

# **NORTH CAROLINA SERIOUS ILLNESS COALITION**

## **2020 Member Survey One Evaluation Report**

### **Report Created by**

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# Executive Summary

## Introduction

As members of the North Carolina Serious Illness Coalition (NCSIC), we agree that **living with a serious illness is one of the biggest challenges we face personally, as a state and amongst our membership**. The NCSIC was formed to fulfill the vision of the North Carolina Institute of Medicine (NCIOM) Task Force on Serious Illness Care, which is, prioritizing quality of living for people with serious illness, their families and their communities.

NCSIC will implement the consensus based, evidence based, and actionable recommendations in the NCIOM report, “Improving Serious Illness Care in North Carolina”, available at: <https://nciom.org/nciom-task-force-makes-recommendations-for-improving-serious-illness-care-in-north-carolina/>. The reader is strongly encouraged to have this report on hand as you review this Evaluation Report.

As part of the early considerations for developing a NCSIC strategic plan, it became clear that Coalition leaders and members would benefit from an understanding of how the membership currently addresses the challenges of assisting those with serious illnesses, within their organization and community. Thus, members of the Coalition’s Communication, Advocacy and Education Workgroup began work on a survey of Coalition members’ serious illness communication practices. A subgroup 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 actions per a request from the NCSIC Executive Committee.

The survey findings provide a point-in-time SWOT analysis of the status of addressing serious illness in North Carolina. As such, it provides vital information for level-setting the Coalition’s strategic goals and objectives.

The Communications Analysis Team (CAT) made every effort to tie the survey findings to all related NCIOM Task Force recommendations. **The CAT team has outlined both the NCIOM recommendations and their specific Action item(s) for the various workgroups to consider in their charters.**

**The four NCSIC workgroups will be identified in this Report as follows:**

- Advance Care Planning – ACP
- Caregiver and Patient Engagement – CPE
- Clinical Practice Workgroup – CP
- Communications, Advocacy and Education – CAE

The survey findings relate to twelve NCIOM Task Force recommendations of which six are *priority recommendations* (indicated with an \*) The twelve recommendations are 2.1\*, 2.3\*, 3.1\*, 3.2, 4.1, 4.2\*, 4.3, 4.4, 4.10, 4.13, 5.2\*, and 5.4\*.

1. **Priority** 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.  
(All workgroups see page 8 of the NCIOM Executive Summary, Actions 1-4)
2. **Priority** 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.  
(All workgroups see page 9 of the NCIOM Executive Summary)
3. **Priority** Recommendation 3.1\*: Deliver goal-concordant, coordinated, team-based care for individuals with serious illness.  
(Page 10 of the NCIOM Executive Summary Actions 1, 2, 3 and 5)
4. Recommendation 3.2: Incorporate regular and timely assessment processes to identify and develop effective and goal-concordant plans of care for individuals with higher health needs.  
(Page 10 of the NCIOM Executive Summary Action 3)
5. Recommendation 4.1: Support patient and family engagement through health care organization policies and processes.  
(Page 12 of the NCIOM Executive Summary Actions 3 and 6)
6. **Priority** Recommendation 4.2\*: Develop statewide initiative for improved awareness of, and support for, completion of advance care planning.  
(Page 13 of the NCIOM Executive Summary Actions a-h)
7. Recommendation 4.3: Promote training on advance care planning for legal and financial planning professionals.  
(Page 13 of the NCIOM Executive Summary Action 4)
8. Recommendation 4.4: Promote training on advance care planning for health care professionals.  
(Page 13 of the NCIOM Executive Summary Actions 1, 2, 3, 5, and 6)
9. Recommendation 4.10: Improve access to advance care planning documents through optimization of health information technology.  
(Page 15 of the NCIOM Executive Summary Actions 1a.)
10. Recommendation 4.13: Develop employer resources for supporting working caregivers.  
(Page 16 of the NCIOM Executive Summary Actions 1 and 3)
11. **Priority** Recommendation 5.2\*: Promote models of inter-professional training for best practices in serious illness care, including palliative care.  
(Page 18 of the NCIOM Executive Summary Action 3)
12. **Priority** 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).  
(Page 18 of the NCIOM Executive Summary Action 2)

## Survey Response Characteristics

- Survey participation was 32.5% of the total Coalition member organizations. Thirty percent (30%) is the published industry standard average response rate for email surveys.
- At least 32 individuals were known to have participated from 26 of the 80 total NCSIC member organizations.
- A similar number of organizations opened the survey but did not complete it; the survey window was brief - the first two weeks of December 2020 - and many potential respondents experienced heavy workloads related to addressing Covid.

*Are these survey findings representative of the larger membership?* From a geographic perspective, analysis of the distribution of corporate office addresses by county of respondents versus non-respondents revealed that the distributions were very similar.

Some of the larger networks were not able to respond. This is a two-edged sword: NCSIC is missing out on probable resources the larger networks have found or created, but their absence won't obfuscate the most telling findings in 1 and 2 below.

## Major Findings

1. The finding of greatest import is *an average of nearly 40% of organizations are not using a website, intranet or internal portal, nor an EAP to make resources on serious illness available*. Websites are used by 25.2% of organizations, followed by Intranet/Internal Portal (19.8%) then EAP (6.9%.) **This finding benefits all workgroups in accomplishing Recommendation 4.10,**  
**Action 1a: All**
2. When asked what educational resources/tools are most beneficial when explaining various serious illness topics, *the overwhelming response for every topic was Not Applicable*, representing 39% of all responses and ranging from 30.8% for Advance Care Planning Process to 42.3% for Hospice-related questions. **This finding benefits the following workgroups in accomplishing Priority Recommendation 3.1**  
**Action 1: ACP, CPE, CP**  
**Action 2: CPE, CP**  
**Action 3: ACP, CPE, CP**  
**Action 5: CAE.**
3. *Only 5 of the 26 responding organizations reported using their website to provide information about the MOST form*, compared to a range of 9 to 16 organizations that use their website to provide information on 11 other serious illness topics. **This finding benefits workgroups in accomplishing Recommendation 4.4**  
**Action 1: ACP, CP, CAE**  
**Action 2: ACP, CPE, CAE**  
**Action 3: ACP, CP**  
**Action 5: ACP, CP**  
**Action 6: ACP, CAE**  
  
**And this finding benefits the following workgroups in accomplishing Recommendation 4.10**  
**Action 1: All**
4. The other topics which respondent organizations did not provide information above the average percentage are: Hospice Care (48.6%), Serious Illness Resources Section (47.6%), Hospice Medicare Benefit (45.7%), Home Health (45.5%) and Palliative Care (41.7%.) **This finding benefits the following workgroups in accomplishing Priority Recommendation 3.1**  
**Action 1: ACP, CPE, CP**  
**Action 2: CPE, CP**  
**Action 3: ACP, CPE, CP**  
**Action 5: CAE,**  
  
**And Recommendation 4.13**  
**Action 1: CPE, CAE**  
**Action 3: ACP, CPE, CAE.**
5. *Just a third (an average of 32.9%) of organizations are providing dedicated resource information about serious illness topics to their employees*. The percentage varies greatly depending on the topic from a low of about 20% for a Wellness Resources section that includes Advanced Care Planning and Directives to almost 65% for the MOST form. About 15% are providing this information as part of new employee orientation trainings, workshops and presentations. **This finding benefits the following workgroups in accomplishing Recommendation 4.13**  
**Action 1: CPE, CAE**  
**Action 3: ACP, CPE, CAE.**

6. *All 100 counties in North Carolina are served by NCSIC members.* Depending on the county, there are between 14 and 20 or 53.8% to 76.9% of the total 26 responding member organizations that provide services to each county in North Carolina. **This finding benefits all workgroups in accomplishing Priority Recommendation 2.1\***  
Action 1: All  
Action 3: All.

7. Seven respondent organizations characterized themselves as Educator/ Educational Institution (11.5%) which suggests potential resources on hand to assist with addressing the many educational aspirations of the Coalition. **This finding benefits all workgroups in accomplishing Priority Recommendation 2.1\***  
Action 1: All.

**This finding will benefit completion of Recommendation 4.3**  
Action 4: ACP, CP, CAE.

**This finding will benefit completion of Recommendation 4.4**  
Action 1: ACP, CP, CAE  
Action 2: ACP, CP, CAE  
Action 3: ACP, CPE, CAE  
Action 5: ACP, CP  
Action 6: ACP, CAE.

**This finding will also benefit Recommendation 5.2 Action 3: All.**

8. *Less than half (42.3%) of responding organizations state that their staff have been advocating for people to plan for an unexpected serious illness for some time.* The remaining organizations are more reactive, or not providing this assistance. **This finding benefits all workgroups in accomplishing Priority Recommendation 2.1\*,**  
Action 3: All.
9. *There are 20 identified respondents who are comfortable with being a spokesperson for public/media presentations in their geographic area on behalf of the Coalition.* **This finding benefits all workgroups in accomplishing Priority Recommendation 4.2\*,**  
Action c: CAE.
10. *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. Print resources are key given that in nearly 20 counties in North Carolina, households only have between 35% to 50% access to the internet. **This finding benefits all workgroups in accomplishing Recommendation 2.3.**

**And benefits all workgroups in accomplishing Priority Recommendation 4.10,**  
Action 1a: All.

**Note:** This finding helps all Coalition members accomplish our NCSIC recommendations, but also key intel to incorporate into an individual organization's strategic communications plan.

**Primary Suggestions of the Communications Analysis Team (CAT) Over The Next 30 to 120 Days:**

1. Coalition workgroups review **Recommendation 2.1\***,  
**Action item 4:** Develop work plans for prioritization and implementation of recommendations, by utilizing the Survey findings. **After review of the survey findings, workgroups could consider revising their charters.**
2. Review the NCSIC website to determine if it is a consumer friendly resource with quick and easy access to needs identified in the Survey and the various audiences outlined in the NCIOM report. **This action will benefit all workgroups in accomplishing Priority Recommendation 4.2\*.**  
**Action 1a: CAE,**  
**Action 1b: All workgroups**  
**Action 1c: CAE**  
**Action 1d: CP**  
**Action 1e: CAE**  
**Action 1f: CAE**  
**Action 1g: ACP**  
**Action 1h: ACP, CPE.**
3. The CAE workgroup consider creating a serious illness communication deliverable (useable in print and online versions) from the NCIOM Final Report language and visuals. This deliverable would focus on the 12 serious illness topics and include current forms. The CAE workgroup would vet this deliverable with the three other workgroups. The goal would be to provide our members, key organizations outlined in the NCIOM Matrix A&B, and other stakeholders identified throughout the NCIOM report with tools related to each recommendation. This NCSIC communication deliverable will provide at least 20% of our member organizations with a resource to incorporate fully or integrate into their existing serious illness communication resources.

**This action will benefit all workgroups in accomplishing Priority Recommendation 2.3.**

**This action also benefits workgroups in accomplishing Priority Recommendation 3.1.**

**Action 1: ACP, CPE, CP**  
**Action 2: CPE, CP**  
**Action 3: ACP, CPE, CP**  
**Action 5: CAE.**

**This action also benefits workgroups in accomplishing Priority Recommendation 4.1.**

**Action 3: CPE, CP**  
**Action 6: CAE.**

**This action will benefit all workgroups in accomplishing Priority Recommendation 4.2\*.**

**Action 1a: CAE**  
**Action 1b: All workgroups**  
**Action 1c: CAE**  
**Action 1d: CP**  
**Action 1e: CAE**  
**Action 1f: CAE**  
**Action 1g: ACP**  
**Action 1h: ACP, CPE.**



**This action also benefits accomplishing Recommendation 4.13.**

**Action 1: CPE, CP**

**Action 3: CPE, ACP, CAE.**

**This action also benefits accomplishing Priority Recommendation 5.4.**

**Action 2: CAE.**

It is key that every member is consistent in providing the full suite (Health Care Power of Attorney, Living Will, Introduction and Explanation of MOST) of Advance Care Planning Resources including descriptions, sample forms and access to workshops to facilitate the process/documents. The CAT recommends that as part of strategic planning, members consider including the MOST form into ACP as a Coalition best practice along with a full suite of resources. This action will benefit the following workgroups in accomplishing Priority Recommendation 4.2\*.

**Action 1a: CAE**

**Action 1b: All**

**Action 1c: CAE**

**Action 1d: CP**

**Action 1e: CAE**

**Action 1f: CAE**

**Action 1g: ACP**

**Action 1h: ACP, CPE.**

**And Recommendation 4.4.**

**Action 1: ACP, CP, CAE**

**Action 2: ACP, CPE, CAE**

**Action 3: ACP, CP, CAE**

**Action 5: ACP, CP**

**Action 6: ACP, CAE.**

4. CAT suggests reviewing the most frequently used tools (see survey tables for Question 10 thru 16, beginning on page 23) to ensure these resources are considered in a description of the full suite of Advance Care Planning documents, and an introduction to the MOST form, how it is different than the DNR, where the form can be obtained, how to disseminate and store completed forms. **This action benefits the following workgroups in accomplishing the following Recommendations 2.3\*.**

**Action 2: All**

**Recommendation 3.1\***

**Action 1: All**

**Action 3: All**

**Recommendation 4.2\***

**Action 1h: All**

**Recommendation 4.4**

**Action 2: CP, CAE.**

5. CAT members contacted some EAPs to confirm that serious illness resources are provided. We suspect that many EAPs may not provide current information on the Advance Care Planning Process, Advance Directive forms, information on Serious Illness or Caregiver Resources. As a result, CAT suggests member(s) of the NCSIC contact regional and/or state EAP association(s) to assess and provide them with these resources. **This action will benefit the following workgroups in accomplishing Recommendation 4.13.**

**Action 1: CPE, CAE**

**Action 3: ACP, CPE, CAE.**

6. CAT suggests the Coalition members provide a list of all of their workshops that include elements of Advance Care Planning available throughout the state to the CAE workgroup to promote ongoing access to resources while supporting National Healthcare Decisions Day. **This action will benefit all workgroups in accomplishing Priority Recommendation 4.2\*.**

**Action 1b: All**

**Action 1h: All**

**Recommendation 4.3.**

**Action 4: ACP, CAE.**

7. CAT suggests workgroups review the NCIOM report, Appendix A to ensure all agencies referenced are included in a listserv for publishing NCSIC events, notifications, documents, etc. It is also recommended each workgroup provide contacts for all of the listed agencies to the CAE Chairs. **This action will benefit all workgroups in accomplishing Priority Recommendation 4.2\*.**
- Action 1h: All.**
8. CAT suggests the Coalition give consideration to devising a recruitment plan to attract Mecklenburg - based members and other strategic members in the many underrepresented non-corporate headquarter counties. *Mecklenburg County is the most populous county in NC, amongst the fastest growing counties for the aging population, and home to multiple Healthcare systems, specialists and physicians supporting statewide patient populations.* **This action will benefit all workgroups in accomplishing Priority Recommendation 2.1\*.**

**Action 1: All**

**And Recommendation 2.3: All.**

9. It may also be fruitful to conduct outreach to targeted individuals of at least some of the 35 non-responding member organizations. **This action will benefit all workgroups in accomplishing Priority Recommendation 2.1\*.**

**Action 1: All.**

# Preamble

## North Carolina Today – Our Aging State

Current key NC Demographics highlighted in the NCIOM Executive Summary and throughout the report:

- 16.3% of North Carolinians are over 65 years of age, (page 6.)
- The 65-plus population is projected to increase by 67% between 2016 and 2036, from 1.6 million to 2.6 million (pages 6 and 7 of the Final Report.)
- The Behavioral Risk Factor Surveillance survey (BRFSS) reported in 2018 that 65.8% of respondents 65 and over had two or more chronic health conditions, and an additional 31.3% of respondents had a chronic condition (page 6.)
- The NCIOM Task Force addressed the needs of younger adults and children with serious illness; 12.9% of respondents answered that their child “...currently needs or uses more medical care, mental health or educational services than is usual for most children of the same age.” (page 7.)
- In nearly 20 North Carolina counties, residents in 35% to 50% of the households have no internet connection (page 64.)
- 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 (page 12 and 51.)
- There are 83 whole or partial counties with a Health Professional Shortage Area (HPSA) designation for primary care (page 62.)

## Health System and Culture Change to Support Serious Illness Care

The Task Force on Serious Illness Care generated recommendations using the previous and ongoing work of many experts throughout the state and nationally. In addition, the Task Force recognized the need for ongoing collaboration and governance to ensure implementation of the 30 recommendations.

Achieving Health Equity requires focused and ongoing societal efforts to address avoidable inequities, historical and contemporary injustices, and the elimination of health care disparities.

Until the promulgation of the NCIOM Task Force Priority 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* -- and the creation of the NC Serious Illness Coalition (NCSIC), there has not been a consortium entity in North Carolina that served to create and enact a comprehensive plan such as is represented by the Task Force's recommendations. Several groups are working on some of the issues outside of NCSIC. Implementation of these recommendations represents a monumental improvement in the quality and effectiveness of serious illness care within our state's health system.

Achieving Health Equity requires focused and ongoing societal efforts to address avoidable inequities, historical and contemporary injustices, and the elimination of health care disparities. The Task Force on Serious Illness Care prioritized health and the reduction of health disparities as guiding principles throughout implementation of all recommendations related to serious illness care.

## Context and Themes of the Survey Findings

CAT envisions the Survey as the first phase of a larger thematic map for providing a comprehensive understanding of Coalition members' status in addressing serious illness care. The collective Survey findings represent a point-in-time baseline of information that can be utilized for strategic planning, workgroup prioritization and measuring our progress over time in accomplishing recommendation goals.

### 1. First Tier (topics of the Survey)

- Resources used to assist patients, staff, medical professionals and the public with 12 serious illness content areas
- Use of internal and external communication channels to publish these resources
- Opinion of how reactive – proactive organization is in providing assistance
- Organization's role in education, advocacy, direct assistance
- Public speaking resources
- Communication media channel preferences for learning about serious illness.

### 2. Second Tier (subsequent analyses – briefer surveys, polling during meetings)

- Organizations serious illness communication strategies, including outreach to historically marginalized populations
- Primary target audiences
- Criteria used to select information to share with target audiences
- Organizations constituents (supporters, collaborators)
- Current projects, initiatives
- Gaps in planning, execution of serious illness initiatives.

### 3. NCSIC organizational SWOT Analysis.

# Description of the North Carolina Serious Illness Coalition Membership Survey One

A Qualtrics questionnaire was created to survey the individual 130 Coalition members representing 80 health care organizations. Members were asked to consult with individuals in their organization who are responsible for assisting fellow employees, medical professionals, patients or the public with education and advocacy about serious illness care. The idea was to provide a consensus response to the survey questions for each member organization.

## Respondent Information

The survey was launched on December 8, 2020 following an instructional email. Respondents were asked to complete the survey by December 21<sup>st</sup>. Reminders were sent every three calendar days.

The responses represent input of at least 32 individuals from 26 of the 80 total NCSIC member organizations. Responses were received from 32.5% of the total coalition member organizations. See *Appendix SA (S- Survey)* for a list of respondents and *Appendix SB* for responding organizations.

## Survey Findings and Recommendations

### Q4: County of Respondent Member Organization's Corporate Office

Of the 26 Member Organization responses, there are 9 counties where member's corporate offices are located. **This finding will benefit all workgroups in accomplishing Priority Recommendation 2.1\*, item 1.**

- Wake County is the predominant corporate office location representing 12 of the 26 responses or 46.15%.
- Forsyth and Guilford (adjoining counties) tied at 11.5%, representing 6 organizations (23%) followed by
- Durham and Pitt with 2 each (15%), ending with Catawba, Chatham, Henderson and Wayne with 1 each.

This analysis provides an opportunity to determine how representative the survey sample is of the entire Coalition membership. CAT was able to determine that four of the non-responding members joined as individuals rather than as representing an organization. We were unable, at this point in time, to determine the corporate connection of 16 other members. Thus, we were able to determine the corporate address counties for the remaining 35 non-respondents. They are presented in the right-hand columns of the table below.

Corporate County	Respondent		Non-Respondent	
	Percentage	Count	Percentage	Count
Wake	46.16%	12	51.43%	18
Guilford	11.54%	3	14.29%	5
Forsyth	11.54%	3	2.86%	1
Durham	7.70%	2	2.86%	1
Pitt	7.70%	2	0.00%	0
Catawba	3.84%	1	0.00%	0
Chatham	3.84%	1	2.86%	1
Henderson	3.84%	1	0.00%	0
Wayne	3.84%	1	0.00%	0
Buncombe	0.00%	0	2.86%	1
Mecklenburg	0.00%	0	8.57%	3
Edgecombe	0.00%	0	2.86%	1
New Hanover	0.00%	0	2.86%	1
Jackson	0.00%	0	2.86%	1
Gaston	0.00%	0	2.86%	1
Rowan	0.00%	0	2.86%	1
<b>TOTALS</b>	<b>100.00%</b>	<b>26</b>	<b>100.00%</b>	<b>35</b>

As can be seen, Wake County predominates the non-respondent distribution as it does the respondent distribution, and they are within 5.27 percent of each other. The second most represented county, Guilford, is equally represented in both groups, being within 2.75 percent of each other. Organizations within four counties achieved 100% response rate to the survey. Seven counties did not contribute responses.

Actual counts being in the low single digits, *it can be reasonably concluded that the respondent distribution represents fairly well all member organizations.*

Corporate office locations are located in 16 of 100 North Carolina counties. This may raise a concern about the emphasis, or rather, over-emphasis of resources in counties that are the site of corporate headquarters. As can be seen in the Question 5 analysis below, however, all 100 state counties are served by the responding member participants. Depending on the county, there are between 14 and 20 or (53.8% to 76.9%) of the total 26 member organizations that responded providing services to each county in North Carolina.

Five (5) NCSI Coalition member organizations serve areas outside of North Carolina. See Appendix SC for a detailed list of the geographic regions covered by those five members.

#### **Q5: Counties Served by Respondent Member Organizations**

All 100 counties in North Carolina are served by our members. Depending on the county, there are between 14 and 20 or (53.8% to 76.9%) of the total 26 member organizations that responded providing services to each county in North Carolina. **This finding will benefit all workgroups in accomplishing Priority Recommendation 2.1\*, Action item 1.**

#### **Q6: Organization Focus/Type: (respondents could select all that apply)**

Many survey respondents selected more than one category of focus/type. The 26 survey respondents selected 61 various focus and types.

Organization Type	Percentage	Respondent
Educator/Educational Institution	11.48%	7
Foundation/Charitable	9.84%	6
Palliative Care	9.84%	6
Consultant	9.84%	6
Serious Illness Care	8.20%	5
Caregiver Organization	6.56%	4
Healthcare Network	6.56%	4
Hospice Provider	6.56%	4
State Agency including Public Health	6.56%	4
Association	6.56%	4
Hospital	4.92%	3
Outpatient clinic	3.28%	2
Employee Assistance Program/Human Resources vendor	1.64%	1
Other: Advocate	1.64%	1
Other: Aging Policy Advocacy and Education	1.64%	1
Other: Community social justice organization	1.64%	1
Other: Consumer Advocate	1.64%	1
Social Mission	1.64%	1
<b>Total</b>	<b>100%</b>	<b>61</b>

**Responses for the 'Other' category choice for Q6:**

- Aging Policy, Advocacy and Education
- Advocate, Consumer Advocate, Social Mission
- Home and community services for older adults and their families
- Healthcare consulting, patient / family / caregiver / community engagement
- Hospice & Palliative Care Association
- Community social justice organization
- Grief Counseling provider.

**Q7: Information Channels Used to Provide Access to Serious Illness Resources**

See *Appendix SD* for bar charts of each communication channel.

The following tables are a side by side summary of four major communication channel options being utilized by our responding members. The tables outline the following:

- A. 12 Serious Illness topics arrayed by
- B. 4 communication channels:
  1. Website,
  2. Intranet or Internal Portal,
  3. Employee Assistance Programs,
  4. No communication channels currently used.

Use of the four communication channels by serious illness topic were ranked in order of highest percentage to lowest percentage. Quartiles were calculated with responding colors:

<b>HIGH</b>	<b>31.58% to 66.67%</b>
<b>MED HIGH</b>	<b>25.71% to 30.77%</b>
<b>MED. LOW</b>	<b>15.56% to 25.00%</b>
<b>LOW</b>	<b>3.33% to 15.38%</b>

Strengths, Weaknesses and Opportunities are provided for each analysis below with the key suggestions and actions identified beginning on page 6 of this report. CAT is not suggesting Threats in the analyses at this time in order to encourage workgroups to focus on the survey findings and suggested actions.

#### 1. Wellness Resources section that includes Advance Care Planning and Directives:

Serious Illness Resource	Website	Response	Intranet or Internal Portal	Response	Via Employee Assistance Program	Response	Currently not available, considering or being developed	Response	SUM of Responses
Wellness Resource section that includes Advance Care Planning and Directives	34.56%	16	28.89%	13	15.56%	7	20.00%	9	45

**Strengths:** 34.56% of the respondents are providing advance care planning and directive documents within the Wellness Resource Section of their website – well above the overall average website use of respondents at 25.17%. This finding is positive news for all workgroups. Having these conversations during wellness visits provides the patients the best available health care pathway, introduces the Advance Care Planning process upstream of a serious illness crisis, allows time for ongoing conversations surrounding goals of care, and provides the opportunity for resources/documents to honor ones' healthcare wishes.

**Weaknesses:** Of our member respondents, 20% are not providing consumer facing portals and 15.56% indicated that these resources were provided via EAP. This is more than double the EAP use average. CAT members contacted EAPs to confirm that these resources are provided. Based on initial conversations there is a concern that EAPs may not provide information on the Advance Care Planning Process, and they may not have up to date, user-friendly and current Advance Directives documents.

**Opportunities:** See CAT suggestion 3 on Page 7.



## 2. Advance Care Planning Resources Section:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Advance Care Planning Resources section	34.21%	13	26.32%	10	7.89%	3	31.58%	12	38

**Strengths:** 34.21% of the respondents are providing a consumer facing portal for Advance Care Resources, – well above the overall average website use of respondents at 25.17%. This finding is positive news for all workgroups and creates access for a variety of audiences to connect to advance care planning resources. It is unclear at this point in time if respondents were thinking their answer includes a description of the Advance Care Planning process, forms, and/or the offering for virtual or in person workshops to complete or have conversations about the Advance Care Planning process.

**Weaknesses:** 31.58% are not currently providing access to these resources via a consumer facing portal.

**Opportunities:** See CAT suggestion 4 on Page 8.

## 3. Advance Care Planning Forms:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Advance Care Planning Forms section	27.78%	10	22.22%	8	8.33%	3	41.67%	15	36

**Strengths:** Though 27.78% are providing Advance Care Planning forms, some survey respondents are within large healthcare systems providing access to these forms to large market shares per county and scope.

**Weaknesses:** Nearly 42% of the respondents are not providing any Advance Care Planning forms/documents. This is above the average of currently not available, considering or being developed as chosen by 39.7% of respondents. Of the 27.78% of respondents that *do* provide forms, it is unclear whether members are providing forms/and or descriptions. This is an ongoing theme in not knowing the full suite of what is provided with Advance Care Planning resources.

**Opportunities:** See CAT suggestion 4 on Page 8.

#### 4. Healthcare Power of Attorney Form:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Healthcare Power of Attorney	30.56%	11	25.00%	9	8.33%	3	36.11%	13	36

**Strengths:** 30.56% of respondents provide this resource via a consumer facing portal, which is notably above the website use average of 25.17%.

**Weaknesses:** 36.11% of respondents are not providing consumer facing portals to this specific Advance Care Directive form. Nearly 42% of the respondents, however, answered “Currently not available, considering or being developed”. *This is a consistent theme that demonstrates respondents are not providing a consumer based platform for Advance Care Directive forms.* This reinforces the need for NCSIC to provide a consumer (or link to one) as well as a clinical facing portal.

**Opportunities:** See CAT suggestion 4 on Page 8.

#### 5. Living Will Form:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Living Will	29.41%	10	20.59%	7	8.82%	3	41.18%	14	34

**Strengths:** The 2<sup>nd</sup> form at 29.41% is still well above the overall average of 25.17% for website use, however the Living Will form is not as accessible as the Health Care Power of Attorney.

**Weaknesses:** Notably more respondents are not providing Living Will information compared to the Healthcare Power of Attorney.

**Opportunities:** CAT would like to point out the inconsistency on Advance Care Directives; see CAT suggestion 4 on Page 8.

## 6. Medical Order for Scope of Treatment:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Medical Order for Scope of Treatment (MOST/ POLST)	13.33%	4	16.67 %	5	3.33%	1	66.67%	20	30

**Strengths:** At least 13.33% of the respondents are providing this resource. Some are large health systems that do have forms available to large market shares.

**Weaknesses:** This Advance Care Directive form has *the lowest accessibility of audiences and the highest percentage of not available, considering or being developed*. This weakness impedes and negatively impacts multiple actions of the 30 NCIOM Task Force recommendations.

**Opportunities:** See CAT suggestion 4 on Page 8.

## 7. Serious Illness Resource Section:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Serious Illness Resources section	26.47%	9	20.59%	7	5.88%	2	47.06%	16	34

**Strengths:** Highlighting 26.47% as a strength but it is only 1% more than the overall average of 25.17% utilization of respondent websites.

**Weaknesses:** Only 2 other categories are weaker than this resource section. Serious Illness Resource section has a very large percentage (47.06%) of respondents that do not have consumer resources.

**Opportunities:** See CAT suggestion 1 on Page 6.

## 8. Caregiver Resource Section:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Care Giver Resources section	30.77%	12	23.08%	9	15.38%	6	30.77%	12	39

**Strengths:** 30.77% of respondents are providing caregiver resources via a consumer facing portal which is above the website use average of 25.17%.

**Weaknesses:** At the same time, the currently not available, considering or being developed is at the same percentage, indicating there is no increase in access.

**Opportunities:** See CAT suggestion 1 on Page 6.

## 9. Information on Home Health Services Section:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Information on Home Health Services section	30.30%	10	18.18%	6	6.06%	2	45.45%	15	33

**Strengths:** 30.30% of the respondents provide a Home Health Section via a consumer facing portal, above the website use average of 25.17%.

**Weaknesses:** Over 45% of respondents do not provide a section on home health services. This is in the top 5 of 12 resources currently not available, considering or being developed.

**Opportunities:** See CAT suggestion 3 on Page 7.

## 10. Information on Palliative Care Section:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Information on Palliative Care section	27.78%	10	25.00%	9	5.56%	2	41.67%	15	36

**Strengths:** 27.78% of the respondents provide Palliative Care Resources via a consumer facing portal, which is above the website use average of 25.17%.

**Weaknesses:** 41.67% of the Respondents do not currently have information available, again a trend above the average of currently not available, considering or being developed at 39.70%.

**Opportunities:** See CAT suggestion 3 on Page 7.

## 11. & 12. Information on Hospice Medicare Benefits, Hospice Care Sections:

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Information on Hospice Medicare Benefit section	25.71%	9	20.00%	7	8.57%	3	45.71%	16	35

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Information on Hospice Care section	25.71%	9	20.00%	7	5.71%	2	48.57%	17	35

**Because the results of these 2 sections are so similar, the CAT combined the responses.**

**Strengths:** The 25.71% accessibility via the website is slightly above the average of 25.17%.

**Weaknesses:** Hospice resource section is the 2<sup>nd</sup> of the highest of the 12 currently not available, considering or being developed. The Hospice Medicare Benefits is the 4<sup>th</sup> of the 12 currently not available, considering or being developed amongst the responding members.

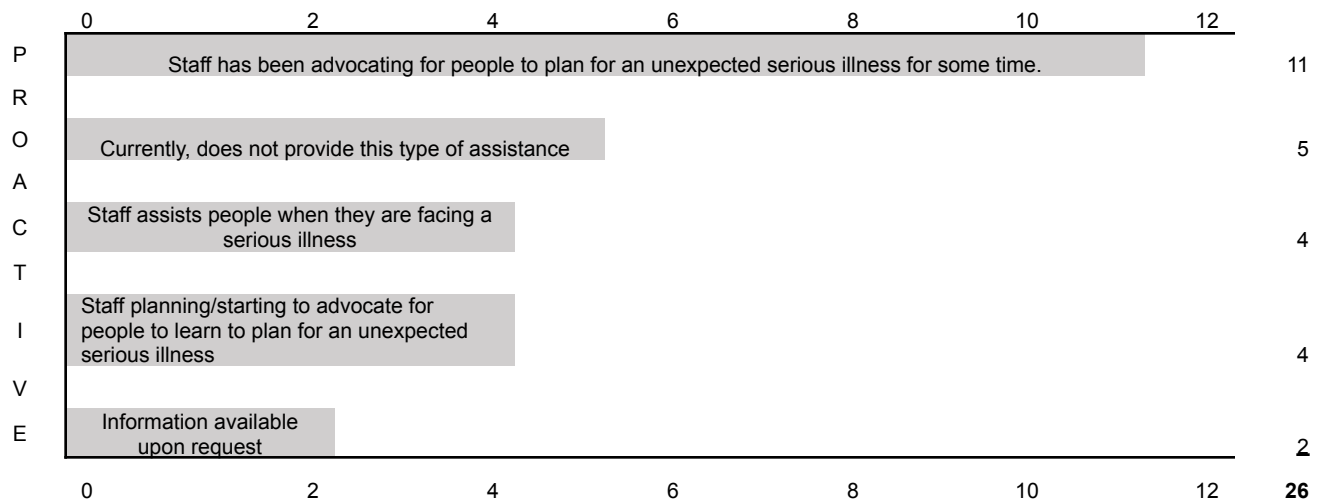
**Opportunities:** See CAT suggestion 3 on Page 7 and suggestion 6 on Page 9.

**Summary: Suggestions were based on the average percentages of responses, above.**

Serious Illness Resource	Website	Responses	Intranet or Internal Portal	Responses	Via Employee Assistance Program	Responses	Currently not available, considering or being developed	Responses	SUM of Responses
Average Percent by Information Channel	25.17%	123	19.80%	97	6.99%	37	39.70%	174	431

**Q8: Which of the following sentences best describe how reactive or proactive your organization is in educating patients, the public, staff, medical professionals on planning for an unexpected serious illness?**

- The following bar chart and table indicate that 22 of the 26 (84.6%) responding organizations are involved in providing some form of assistance, with nearly half stating that they have been advocating with people to plan for an unexpected serious illness for some time.
- Another 4 are planning or starting to do so. This leaves 5 organizations that can be considered reactive as opposed to proactive in providing assistance.
- Please note that the remaining 5 organizations – 19.2% of the total -- state that they do not provide assistance.



<b>Selection</b>	<b>Percentage</b>	<b>Count</b>
Our staff has been advocating for people to plan for an unexpected serious illness for some time.	42.30%	11
Currently, our organization does not provide this type of assistance.	19.20%	5
Our staff assists people when they are facing a serious illness.	15.40%	4
Our staff is planning/starting to advocate for people to learn how to plan for an unexpected serious illness.	15.40%	4
Information is provided upon request	7.70%	2
Total	100%	26

### **Q9: Respondent descriptions of their organization's role as it relates to education, advocacy or direct assistance dealing with serious illness needs**

The reader is directed to Appendix SE to review responses.

### **Q 10 - 16: Educational resources/tools most beneficial when explaining various serious illness topics.**

It is not the intention of the CAT to represent all of the over 150 sources mentioned by respondents in the following tables. The reader is directed to Appendix SF for a complete listing of every resource. If a particular resource was not mentioned at least twice for any one of the 6 topics, it was not included in the tables below.

Uncounted resources include a number of internally developed tools such as the Vidant ACP Toolkit, webinars, presentations as well as many websites such as the CDC's advanced care planning resources for patients and the public, CMS Medicare, NC Legal Aid, faith-based, transgender and cancer care resources, [www.caregiver.org](http://www.caregiver.org).

MEDICAL ORDER FOR SCOPE OF TREATMENT (MOST / POLST)						
Resource	Patient	Public	Staff	Med Pro	Total	Percent
Not Applicable	4	1	5	5	15	15.80%
Advance Care Planning Guide on MOST form/sample MOST form	3	3	2	2	10	10.50%
Got Plans	2	3	1	2	8	8.40%
Respecting Choices	2	1	2	2	7	7.40%
NC Medical Society	1	1	2	3	7	7.40%
Vital Talk	1	1	1	1	4	4.20%
Five Wishes	1	1	1	1	4	4.20%
Got Palliative Care	1	1	1	1	4	4.20%
Hello / Hi	1	1	1	1	4	4.20%
CAPC	1	1	1	1	4	4.20%
Krames education tools	1	1	1	1	4	4.20%
NC DHHS	1	1	1	1	4	4.20%
NCIOM	1	1	1	1	4	4.20%
Polst.org	1	1	1	1	4	4.20%
Compassionate Care.org	1	1	1	1	4	4.20%
Medicare website	1	1	1	1	4	4.20%
NHPCO	1	1	1	1	4	4.20%
<b>TOTALS</b>					<b>95</b>	<b>100.00%</b>

**Summary:** Fully 12 of the 26 respondents chose Not Applicable for all 4 audiences -- Patients, the Public, Staff and Medical Professionals. *This is the highest number of N/A amongst all 7 serious illness topics.* The instructions of the MOST form, then Got Plans were favorite resources.



ADVANCE CARE PLANNING PROCESS						
Resource	Patient	Public	Staff	Med Pro	Total	Percent
Not Applicable	14	8	13	14	49	43.80%
Got Plans	2	4	1	2	9	8.00%
Respecting Choices	2	1	3	2	8	7.10%
Harvard Ser. Illness Conversation Guide/Project	1	1	2	4	8	7.10%
Vital Talk	1	1	2	4	8	7.10%
Hello / HI	2	2	4	0	8	7.10%
Adv Care Planning Guide	1	2	2	2	7	6.30%
Five Wishes	1	3	1	1	6	5.40%
Got Palliative Care	1	1	1	1	4	3.60%
CAPC	1	1	1	1	4	3.60%
ELNEC	0	0	0	1	1	0.90%
TOTALS					112	100.00%

**Summary:**

As with the MOST form, the predominant response was Not Applicable, especially for the Patient and Medical Professional audiences. There was notably less N/A for the Public. Almost a third (8 respondents of 26) chose N/A for all audiences. Unlike the other 6 serious illness topics, there were a number of favored resources that were equally represented.

## ADVANCE DIRECTIVES FORMS

Resource	Patient	Public	Staff	Med Pro	Total	Percent
Not Applicable	16	11	15	17	59	54.60%
Got Plans	2	5	2	2	11	10.20%
Five Wishes	2	4	1	1	8	7.40%
Vital Talk	1	1	1	1	4	3.70%
Hello / HI	1	1	1	1	4	3.70%
Adv Care Planning Guide	1	1	1	1	4	3.70%
Got Palliative Care	1	1	1	1	4	3.70%
MOST / DNR	1	1	1	1	4	3.70%
CAPC	1	1	1	1	4	3.70%
Respecting Choices	2	1	0	0	3	2.80%
Harvard Ser. Illness Conversation Guide/Project	0	0	1	2	3	2.80%
<b>TOTALS</b>					<b>108</b>	<b>100.00%</b>

**Summary:** As with the MOST form, the predominant response was Not Applicable, especially for the Patient and Medical Professional audiences and like the MOST, less so for the Public. N/A accounted for over half of all responses and 9 of 26 respondents answered N/A for all audiences (34.6%.) Got Plans than Five Wishes were clearly the favorite resources.

CAREGIVER RESOURCES						
Resource	Patient	Public	Staff	Med Pro	Total	Percent
Not Applicable	13	12	14	15	54	60.70%
AARP	3	4	2	2	11	12.40%
Got Plans	1	1	1	1	4	4.50%
CAPC	1	1	1	1	4	4.50%
CTAC	1	1	1	1	4	4.50%
Aunt Bertha	1	1	1	1	4	4.50%
Councils of Governments	1	1	1	1	4	4.50%
Depts. Social Services	1	1	1	1	4	4.50%
<b>TOTAL</b>					<b>89</b>	<b>100.00%</b>

**Summary:** As with the MOST form, the predominant response was Not Applicable, but uniform across the audiences. N/A accounted for over half of all responses and 10 of 26 respondents (38.5%) answered N/A for all audiences. AARP was clearly the predominant choice of resources.

## PALLIATIVE CARE

Resource	Patient	Public	Staff	Med Pro	Total	Percent
Not Applicable	17	14	16	15	62	68.10%
Vital Talk	1	1	1	2	5	5.50%
ELNEC	0	0	2	2	4	4.40%
Five Wishes	1	1	1	1	4	4.40%
CAPC	1	1	1	1	4	4.40%
Got Palliative Care	1	1	1	1	4	4.40%
Hello / HI	1	1	1	1	4	4.40%
AARP	1	1	1	1	4	4.40%
<b>TOTALS</b>					<b>91</b>	<b>100.00%</b>

**Summary:**

As with the MOST form, the predominant response was Not Applicable, and the highest percentage amongst the 7 topics at 71.3%. N/A is especially high for Patients. Like Caregiver Resources, 10 respondents representing 38.5% answered N/A for all audiences. No one or more resources predominated.

## HOSPICE CARE

Resource	Patient	Public	Staff	Med Pro	Total	Percent
Not Applicable	15	13	14	14	56	49.10%
Brochures	4	3	2	2	11	9.60%
Presentations	1	5	4	2	12	10.50%
NHPCO	1	1	2	2	6	5.30%
Vital Talk	1	1	1	2	5	4.40%
Medicare website	1	1	1	1	4	3.50%
Five Wishes	1	1	1	1	4	3.50%
Got Palliative Care	1	1	1	1	4	3.50%
CAPC	1	1	1	1	4	3.50%
Vital Talk	1	1	1	1	4	3.50%
Hello / Hi	1	1	1	1	4	3.50%
<b>TOTALS</b>					<b>114</b>	<b>100.00%</b>

### Summary:

As with the MOST form, the predominant response was Not Applicable, with 11 of 26 respondents (42.3%) answering N/A for all 3 audiences, the second highest rate amongst the 7 serious illness topics. *Internal resources -- brochures and presentations - were the favored resources, unlike the other topics.*

HOSPICE MEDICARE BENEFIT						
Resource	Patient	Public	Staff	Med Pro	Total	Percent
Not Applicable	14	15	13	14	56	61.50%
Medicare.gov	3	3	2	2	11	12.10%
AARP	2	2	1	1	4	4.40%
Five Wishes	1	1	1	1	4	4.40%
Got Palliative Care	1	1	1	1	4	4.40%
Vital Talk	1	1	1	1	4	4.40%
Hello / HI	1	1	1	1	4	4.40%
NHPCO	1	1	1	1	4	4.40%
<b>TOTALS</b>					<b>91</b>	<b>100.00%</b>

**Summary:**

As with the MOST form, the predominant response was Not Applicable, with 11 of 26 respondents (42.3%) answering N/A for all 3 audiences, the second highest rate amongst the 7 serious illness topics. *Medicare.gov* was the clear favored resource.

**Q17: Are you experienced in presenting to the media?**

Response	Percentage	Count
Yes	74.07%	20
No	25.93%	7
<b>Total</b>	<b>100%</b>	<b>27</b>

**Q18: Are you comfortable with being a spokesperson for public/media presentations in your area on behalf of the North Carolina Serious Illness Coalition?**

Response	Percentage	Count
Yes	74.07%	20
No	25.93%	7
<b>Total</b>	<b>100%</b>	<b>27</b>

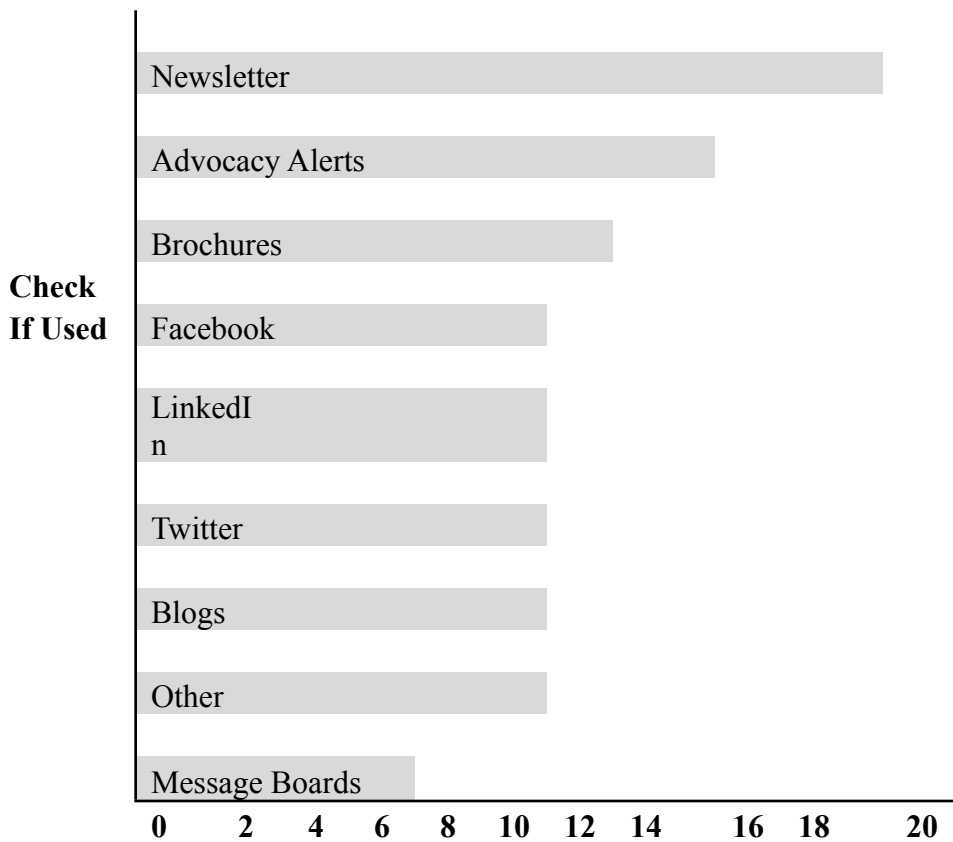
**Q18a. If you answered yes to question 18, select all that apply.**

Rank	Response	Percentage	Count
1	Health system and social change to address serious illness care	30.35%	17
2	High-quality person-centered care	26.79%	15
3	Engagement with patients and families to meet goals of care	26.79%	15
4	Development of the health and human services workforce and infrastructure	16.07%	9
<b>Total</b>		<b>100.00%</b>	<b>56</b>

**Q18b. Are you interested in media training?**

Three respondents expressed interest in receiving the training.

**Q19. Please check all the communication media channels you use most frequently to find serious illness resources.**



#### All Communication Channels Used

Response	Percentage	Count
Newsletter	20.65%	19
Advocacy Alerts	16.30%	15
Brochures	13.04%	12
Facebook	10.86%	10
LinkedIn	10.86%	10
Blogs	10.86%	10
Other (please specify)	10.86%	10
Message Boards	6.57%	6
<b>Totals</b>	<b>100.00%</b>	<b>92</b>

Responses provided for **Other** include:

- Websites
- TCC, CAPC, AHHC, NHPCO, Conversation Project, Vital Talk, Ariadne Labs as some of the top ones
- Podcast
- NCSIC website
- I use references I learn about from my employment contacts, from news feeds, & from my volunteer work.
- Web resources (CTAC, AARP)
- Emails
- Email Blast
- Professional associations, networks
- Instagram



# Appendix

## Appendix SA: Responding Members, Q1

The members of the Coalition's Communications, Advocacy and Education Work Group wish to thank the survey respondents:

1. Christine Brown-Auman	Strategic Marketing & Healthcare Consultant, Brown-Auman, Inc.
2. Karen Bullock	School of Social Work, Head, North Carolina State University
3. Heather Burkhardt	Executive Director, North Carolina Coalition on Aging
4. Rev. Odell Cleveland	Pastor – Chief Administrative Officer, Mount Zion Baptist Church of Greensboro, NC
5. Sue Collier	Chief Engagement Officer, Patient Centered Innovation, Inc.
6. Wendee M. Cutler	Executive Director, Carolina Foundation for Jewish Seniors
7. Linda Darden	President & CEO, Trellis Supportive Care
8. Glenn Field	Community Development Specialist II, North Carolina Office of Rural Health, NC DHHS
9. Scottie Gaskins	Sr. Administrator, Vidant Health
Ellie Ward	Advance Care Planning Outreach Coordinator, Vidant Health
10. Marisette Hasan	President & CEO, The Carolinas Center for Hospice and End of Life Care
11. Mark Hensley, Steve Hahn & Catherine Sevier	Associate State Director, AARP NC
12. Leo John	Legislative Liaison, NC Department of the Secretary of State
13. Parvathy Krishnan	Director, Patient Engagement Chair – UNC Patient Family Advisory Board, Rare Disease Innovations Institute; UNC Children's Hospital
14. Donna Lake	Professor of Nursing, East Carolina University College of Nursing
15. Kristen Lakis	Strategic Services Associate – Palliative Care, Duke Health
16. Christopher Morrisette	Chief Operating Officer, Teleios Collaborative Network
17. Debi Nelson	Branch Manager, NC Division of Public Health
18. Catherine Sevier	Co-Convener, North Carolina Serious Illness Coalition
19. Ames Simmons	Policy Director, Equality North Carolina
20. F. Keith Stirewalt	Program Director – FaithHealth Clinical Medicine, Wake Forest Baptist Health
21. Dennis Streets	Director, Chatham County Council on Aging
22. Charlotte A Sweeney, MD	Associate Medical Director, Center for Personalized Education for Physicians and other healthcare personnel (CPEP)
23. Dana S. Thomson	Manager, Advance Care Planning, Novant Health
24. Laura Jane Ward	Family Caregiver Support Program Consultant, NC Department of Health and Human Services; Division of Aging and Adult Services
25. Madison Ward Willis	Performance Improvement Specialist, North Carolina Healthcare Association
26. Lauren Zingraff	Executive Director, Friends of Residents in Long Term Care (FOR)

## Appendix SB: Alphabetic List of Respondent Member Organizations, Q2

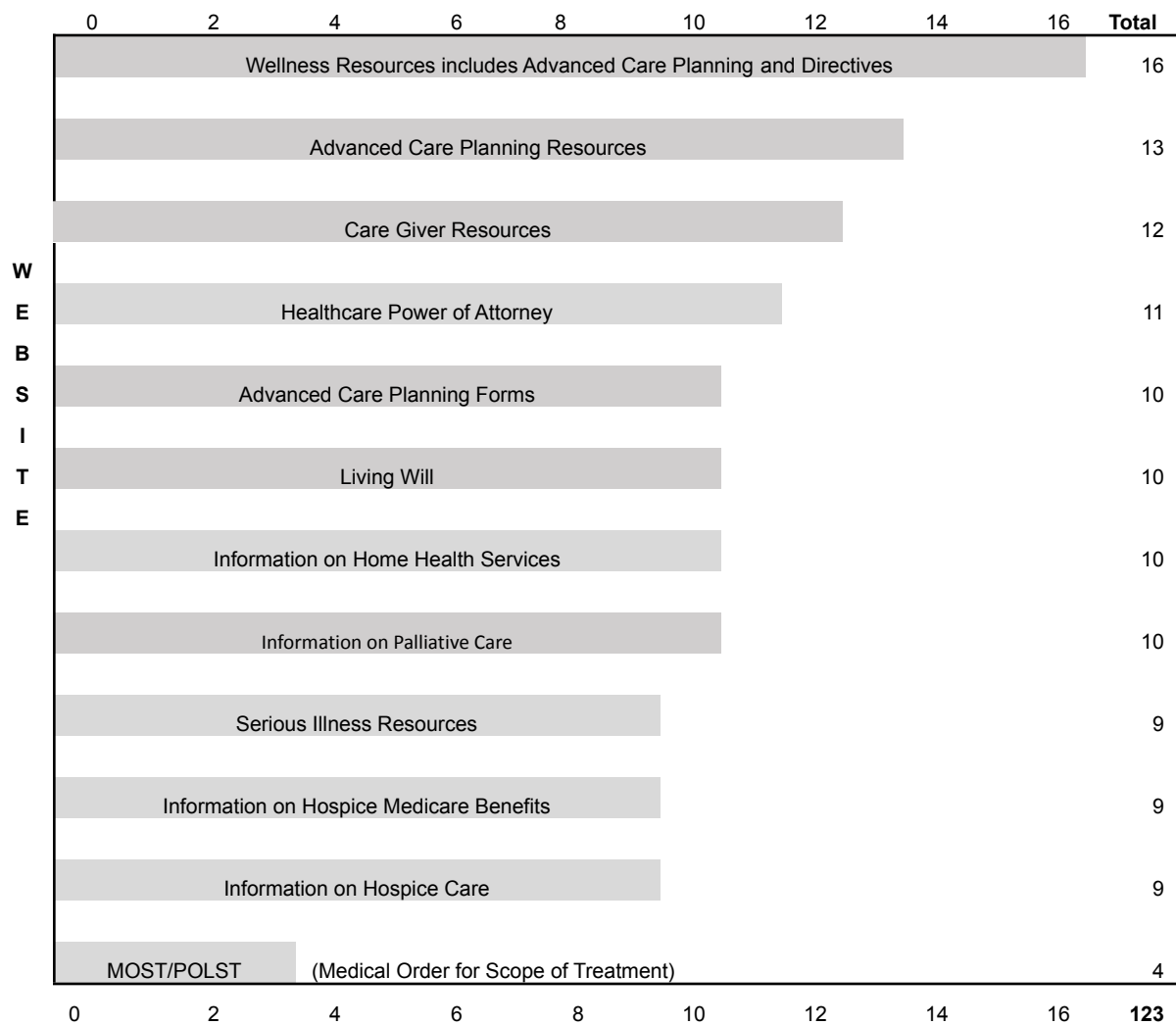
1. AARP NC
2. Brown-Auman, Inc.
3. Carolina Foundation for Jewish Seniors
4. Center for Personalized Education for Physicians and other healthcare personnel (CPEP)
5. Chatham County Council on Aging
6. Duke Palliative Care
7. East Carolina University College of Nursing
8. Equality
9. Friends of Residents in Long Term Care (FOR)
10. Mount Zion Baptist Church of Greensboro, Inc.
11. North Carolina Coalition on Aging
12. North Carolina Department of Health and Human Services, Division of Aging and Adult Services
13. North Carolina Department of Health and Human Services, Division of Public Health
14. North Carolina Department of Health and Human Services, Office of Rural Health
15. North Carolina Department of the Secretary of State
16. North Carolina Healthcare Association
17. North Carolina Serious Illness Coalition
18. North Carolina State University
19. Novant Health
20. Patient Centered Innovation, Inc.
21. Rare Disease Innovations Institute, UNC Children's Hospital
22. Teleios Collaborative Network
23. The Carolinas Center for Hospice and End of Life Care
24. Trellis Supportive Care
25. Vidant Health
26. Wake Forest Baptist Health

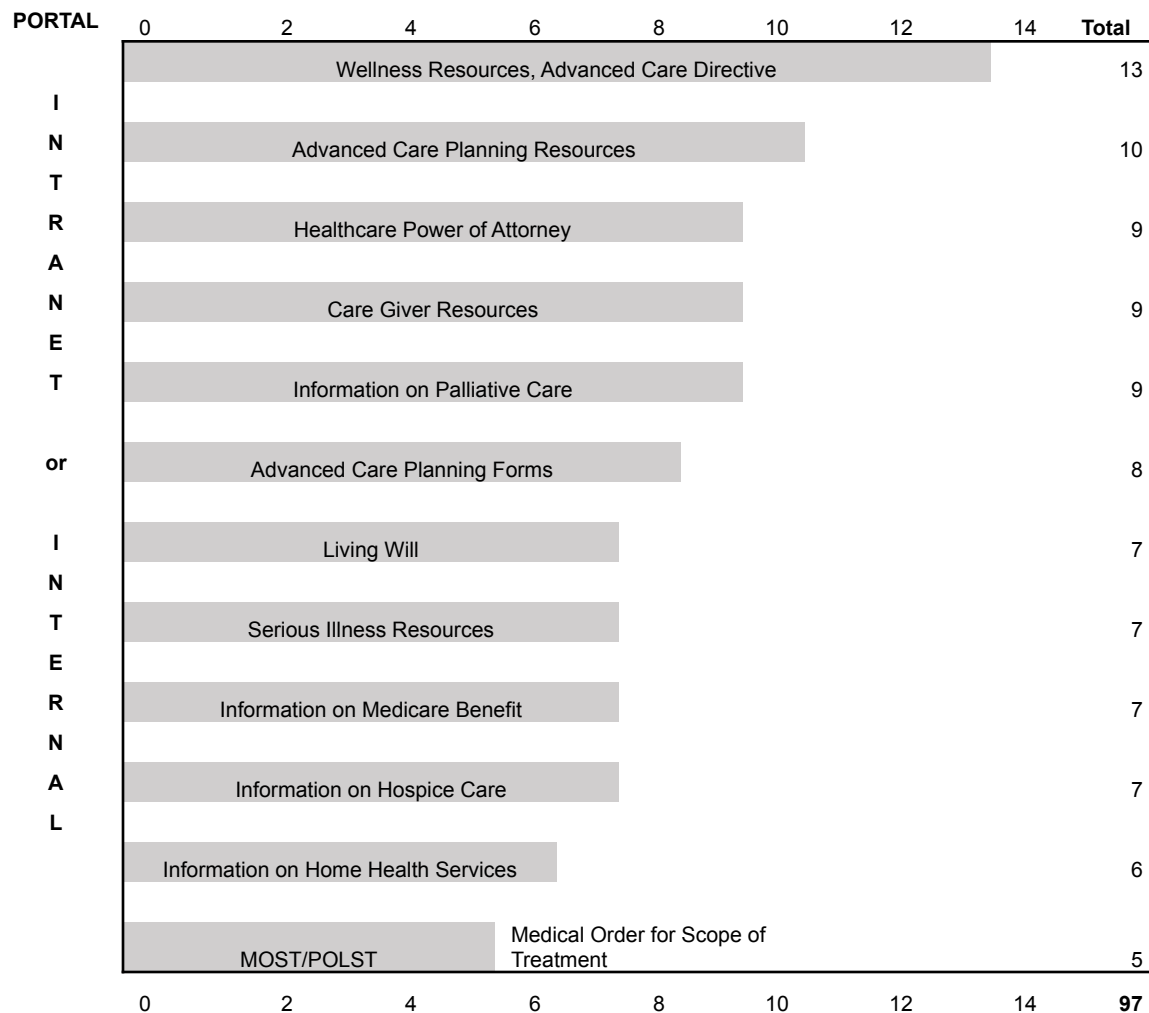
## Appendix SC: Locations of Out of State Responding Members (Q5)

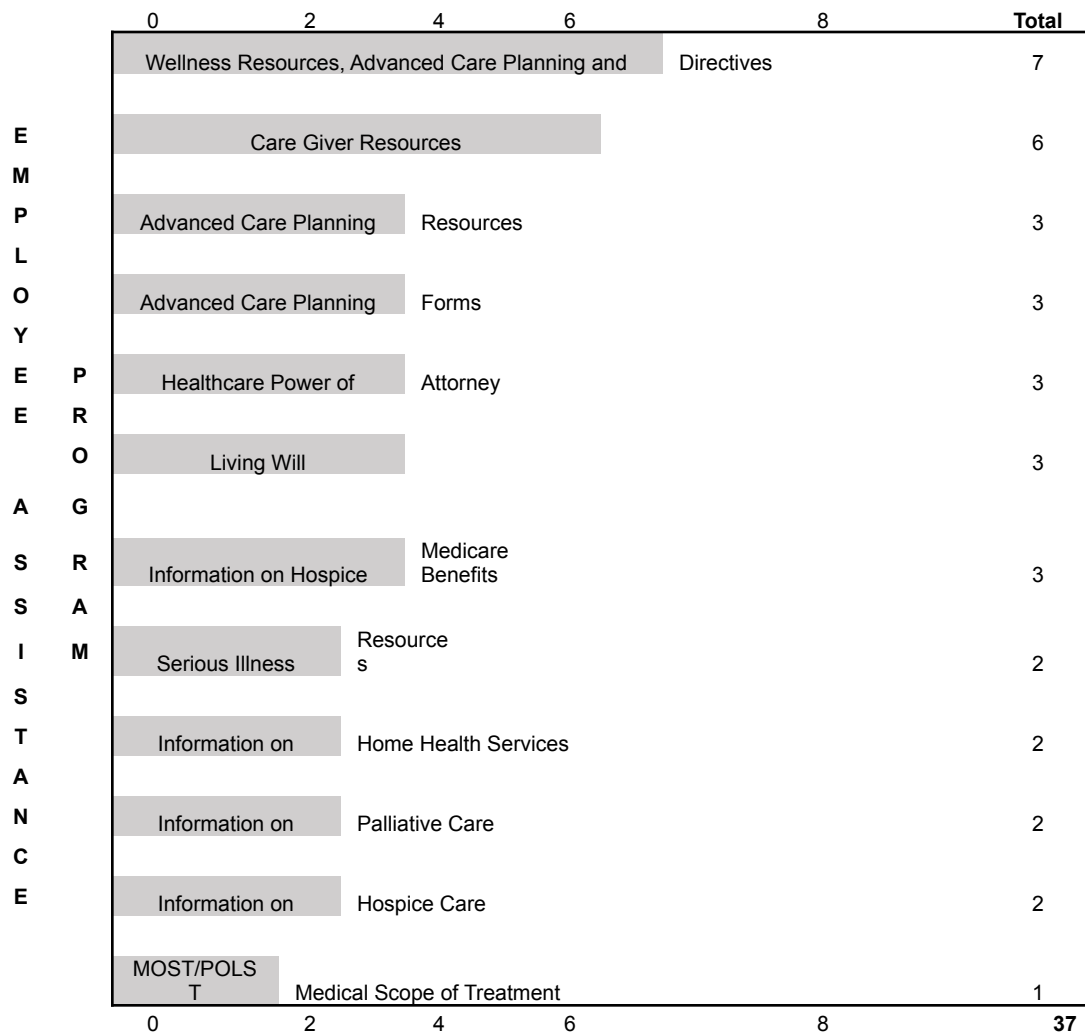
What agency/organization has resources for serious illness accessible to clinicians in other states? NY, SC, etc. fastest growing. Hospital groups in AZ, FL fastest growing. Where are the communication channels housed in other states? Where do they see their patient population accessing information?

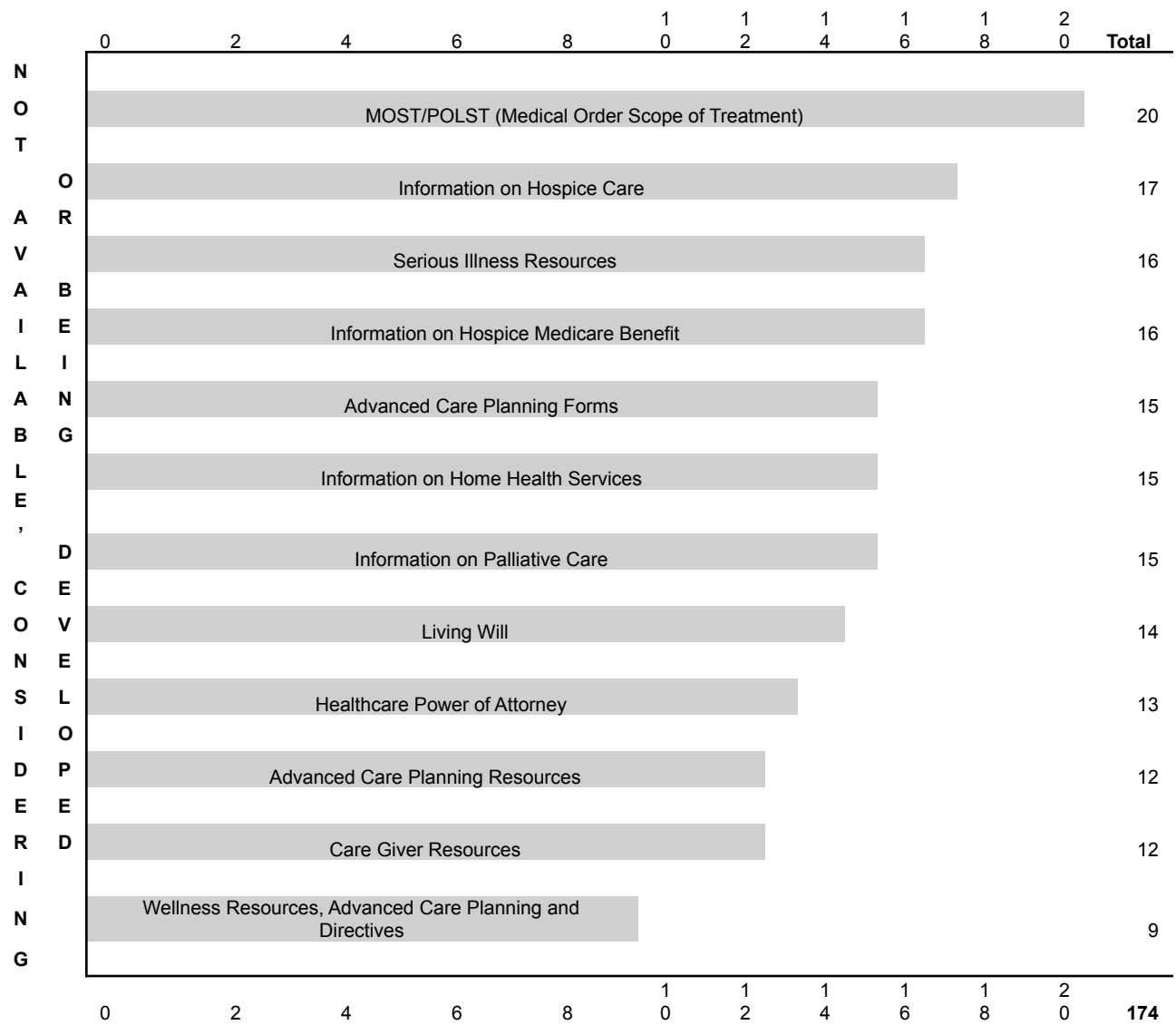
- Berkeley County, South Carolina (adjacent to Mecklenburg County, North Carolina)
- Charleston, Columbia and Greenville, South Carolina (\*many of this population drive to NC for higher acuity care needs. For example, patients will seek care at many of our members such as Novant, Atrium, Duke University, UNC Chapel Hill, Vidant Health.
- Members provide care and resources in Louisiana, South Carolina, Texas and Virginia
- A Member organization provides care and resources to all 50 USA states & Canada
- A Member organization provides consulting on a national basis

## Appendix SD: Bar Graphs of Counts of Serious Illness Resources by The Four Information Channels, Q7









## Appendix SE: Respondent Descriptions of Their Organization's Role in Providing Education, Advocacy and/or Direct Assistance, Q9

HR functions within the University is basic healthcare policy only.

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The Coalition is available to share information to our members as well as advocate for systems change.

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Very passionate and actively engaged in education, advocacy and direct assistance to support unplanned or existing serious illness needs.

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Vidant Health has long been a leader in promoting education, advocacy and direct assistance with advance care planning for patients, the community and our own team members. Vidant has a system-wide multi-disciplinary workgroup dedicated to enhancing serious illness and end of life care, including a dedicated team for advance care planning outreach and education. Vidant has trained 500 healthcare professionals in the past 5 years in Respecting Choices and ELNEC to develop their proficiency in having difficult and meaningful SIC discussions and is in process of training 24 providers as faculty of VitalTalk to expand education to providers across our health system. This work extends in collaboration with ECU to teach Communication Skills to ECU medical students. These system wide efforts reach across the various disciplines and departments within the system to provide goal concordant care to our seriously ill patients.

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We've started and currently fund a nonprofit named "Caregivers Connect," to continue to serve families in need.

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Integrated approach to care from planning to treatment

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Our Palliative and Hospice services have been available to patients for decades. We have recent renewed focus on education, advocacy and assistance with planning for serious illness through the Duke Palliative Care Task Force. We are working to develop an interdisciplinary workforce in all care settings to provide serious illness care, to educate staff on key communication skills and care needs, and to build data systems that track care provided and ensure that we target the best care, advocacy and resources to high risk patients.

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We are a network of serious illness practices supporting patients through the continuum care including Home Based Primary Care, Palliative Care, Home Care and Hospice. We have an intentional focus in advance care planning, goal concordant care. We take an active role in supporting patients in their decision making, starting at our first encounter.

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CPEP provides resources for clinical competence assessment, educational interventions, and a process for re-entry to clinical practice.

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Convener of organizations committed to advocating for or providing serious illness care and policy support.

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NCHA has a robust education department that provides educational opportunities on a variety of healthcare topics via webinars, learning sessions, and annual meetings.

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SOSNC provides education & assistance for those dealing with serious illness needs through our website & community outreach. On our website, we provide the statutory legal forms for advance care planning. Secretary Marshall's message encourages planning before emergency strikes. FAQs provide answers to common questions. Links connect to organizations providing additional support. During the pandemic, SOSNC highlighted the legislatively authorized, limited-time option of executing notary-only Health Care Power of Attorney & Living Will & made emergency-law-adapted forms available. We also make it easier to find nearby notaries with hours to accommodate special needs. Insofar as outreach, SOSNC educates & advocates within the community about the desirability & availability of such documents, resources for guidance on executing them, & the importance not only of executing them but also sharing them & ensuring they are readily available when needed. We raise awareness of the legislatively created Advance Health Care Directives Registry: what it does & why it helps.

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AARP's strength is in education and advocacy. We provided educational programs like "living longer, living smarter" (decide/create/share) to the public. We are the loudest advocacy voice for people as they age at the federal and state level with elected officials.

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Vidant has been promoting education, advocacy and direct assist for many years. The challenges are multi-factorial and largely driven by clinicians' viewpoints of relevance. In other words, those that are bought in are fully supportive, and those that aren't will likely never be.

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We focus on conversations, conversation beginning when an individual is healthy. These conversations lead to what individual's desires while they are living. As these conversations transition once an individual is coping with serious illness, the conversations do not feel as strained or challenging and identifies what an individual does not want from their medical team. We have developed educational collateral for our underserved populations to assist with creating awareness, offering support, and providing assistance. We have engaged our community members by taking services to them, making access easier for preventative screenings as well as opening clinics in areas of heightened need.

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The Division of Aging and Adult Services, as the state's unit on aging is mandated by the Older Americans Act to advocate for the well-being of older adults and their caregivers. Much of the education, advocacy, and direct assistance we provide is done through our network of area agencies on aging, local community providers (ex: senior centers, councils

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on aging), and advocacy agencies that serve our population as well (such as NC Council on Aging, Coalition on Aging, FORLTC, etc..)

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The goal of our educational institution is to be accessible to North Carolina residents and others wishing to achieve a degree that will enable them to contribute to the state's economy and the well-being of our general population.

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Our mission is to empower residents and families and to improve the quality of long-term care in North Carolina by providing a statewide network of education, advocacy, and support.

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It is not currently offered that I am aware of

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We work with a vulnerable senior population and do our best to assist them in remaining living safely at home through a variety of services, programs and supports.

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As a volunteer of the NC SI Coalition and co-owner of the consulting company, I provide education and advocacy when appropriate to support SI care in NC and SC.

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We lead and/or partner with other organizational stakeholders to provide education for consumers and clinicians and engage in legislative advocacy related to the serious illness care continuum needs hospice, palliative care, advance care planning legislation, MOST, payer reimbursement for serious illness care

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Not providing this type of assistance

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Community education about aging, chronic illness (especially HIV) advance care planning (especially for transgender people), for both LGBTQ conferences like Creating Change and Lavender Law, as well as health meetings like geriatrics grand rounds, post-acute long-term care. Advocacy about aging and chronic illness in the LGBTQ community with NC DHHS, Area Agencies on Aging, NC Coalition on Aging.

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As a member (and chair) of the PFAB at UNC: We provide education to healthcare professionals (in training/students and through grand rounds and such) content on living with a serious illness. We also participate in various QI projects to improve patient safety and reduce caregiver burden. We identify projects to support patients and caregivers. Through the non-profit I represent: 1. We connect experts to patients who get in touch with us to provide faster pathways through the diagnostic odyssey. 2. We create legislative toolkits and support Rare disease coalition with bipartisan support to help create laws to protect rare disease patients. (NBS for example.)

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We engage with various organizations working with the senior population. We facilitate relationships between the organizations by sharing information to improve resources reaching senior populations throughout the North and South Carolina.

## Appendix SF: Complete Listing of Educational Resources/Tools Most Beneficial When Explaining Various Serious Illness Topics, Q 10 – 16

### Q10. Educational resources/tools most beneficial when explaining the Advance Care Planning Process

Patients	Public	Staff	Medical professionals
N/A (14)	N/A (8)	N/A (13)	N/A (14)
	<b>Five Wishes (3)</b>		
<b>Got Plans? (2)</b> Advance Care Planning Guide	<b>Got Plans? (3)</b> <b>Advance Care Planning Guide (2)</b>	Got Plans? Advance Care Planning Guide (2)	Got Plans? Advance Care Planning Guide and Resources (2)
Vidant ACP Toolkit NC Legal Aide ACP Video 1:1 or small group ACP Visits/Events	Vidant ACP Toolkit <b>HELLO/Hi (2)</b> ACP (1)Educational Events/Visits, Book Reviews, Documentaries (such as Being Mortal), NC Legal Aide ACP Video	Vidant ACP Toolkit HELLO/Hi (2) ACP Educational Events/Visits ELNEC Respecting Choices (2) Psychiatric Advance Directive Training	Vidant ACP Toolkit, <b>Vital Talk, (4)</b> Serious Illness Conversation Guide (4)
Education provided by chaplain residents	<a href="http://www.gotplans123.org">www.gotplans123.org</a>	Internal website and webinars	Educational opportunities (group and individual)
MyChart Preparing for Your Care PCforMe		<b>Serious Illness Conversation Project 2</b> Respecting Choices	Vital Talk, The SIC Guide <b>Respecting Choices (2)</b>
Five wishes Gotpalliativecare.org CAPC Vital Talk Hello	Five Wishes Gotpalliativecare.org CAPC Vital Talk Hello	Five wishes Gotpalliativecare.org, CAPC <b>Vital Talk (2)</b> Hello	Five wishes, Gotpalliativecare.org, CAPC, Vital Talk Hello,

			Harvard Serious Illness Conversation Guide
<p>Information for patients &amp; public may be grouped together:  <a href="https://www.cdc.gov/aging/pdf/acp-resources-public.pdf">https://www.cdc.gov/aging/pdf/acp-resources-public.pdf</a></p> <p><a href="https://www.nc.gov/advanced-search?s=advance+directives&amp;form_build_id=form-2Ael3dG9z7INycx6V15-fsCqM7nwoBJf-Jro-ykGjjw&amp;form_id=nc_search_block_form#gsc.tab=0&amp;gsc.q=advance%20directives&amp;gsc.page=1">https://www.nc.gov/advanced-search?s=advance+directives&amp;form_build_id=form-2Ael3dG9z7INycx6V15-fsCqM7nwoBJf-Jro-ykGjjw&amp;form_id=nc_search_block_form#gsc.tab=0&amp;gsc.q=advance%20directives&amp;gsc.page=1</a></p> <p><a href="https://search.aarp.org/gss/everywhere?q=advance%20directive">https://search.aarp.org/gss/everywhere?q=advance%20directive</a>  file:///Users/Owner/Library/Mobile%20Documents/com~apple~CloudDocs/Hello!%20Hi!/Versions%20of%20%22Hello%20%20-%20Common%20Practice.webarchive</p> <p><a href="https://www.caregiver.va.gov/file:///Users/Owner/Library/Mobile%20Documents/com~apple~CloudDocs/NCSI%20Coalition/FaithHealthNC%20-%20Community%20Partnerships%20for%20Better%20Health.webarchive">https://www.caregiver.va.gov/file:///Users/Owner/Library/Mobile%20Documents/com~apple~CloudDocs/NCSI%20Coalition/FaithHealthNC%20-%20Community%20Partnerships%20for%20Better%20Health.webarchive</a></p> <p>....and other faith-based organizations Medical health systems – Duke, UNC, Vidant, Carolinas, etc.</p> <p>Immerman Angels Cornucopia Cancer Support and cancer foundations</p> <p>NAMI Foundations for disease entities, BCAN, for example; Michael J. Fox Parkinson Foundation; AARP</p>	See above.	<p>Information for staff &amp; medical professionals grouped together:</p> <p><a href="https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf">https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf</a></p> <p><a href="https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/previentive-services/medicare-wellness-visits.html">https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/previentive-services/medicare-wellness-visits.html</a></p> <p>NCMS Specialty professional medical groups, such as AAFP, for example, local hospice and palliative care entities</p>	See above.
Ask, Tell, Ask (Tailor response to their interests/needs)	Basic information specific to advance care planning	Personal engagement strategies. Not just about patient care. We ALL need this	COMMUNICATION Skills training!

In-person and virtual meetings, printed collateral, websites in English and Spanish, dedicated call line and email	In-person and virtual meetings, printed collateral, websites in English and Spanish, dedicated call line and email	In-person and virtual educational sessions, printed collateral, internal website resource library, dedicated call line and email	Onboarding education requirements, In-person and virtual educational sessions, printed collateral, internal website resource library, dedicated call line and email
<a href="https://www.sosnc.gov/divisions/advance_healthcare_directives">https://www.sosnc.gov/divisions/advance_healthcare_directives</a> ; <a href="https://www.caregiver.org/advance-health-care-directives-and-polst">https://www.caregiver.org/advance-health-care-directives-and-polst</a> <a href="https://www.caregiver.org/conservatorship-and-guardianship">https://www.caregiver.org/conservatorship-and-guardianship</a> ; <a href="https://www.caregiver.org/making-end-life-decisions-what-are-your-important-papers">https://www.caregiver.org/making-end-life-decisions-what-are-your-important-papers</a>	<a href="https://www.caregiver.org/making-end-life-decisions-what-are-your-important-papers">https://www.caregiver.org/making-end-life-decisions-what-are-your-important-papers</a> <a href="https://www.caregiver.org/advance-health-care-directives-and-polst">https://www.caregiver.org/advance-health-care-directives-and-polst</a> ; <a href="https://www.caregiver.org/conservatorship-and-guardianship">https://www.caregiver.org/conservatorship-and-guardianship</a>	<a href="https://www.sosnc.gov/forms/by_title/_advance_healthcare_directives">https://www.sosnc.gov/forms/by_title/_advance_healthcare_directives</a>	N/A
N/A	provide information to cancer survivors	N/A	N/A
N/A	workshops	workshops	N/A
Respecting Choices  Serious Illness Conversation Guide	Isn't It Time We Talk  Respecting Choices  Five Wishes  The Serious Illness Conversation Guide	Serious Illness Conversation Guide  Vital Talk	Respecting Choices  ELNEC  Serious Illness Conversation Guide  Vital Talk
N/A	GotPlans	N/A	N/A
N/A	<a href="http://transgenderlawcenter.org/wp-content/uploads/2020/04/TLC_Life-Planning-Documents-Transgender.pdf">http://transgenderlawcenter.org/wp-content/uploads/2020/04/TLC_Life-Planning-Documents-Transgender.pdf</a>	N/A	<a href="https://www.ncmedicaljournal.com/content/81/4/257">https://www.ncmedicaljournal.com/content/81/4/257</a>
N/A	Got Plans 123.org  Five Wishes	N/A	N/A

## Q11, Educational resources/tools most beneficial when explaining the Advance Directives Forms

<b>Patients</b>	<b>Public</b>	<b>Staff</b>	<b>Medical professionals</b>
N/A (16)	N/A (11)	Presentation with ADF forms	Presentation with ADF forms
N/A	<b>Five Wishes 4</b>	N/A (15)	N/A (17)
<b>Got Plans? (2)</b>	<b>Got Plans? 4</b>	<b>Got Plans? 2</b>	Got Plans?
Advance Care Planning Forms Tabs with Downloadable forms	Advance Care Planning Guide with downloadable forms	Advance Care Planning Guide with downloadable forms	Advance Care Planning Website Forms Tab
<b>Vidant ACP Toolkit 2</b> (including NC Practical Form)	<b>Vidant ACP Toolkit 2</b>	Vidant ACP Toolkit	Vidant ACP Toolkit
MOST/DNR	MOST/DNR	MOST/DNR	MOST/DNR
AIMHT	AIMHT	AIMHT	AIMHT
NC Legal Aide ACP Video	ACP Educational Events/Visits	ACP Educational Events/Visits	EPIC ACP Navigator
1:1 or small group ACP Visits/Events	NC Legal Aide ACP Video	NC Legal Aide ACP Video	
Chaplain Resident one-on-one	GotPlans 123.org	Internal education group	Educational opportunities (group and individual)
SICP	N/A	Serious Illness Conversation Guide	<b>Harvard Serious Illness conversation Guide 2</b>
Prepare for Your Care		Prepare for Your Care	Prepare for Your Care
		SOS	SOS
<b>Five wishes 2</b>	Five wishes	Five Wishes	Five Wishes
Gotpalliativecare.org	Gotpalliativecare.org,	Gotpalliativecare.org	Gotpalliativecare.org,
CAPC	CAPC	CAPC	CAPC
Vital Talk Hello	Vital Talk Hello	Vital Talk Hello	<b>Vital Talk 2</b>
			Hello
			Harvard Serious Illness

			Conversation Guide
N/A	Caregiver Resource Center: <a href="https://www.aarp.org/caregiving/">https://www.aarp.org/caregiving/</a>	N/A	N/A
Vidant Health Toolkit	Vidant Health Toolkit	Hello/Hi Game	Vital Talk Communication skills training
In-person and virtual meetings, Printed collateral, websites in English and Spanish, dedicated call line and email	In-person and virtual meetings, printed collateral, websites in English and Spanish, dedicated call line and email	In-person and virtual educational sessions, printed collateral, internal website resource library, dedicated call line and email	Onboarding education requirements, In-person and virtual educational sessions, printed collateral, internal website resource library, dedicated call line and email
Same as above #10 and <a href="https://www.gotplans123.org/">https://www.gotplans123.org/</a>	Same as above #10 and <a href="https://www.gotplans123.org/">https://www.gotplans123.org/</a>	Same as above #10 and <a href="https://www.gotplans123.org/">https://www.gotplans123.org/</a>	N/A
N/A	provide information to cancer survivors	N/A	N/A
N/A	workshops	workshops	N/A
Isn't It Time We Talk?	Isn't It Time We Talk?		
Respecting Choices	Five Wishes	NA	NA
Five Wishes	Respecting Choices		
N/A	GotPlans	N/A	N/A
N/A	Got Plans 123.org Five Wishes	N/A	N/A

## Q12. Educational resources/tools most beneficial when explaining Caregiver Resources

Patients	Public	Staff	Medical professionals
N/A 13	AARP Prepare to Care	N/A 14	N/A 15

Got Plans? Checklist Guide	Got Plans? Checklist Guide	Got Plans? Checklist Guide	Got Plans?  Workshops, Caregiver Resources and overall website offerings that include organ donations and a wealth of tools for various serious illness needs
Area Agency on Aging 2  Council of Governments  Departments of Social Services  Home Health and Hospice resources  AARP 4  Private agency materials	Area Agency on Aging 2  Council of Governments  Departments of Social Services  Home Health and Hospice resources  AARP 4  Private agency materials	Area Agency on Aging 2  Council of Governments  Departments of Social Services  Home Health and Hospice resources  AARP 4  Private agency materials	Area Agency on Aging 2  Council of Governments  Departments of Social Services  Home Health and Hospice resources  AARP 4  Private agency materials
Care Coordination	N/A 12	Intranet site	Care Coordination
utilize our CM team for this primarily	N/A	NC Care 360	rely on our CM/SW team
Aunt Bertha	Aunt Bertha	Aunt Bertha	Aunt Bertha
CAPC	CAPC	CAPC	CAPC
CTAC	CTAC	CTAC	CTAC
Support Member choice	Support Member choice	Support Member choice	Support Member choice
<a href="https://www.aarp.org/caregiving/">https://www.aarp.org/caregiving/</a>	<a href="https://www.aarp.org/caregiving/">https://www.aarp.org/caregiving/</a>	<a href="https://www.aarp.org/caregiving/">https://www.aarp.org/caregiving/</a>	<a href="https://www.aarp.org/caregiving/">https://www.aarp.org/caregiving/</a>
AARP	AARP	AARP	AARP
Printed educational/resources, website	Printed educational/resources, website	Printed educational/resource s, website	Printed educational/resource s, website
Local area agency on aging;  <a href="https://www.ncdhhs.gov/assistance/adult-services/family-caregiver-support">https://www.ncdhhs.gov/assistance/adult-services/family-caregiver-support</a> ;  <a href="https://www.caregiver.org/">https://www.caregiver.org/</a> ;	Local area agency on aging;  <a href="https://www.ncdhhs.gov/assistance/adult-services/family-caregiver-support">https://www.ncdhhs.gov/assistance/adult-services/family-caregiver-support</a> ;  <a href="https://www.caregiver.org/">https://www.caregiver.org/</a> ;	N/A	N/A

<a href="https://www.caregiving.org/">https://www.caregiving.org/</a>	<a href="https://www.caregiving.org/">https://www.caregiving.org/</a>		
N/A	provide information to cancer survivors and caregivers	N/A	N/A
N/A	directory; website; person to person	meetings	website
AARP's booklet for Caregivers	AARP's booklet for caregivers	NA	NA
NORD,  Global Genes	Global GENes  American Academy of Pediatrics	N/A	N/A



### Q13. Educational resources/tools most beneficial when explaining the Hospice Medicare Benefit

Patients	Public	Staff	Medical professionals
N/A 14	N/A 15	website video information	website video information
N/A	CMS Publications	N/A 13	N/A 14
<b>Medicare.gov - 3</b>	<b>Medicare.gov - Hospice Medicare explanation of services 3</b>	Medicare.gov-2 pager-Hospice Medicare explanation of services 2	Medicare.gov- 2 pager-Hospice Medicare explanation of services 2
Vidant HHH Liaison and Admission Booklet	Vidant HHH Education Materials	Vidant HHH Education Materials	Vidant HHH Education Materials
KRAMES educational tools within our EPIC system	CMS	CMS	CMS
CMS information			
Care Coordination	N/A	Care Coordination	Care Coordination
rely on our CM/SW team	N/A	CM/SW	CM/SW, presentations, rotation on service
Medicare Website	Medicare Website	Medicare Website	Medicare Website
NHPCO	NHPCO	NHPCO	NHPCO
Five Wishes	Five Wishes	Five Wishes	Five Wishes
Gotpalliativecare.org,	Gotpalliativecare.org,	Gotpalliativecare.org,	Gotpalliativecare.org,
CAPC	CAPC	CAPC	CAPC
Vital Talk	Vital Talk	Vital Talk	Vital Talk
Hello	Hello	Hello	Hello
See above	See above	See above	See above
Support Member choice	Support Member choice	Support Member choice	Support Member choice
<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL_2">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL_2</a>	<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL_2">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL_2</a>	<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL</a>	<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL</a>
Verbal explanation	Verbal explanation	Verbal explanation	Verbal explanation
Printed educational/resources, website	Printed educational/resources, website	Printed educational/resources, website	Printed educational/resources, website
<a href="https://www.medicare.gov/coverage/hospice-care">https://www.medicare.gov/coverage/hospice-care</a>	<a href="https://www.medicare.gov/coverage/hospice-care">https://www.medicare.gov/coverage/hospice-care</a>	N/A	N/A

<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html</a> ; <a href="https://info.ncdhhs.gov/dhsr/data/hhhos.pdf">https://info.ncdhhs.gov/dhsr/data/hhhos.pdf</a>	<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html</a>		
N/A	workshops	workshops	N/A
Agency handbooks	NA	Training Courses offered by TCC & PGBA	Training courses offered by TCC H101, H201 & PGBA

# **Q14. Educational resources/tools most beneficial when explaining the importance and use of Medical Order for Scope of Treatment (MOST/POLST)**

<b>Patients</b>	<b>Public</b>	<b>Staff</b>	<b>Medical professionals</b>
Got Plans?  <b>Advance Care Planning Guide section on MOST 2</b>	<b>Got Plans? 2</b>  <b>Advance Care Planning Guide section on MOST 3</b>	Got Plans?  <b>Advance Care Planning Guide section on MOST 2</b>	Got Plans?  <b>Advance Care Planning Guide section on MOST 2</b>  NC Medical Society MOST online education
Vidant ACP Toolkit	Vidant ACP Toolkit	Vidant ACP Toolkit	Vidant ACP Toolkit
Krames materials	Krames materials	Krames materials	Krames materials
Respecting Choices	Respecting Choices	Respecting Choices	Respecting Choices
sample MOST forms	sample MOST forms	sample MOST forms	sample MOST forms
Provider based	Workshops	continuing education	continuing education
N/A	N/A	N/A	We have a Duke specific form and LMS module. Only providers (MDs, no APPs utilize at Duke) who have completed the LMS module can utilize the form.
ncdhhs.org	ncdhhs.org	ncdhhs.org	ncdhhs.org
ncmedsoc.org	ncmedsoc.org	ncmedsoc.org	ncmedsoc.org
NCIOM	NCIOM	NCIOM	NCIOM
Polst.org	Polst.org	Polst.org	Polst.org
Compassionate Care.org	Compassionate Care.org	Compassionate Care.org	Compassionate Care.org
Medicare website	Medicare website	Medicare website	Medicare website
NHPCO	NHPCO	NHPCO	NHPCO
Five Wishes	Five Wishes	Five Wishes	Five Wishes
Gotpalliativecare.org	Gotpalliativecare.org	Gotpalliativecare.org	Gotpalliativecare.org
CAPC	CAPC	CAPC	CAPC
Vital Talk	Vital Talk	Vital Talk	Vital Talk
Hello	Hello	Hello	Hello
<a href="file:///Users/Owner/Library/Mobile%20Documents/co">file:///Users/Owner/Library/Mobile%20Documents/co</a>	<a href="file:///Users/Owner/Library/Mobile%20Documents/">file:///Users/Owner/Library/Mobile%20Documents/</a>	N/A	N/A

<a href="https://m~apple~CloudDocs/NCSI%20Coalition/MOST/The%20Conversation%20Project%20-%20Have%20You%20Had%20The%20Conversation%3F.webarchive">m~apple~CloudDocs/NCSI%20Coalition/MOST/The%20Conversation%20Project%20-%20Have%20You%20Had%20The%20Conversation%3F.webarchive</a>	<a href="https://com~apple~CloudDocs/NCSI%20Coalition/MOST/The%20Conversation%20Project%20-%20Have%20You%20Had%20The%20Conversation%3F.webarchive">com~apple~CloudDocs/NCSI%20Coalition/MOST/The%20Conversation%20Project%20-%20Have%20You%20Had%20The%20Conversation%3F.webarchive</a>		
Support Member choice	Support Member choice	Support Member choice	Support Member choice
Verbal explanation	Verbal explanation	Respecting Choices advance steps	Respecting Choices advanced steps
In-person and virtual meetings, printed collateral, websites in English and Spanish, dedicated call line and email	In-person and virtual meetings, printed collateral, websites in English and Spanish, dedicated call line and email	In-person and virtual educational sessions, printed collateral, internal website resource library, dedicated call line and email	Onboarding education requirements, In-person and virtual educational sessions, printed collateral, internal website resource library, dedicated call line and email
		N/A	N/A
N/A	workshops	workshops	N/A
unaware of what exists	unaware of anything that exists	webinars provided by NCSIC	webinars provided by NCSIC
N/A	MOST form instructions	N/A	N/A
N/A	Got Plans123.org	N/A	N/A

## Q15. Educational resources/tools most beneficial when explaining Palliative Care

Patients	Public	Staff	Medical professionals
N/A 17	presentations zoom	N/A 16	presentations zoom
<p>Resources/tools offered depends on the regional location of need. Provide Carolina Caring Palliative Resources, NOVANT HEALTH, Atrium and others</p> <p>Would recommend a statewide portal that shares all county palliative programs by location of services.</p> <p>Always encourage patients having assessment to determine need- give them phone numbers to call</p>	<p>Resources/Tools offered depends on the regional location of need. Atrium, NOVANT, Carolina Caring, Wake Forest Baptist Health, Duke, and area specific providers by county.</p> <p>Always encourage public that is caring for someone or has needs to call themselves to get an assessment or discuss needs.</p>	<p>Palliative Care App-provides explanation of patients that would benefit from PC, that allows for immediate palliative care referrals,</p> <p>Resources/Tools offered depends on the regional location of need.</p> <p>One page with zip code coverage of palliative care service providers</p>	<p>Palliative Care App-provides explanation of patients that would benefit from immediate palliative care referrals,</p> <p>Direct phone numbers to palliative care</p> <p>make referrals</p> <p>CAPC</p> <p>One page with Palliative Care Resources by zip code and location of care options- i.e. home care /palliative care</p>
<p>Vidant Handout</p> <p>Palliative Care Consult, Inpatient Video on demand</p> <p>Krames Materials via EPIC</p>	<p>Vidant Handout</p> <p>Krames materials</p>	<p><b>ELNEC 3</b></p> <p>Respecting Choices</p> <p>Department inservices/orientation</p>	<p><b>Vital Talk 2</b></p> <p><b>ELNEC 3</b></p> <p>Respecting Choices</p>
N/A	N/A 14	N/A	N/A 15
Palliative Care staff, chaplains	Website	Palliative Care staff, chaplains	Palliative Care staff
PCforME	N/A	CAPC	CAPC
brochures		grand rounds	grand rounds
		rotations on service	rotations on service
Five Wishes	Five Wishes	Five Wishes	Five Wishes
Gotpalliativecare.org	Gotpalliativecare.org	Gotpalliativecare.org	Gotpalliativecare.org
CAPC	CAPC	CAPC	CAPC
Vital Talk	Vital Talk	Vital Talk	Vital Talk
Hello	Hello	Hello	Hello

Support Member choice <a href="https://www.aarp.org/caregiving/health/info-2019/palliative-care.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/palliative-care.html?intcmp=AE-CAR-CRC-LL</a>	Support Member choice <a href="https://www.aarp.org/caregiving/health/info-2019/palliative-care.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/palliative-care.html?intcmp=AE-CAR-CRC-LL</a>	Support Member choice <a href="https://www.aarp.org/caregiving/health/info-2019/palliative-care.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/palliative-care.html?intcmp=AE-CAR-CRC-LL</a>	Support Member choice <a href="https://www.aarp.org/caregiving/health/info-2019/palliative-care.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/palliative-care.html?intcmp=AE-CAR-CRC-LL</a>
Verbal explanation	Verbal explanation	ELNEC	ELNEC
Printed educational/resources, website <a href="https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care">https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care</a> ; <a href="https://www.caregiver.org/understanding-palliative-supportive-care-what-every-caregiver-should-know">https://www.caregiver.org/understanding-palliative-supportive-care-what-every-caregiver-should-know</a> ; <a href="https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet#what-is-palliative-care">https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet#what-is-palliative-care</a> ;	<a href="https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care">https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care</a> ; <a href="https://www.caregiver.org/understanding-palliative-supportive-care-what-every-caregiver-should-know">https://www.caregiver.org/understanding-palliative-supportive-care-what-every-caregiver-should-know</a>	N/A	N/A
N/A	provide information to cancer survivors	N/A	N/A
N/A	workshops	workshops	N/A
N/A	N/A	ELNEC	ELNEC
N/A	N/A	N/A	<a href="https://jmla.pitt.edu/ojs/jmla/article/view/766">https://jmla.pitt.edu/ojs/jmla/article/view/766</a>
N/A	Got Plans 123.org	N/A	N/A

## Q16. Educational resources/tools most beneficial when explaining Hospice Care

Patients	Public	Staff	Medical professionals
N/A 15	Presentations	Presentations/ discussion	Presentations / discussion
Promote Hospice websites in service area,  <b>brochures and workshops provided to learn more about resources available to them. 3</b>  Promote self-referral calls to discuss their needs	Promote Hospice websites,  <b>brochures and workshops to learn more about resources available in their community. 5</b>  Always promote public to call to discuss their needs and or/assessment.	<b>Promote various Hospice websites, resources, apps and workshops that support needs in the region 4</b>	Hospice Patient Eligibility Guide  Hospice Patient Referral App with Eligibility listed
Krames Materials via EPIC	Vidant Handout  Krames materials	<b>ELNEC 2</b>  Respecting Choices  Department inservices/orientation	<b>Vital Talk 2</b>  <b>ELNEC 2</b>  Respecting Choices
Palliative Care		Palliative Care	Palliative Care
Care Coordination	Workshops	Care Coordination	Care Coordination
Chaplains		Chaplains	
cm/sw	N/A 13	<b>NHPCO 2</b>	<b>NHPCO 2</b>
Medicare Website	Medicare Website	Medicare Website	Medicare Website
NHPCO	NHPCO	NHPCO	NHPCO
Five Wishes	Five Wishes	Five Wishes	Five Wishes
Gotpalliativecare.org	Gotpalliativecare.org	Gotpalliativecare.org	Gotpalliativecare.org
CAPC	CAPC	CAPC	CAPC
Vital Talk	Vital Talk	Vital Talk	Vital Talk
Hello	Hello	Hello	Hello
Support Member choice	Support Member choice	Support Member choice	Support Member choice
<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL</a>	<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL</a>	<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL</a>	<a href="https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL">https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html?intcmp=AE-CAR-CRC-LL</a>

			<a href="#">ntcmp=AE-CAR-CRC-LL</a>
Verbal explanation	Verbal explanation	ELNEC	ELNEC
Printed educational/resources	Printed educational/resources	Printed educational/resources	Printed educational/resources
Website	Website	Website	Website
<a href="https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care">https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care</a> ; <a href="https://www.gotplans123.org/">https://www.gotplans123.org/</a> ; <a href="https://www.caregiver.org/understanding-palliativesupportive-care-what-every-caregiver-should-know">https://www.caregiver.org/understanding-palliativesupportive-care-what-every-caregiver-should-know</a>	<a href="https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care">https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care</a> ; <a href="https://www.gotplans123.org/">https://www.gotplans123.org/</a> ; <a href="https://www.caregiver.org/understanding-palliativesupportive-care-what-every-caregiver-should-know">https://www.caregiver.org/understanding-palliativesupportive-care-what-every-caregiver-should-know</a>	N/A 14	N/A 14
N/A	provide information to cancer survivors	N/A	N/A
N/A	workshops	workshops	N/A
agency brochures	???	H101 H201 provided by TCC or agency orientation	H101 H201 or agency training
N/A	N/A	N/A	<a href="https://jmla.pitt.edu/ojs/jmla/article/view/766">https://jmla.pitt.edu/ojs/jmla/article/view/766</a>