



ADVANCE CARE PLANNING SURVEY RESULTS QUALITATIVE FINDINGS

Prepared for Honoring Care Decisions by:
ReThink Health: Upper Connecticut River Valley

With thanks to all of our community partners

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I. BACKGROUND

In the fall of 2015, ReThink Health: Upper Connecticut River Valley (RTH: UCRV) developed a survey on Advance Care Planning (ACP) in consultation with Honoring Care Decisions and Partners for Community Wellness. Together, RTH: UCRV's backbone team and their community partners—which included 34 employers, 6 of which were hospitals, 6 social service agencies and 5 volunteer groups—disseminated the survey in the UCRV region. The aim was to improve our knowledge of the current state of advance care planning in the UCRV. 1850 respondents took the survey representing 1% of our 69-town service area—well above our goal of 690 responses (representing an average of 10 people for each of the towns). This report highlights the key findings from the comments we received through our survey. Moving forward, our goal is to work with Honoring Care Decisions and Partners for Community Wellness, as well as other community partners, to effectively leverage the data collected.

II. DEMOGRAPHICS

Age & Gender

In table 1, we show the age and gender of survey respondents. Sixty-two respondents did not disclose their gender or age; 6 selected “Other” for gender; another 5 respondents only disclosed their gender but not their age (not shown in Table 1).

Table 1: Age and gender distribution of respondents

Gender	Age								Total #
	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
Female	57	177	189	286	359	138	58	14	1278 (72%)
Male	24	60	81	104	117	73	29	11	499 (28%)
Total #	81 (5%)	237 (13%)	270 (15%)	390 (22%)	476 (27%)	211 (12%)	87 (5%)	25 (1%)	1777 (100%)

Residence

57% of our survey respondents reside in New Hampshire, and 37% are residents of Vermont. A small minority of respondents (5%) did not disclose their state of residence.

III. QUALITATIVE COMMENTS

Out of the 1850 responses to our survey, 181 respondents left written-in comments when asked to leave comments about the survey or advance care planning. We explore the major themes that emerged from these comments below (see Table 2 for outline). Although there were other questions that allowed survey respondents to write-in a comment, only the final question yielded responses that were suitable for analysis. In total, 16

Major Themes	Explanation
1. Demand for more information about ACP	Respondents indicated a desire for more access to information about ACP
2. Involvement of the healthcare sector in ACP	Respondents expressed a desire for greater involvement from the healthcare sector at different stages of ACP and a greater role for PCPs.
3. Personal Experiences	Respondents shared their experiences with ACP or lack thereof.
4. Intention to Act	Respondents declared that they intended to act by having a conversation or completing an AD.
5. Age	Respondents shared their beliefs on the appropriateness of ACP for different age groups.

Table 2: Major themes in qualitative analysis.

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codes were developed in the analysis phase of the project. For a full list of the codes, please contact ReThink Health at rth@rethinkhealthucrv.org.

1. Demand for More Information about ACP

The most prominent theme to emerge from the comments was the need for more information on ACP or suggestions to increase access to information through community resources. Twenty comments were coded with this theme.

A. More access to information through community resources

Ten of the respondents, or half of all comments about information, expressed interest in having increased access to information about ACP through community resources, such as workshops in the community, library programs, senior center forums, or free “clinics” at local hospitals. A handful of respondents suggested establishing a website with free resources to guide individuals through the process or to provide more information about ACP in general.

B. What is ACP and how do I get started?

The other half of respondents’ comments, in which the theme of information emerged, requested more information. For example, some comments asked where advance directives can be obtained while others expressed not knowing what is involved in the ACP process.

2. Involvement of the Healthcare Sector

Fifteen respondents made references to the current role of the healthcare sector in advance care planning. A couple of respondents argued that because healthcare workers should have increased awareness of ACP, this group should have a higher share of people with completed advance directives. Others suggested that hospital staff should have access to resources that would enable them to complete an advance directive in the workplace. The implication behind these comments was that if those in healthcare do not possess advance directives, what is the impetus for those in the broader community to complete an advance directive?

A. The Role of Primary Care Physicians

Of the fifteen comments that referenced the involvement of the healthcare sector in ACP, ten cited the role that primary care physicians play in ACP—or rather, the role that survey respondents believe PCPs *should* have. The majority of these respondents indicated that PCPs should take a more involved role in ACP by initiating conversations about end-of-life care and providing the necessary forms in their offices. Importantly, one respondent remarked that at their PCP’s office, a secretary provides the forms but there is no accompanying conversation about ACP with the physician. Survey respondents also commented on the discomfort that some PCPs express when discussing end-of-life care.

3. Personal Experiences

Respondents left comments about their own experiences with advance care planning and end-of-life care. With twelve comments that cited personal experience, this was the third most common type of comment. Although a majority of the comments were about the respondents’ experiences taking care of a family member or their own experience with advance directives, three of the comments were provided by individuals who work in healthcare and shared their experiences with patients who did not have advance directives.

A. Negative

For the two respondents who had negative experiences with end-of-life care, the common factor was that the loved one in question had not completed an advance directive beforehand. One respondent shared her experience watching her mother receive “exactly the opposite” type of care she would

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have wanted because she had failed to plan accordingly. Another respondent experienced a similar situation with two family members.

B. Positive

For respondents with a positive experience concerning a loved one's end-of-life care, an advance directive was in place. Respondents felt relieved when their loved one's advance directive took effect, as they felt that the burden of deciding what type of care their loved ones wanted was known. Other respondents whose loved ones are suffering from advanced dementia are happy that their family members completed an advance directive before dementia could incapacitate them.

C. Professional

Three respondents included their experiences working in healthcare. One respondent works as an EMT and expressed concern that families may incorrectly believe that their loved ones have appropriately completed and stored an advance directive when there is no document accessible to EMTs. The other two respondents suggested that the role that providers currently play in advance care planning is insufficient. One respondent expressed frustration over physician-patient conversations about advance care planning: *It is either avoided completely, or it is so clinical and brief that patients don't really understand the immense and complicated decision process. When asked "Do you want us to use all possible resources to save your life?" most patients say yes, as in "Please don't just walk away and leave me to die". Most patients simply don't understand the difference between palliative care /common sense interventions and heroic measures.*

4. Intention to Act

Eleven respondents indicated that they intend to act by completing an advance directive or having a conversation about end-of-life care. Two of the respondents indicated that they had made plans to have a conversation before they took the survey, while the rest of the respondents indicated that the survey has helped "remind" them to act. Thus, the survey served as a motivator for different individuals at different stages of the advance care planning process—from those who have yet to have a conversation about end-of-life care to those that need to go back and make adjustments to their advance directive.

Although the responses to other questions in the survey are not reported here, it is important to note that survey respondents expressed an intent to act in comments for two other questions in our survey. These were the questions that asked *why did the survey respondent not have a conversation about end-of-life care* and *why did the survey respondent not have an advance directive*.

5. Age

The most polarized comments were on the subject of age. Out of the ten comments, five respondents indicated that they thought ACP was relevant for everyone, regardless of age—although one respondent specifically mentioned that everyone aged 21+ should have an AD. The other five respondents that mentioned age argued that the survey was inappropriate for young adults (three of these responses were submitted by WIC beneficiaries) or that ACP was relevant to older individuals.