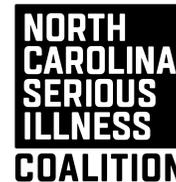


Overview of the 2020 NCSI Coalition Member Survey



SUMMARY

As the NCIOM Task Force on Serious Illness Care completed its year-long work in early 2020, the first recommendation from the Task Force was to create a Coalition to carry on the group's efforts and to seek implementation of a number of specific recommendations. The NC Serious Illness Coalition (NCSIC) was quickly created and began work to implement those goals. In subsequent months the Coalition has grown to over 150 members and 80+ organizations represented across NC.

In early considerations for a NCSIC strategic plan, it was clear that Coalition members would benefit from better understanding how various organizations and communities address the challenges of assisting those with serious illnesses. Thus, members of the Coalition's Communication, Advocacy and Education Workgroup began work on a survey of Coalition members' serious illness communication practices. A subset of this work group, the Communications Analysis Team (CAT), created a survey, managed its launch, analyzed the findings, and offered a baseline of suggestions for Coalition workgroup consideration

The Survey itself provides a beginning point for information about the many organizations engaged in serious illness care across the state, broken out according to interests of our Work Groups (Advance Care Planning, Clinical Practice, Caregiving and Patient Engagement, and Communications, Advocacy and Education). One goal of the Coalition is to provide these valuable resources as point-in-time findings, and to then build ongoing capability to update regularly as new information is gained. We hope to organize this in a "dashboard" format for key data relating to these issues.

One of the most significant findings of the Survey was the breadth and availability of resources being used by respondents to aid many aspects of serious illness topics. They are subdivided into four categories: patients, public, staff, and medical professionals. While not exhaustive, the charts provide a snapshot of tools currently used in NC.

A further benefit of this substantial document is represented through the depth of knowledge reflected by the key Coalition members contributing to this resource. Experts in their own right, each of the CAT members contributed substantially to the production of this prodigious volume of information, making this a truly collaborative effort benefitting many within the state addressing serious illness care.

KEY POINTS

The Communications Analysis Team (CAT) has outlined both the NCIOM recommendations and their specific Action item(s) for the various workgroups to consider in their charters.

The survey findings provide vital information for level-setting the Coalition's strategic goals and objectives.

- **Only 5/26 responding organizations reported using their website to provide information about the MOST form**, compared to a range of 9-16 organizations that use their website to provide information on 11 other serious illness topics.
- **Newsletters, Advocacy Alerts and Brochures are the media used most frequently to find serious illness information.** Newsletters are the first priority for 45% of respondents. In nearly 20 counties in North Carolina, households only have between *35% to 50% access to the internet.*
- **Currently in North Carolina, the ratio of potential caregivers aged 46-64 to those over the age of 80 is eight to one.** By 2030, there will only be *four potential caregivers* for every older adult in the state.

We look forward to next steps in maintaining and updating data relating to the growing role of the NCSI Coalition. [Review the primary document here](#) in order to access its rich trove of information, and join us in our thanks to its capable producers: Glenn Field, Christine Brown, Wendee Cutler, and David Britt.