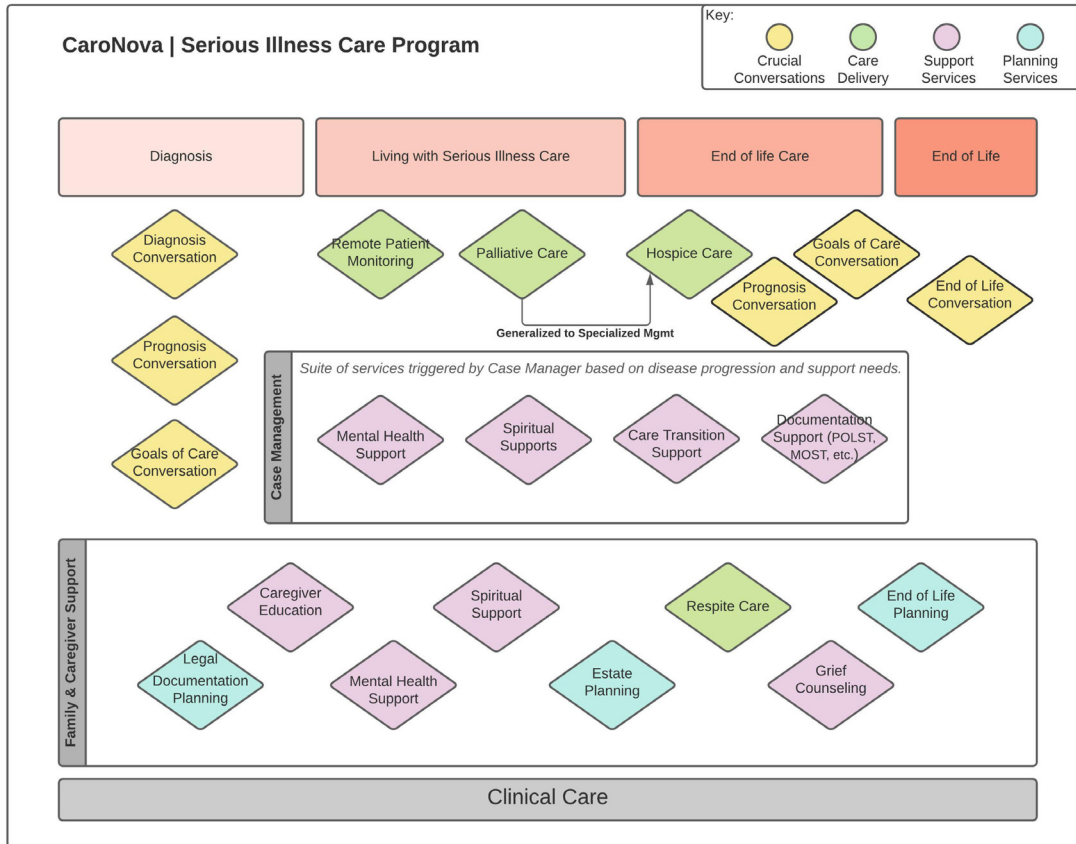
1. Crucial conversations throughout the life of the patient
2. Case management inclusive of:
 - › Mental health and spiritual support
 - › Care transitions
 - › Documentation support & end of life planning
 - › Remote patient monitoring
3. Family and caregiver support inclusive of:
 - › Caregiver education
 - › Mental health and spiritual support
 - › Legal documentation and end of life planning
 - › Respite care
 - › Grief counseling
4. Palliative care and hospice care
 - › Generalized to specialized management

Each of the four components of the serious illness care program model has evidence-based and evidence-informed strategies that are currently being deployed in the Carolinas. However, there are currently no programs that are coordinating and reimbursing across a full continuum for these services.

In keeping with the purpose of CaroNova to redefine systems of care to equitably and sustainably meet the health needs of the Carolinas, **CaroNova will take a multi-pronged approach of working with subject matter experts to align the care delivery model, while collaborating closely with experts in health care finance to co-develop the guidelines for effective reimbursement.**

Subject matter experts have been recruited from both North Carolina and South Carolina to form a topic action team (TAT). The TAT will review the drafted program framework, identify a disease state of focus, and work to establish core elements of care delivery for serious illness care. It is understood that between the two states there may be nuances in program details and application based on state-specific regulatory or finance parameters, however the model structure can potentially be similar enough to facilitate co-design efforts by representatives from both states.

PROGRAM FRAMEWORK



THE PATH FORWARD

July 2021-September 2021

- › Recruit subject matter experts from North & South Carolina to form a topic action team (TAT) to review program framework and establish payment pilot core suite of services
- › Engage health finance experts to refine metrics
- › Determine disease state to design model for based on payor and provider interest and opportunity

September 2021-November 2021

- › Work with TAT to establish core suite of services for identified disease state pilot
- › Engage payor(s) with interest in topic to review metrics and provide feedback
- › Engage provider(s) with the capabilities/flexibility to incorporate all elements of our proposed model to provide feedback

November 2021-June 2022

- › Create guidelines for effective reimbursement leveraging health care finance experts from the Carolinas
- › Recruit payor & provider to act as initial pilot sites
- › Formalize commitment with provider and payor to refine and test potential payment design model
- › Onboard sites for late 2022 program launch