

ADVANCE CARE PLANNING SURVEY RESULTS KEY 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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ADVANCE CARE PLANNING SURVEY RESULTS

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 of 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. ASSESSMENT OF ADVANCE CARE PLANNING IN THE UCRV

The number of respondents who have had a conversation about end-of-life care is a large majority of our sample (69%). An even larger share of our sample (92%) indicated that there is someone they trust to make decisions about their health care should they be unable to make their own decisions (not shown here). Of these, only 71% said that this person has agreed to be responsible for making these decisions. When respondents were asked whether they currently have an Advance Directive, 42% of respondents said “Yes”; 2% said they are not sure, and 1% said that they are unfamiliar with Advance Directives, respectively. In the next sections, we examine which groups are most

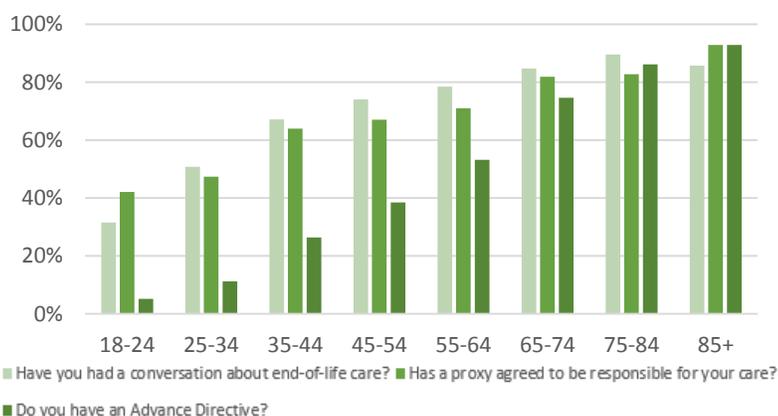


Figure 1: Percent of female respondents answering affirmatively to each question on survey.



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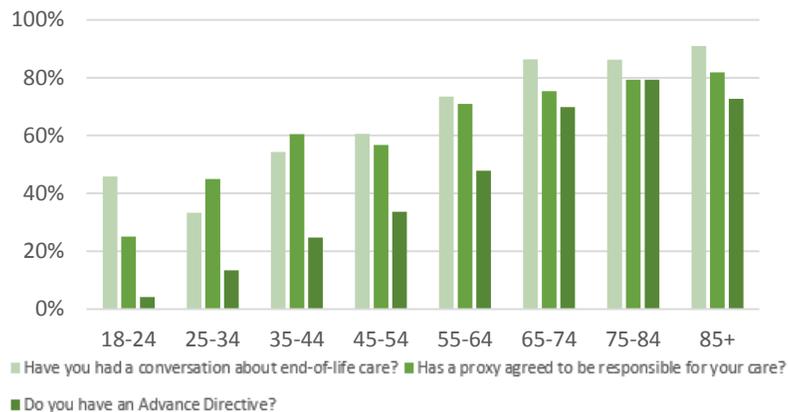


Figure 2: Percent of male respondents answering affirmatively to each question on survey.

likely to engage in conversations about ACP, have a health care agent, and have an advance directive, and we identify the barriers associated with each step, respectively.

Who is having conversations?

Figures 1 and 2 illustrate how our male and female respondents compare in their responses to our survey questions. Among women, those who were between 18-24 years old had the lowest share of respondents participating in end-of-life conversations (32%), while women in the 75-84 age band had the highest reported share of women having

these types of conversations (90%; see Figure 1). Among men, those aged between 25-34 years of age had the lowest share of participating in end-of-life conversations (33%), while those in the 85+ age group had the largest share of respondents talking about end-of-life care at 91% (see Figure 2). From our sample, older age groups have larger shares of people engaging in conversations regardless of gender. Despite 92% of all respondents indicating that there is someone they would trust to carry out their medical decisions, the share of people having conversations is smaller at all age levels. As reported earlier, 69% of all respondents have

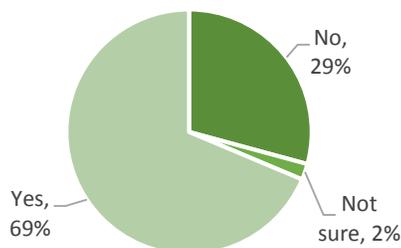


Figure 3: Percent of respondents having conversations about end-of-life care.

previously had a conversation about end-of-life care, while 29% have not had a similar conversation and 2% of respondents were unsure (see Figure 3). Of those that did have a conversation, most individuals participated in conversations with family members (95%), a friend (42%), a health care provider (25%), and a lawyer (24%). Religious leaders and trained facilitators were engaged the least, with only 2% of respondents having conversations with each group. The following section identifies the most commonly cited reasons for not having a conversation about end-of-life care.

Barriers to Conversations

Table 2 outlines the five most commonly cited reasons for not having a conversation about end-of-life care. 15% of all respondents have not had a conversation about end-of-life care because they “*have not gotten around to it.*” When we restrict our sample to only those who have not had a conversation, this represents over half of all respondents (51%). The second most common reason for not having a conversation about end-of-life care is that respondents believed *they are too young to have a discussion* (10% of sample; 36% of restricted sample). The other most common responses among our sample were “*never thought about [having a conversation] before*” (8% of sample; 28% of restricted sample); “*not [being] sick enough*” (6% of sample; 19% of restricted sample); and “*don’t know who to talk to*” (4% of sample; 15% of restricted sample).

Table 2: Most commonly cited barriers to ACP conversations

Top 5 Reasons for Not Talking about end-of-life care
1. I haven’t gotten around to it
2. I’m not old enough
3. I never thought about it
4. I’m not sick enough
5. I don’t know who to talk to



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Health Care Agent Agreement

Respondents who indicated that they knew someone they would trust with making health care decisions on their behalf (92% of respondents) were subsequently asked whether this person had agreed to be responsible for making these decisions. 71% of these respondents indicated that a health care agent had agreed to take on the responsibility of making medical decisions (see Figure 4). Of the remaining respondents, 15% had not reached an agreement with their potential health care agent, and 14% were unsure whether they had reached an agreement regarding the responsibility for making medical decisions on behalf of the respondent.

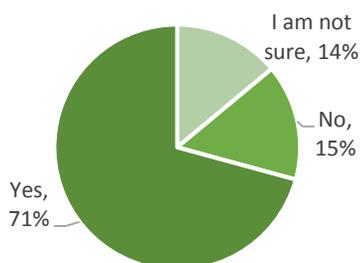


Figure 4: Percent of respondents who indicate that a health care agent has agreed to be responsible for making health care decisions.

Who is talking to their health care agents?

Figures 1 and 2 show the share of respondents across gender and age that said they have come to an agreement with a health care agent concerning medical decisions for end-of-life care. At younger ages, a smaller percentage of respondents said they have an agreement with their health

care agent – irrespective of gender. Although the share of respondents answering affirmatively increases as respondents age for both men and women, the men in our sample have lower rates of health care agent agreement across age bands than women. For instance, for respondents age 85+, 93% of female respondents have come to an agreement with their health care agent whereas 82% of men in the same age group have a consenting health care agent.

Advance Directives

In our sample, 42% of respondents answered that they currently have an Advance Directive (see Figure 5). Only 1% of respondents did not know what an Advance Directive was, and 2% were uncertain whether they had one. A majority of respondents did not have an Advance Directive. Notably, the share of respondents who do have an Advance Directive is relatively smaller than the share of respondents who have had conversations about end-of-life care and those that have a consenting health care agent. Therefore it is important to understand the populations who currently do not have an Advance Directive, the barriers associated with completing one, and whether individuals that possess Advance Directives have stored them properly to ensure that their decisions are honored. We explore these questions in the sections that follow.

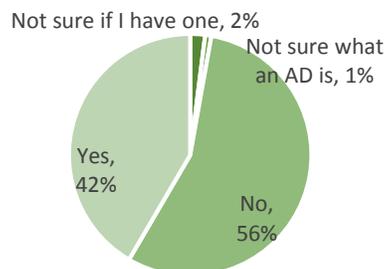


Figure 5: Percent of respondents who have an Advance Directive.

Who has an Advance Directive?

According to Figures 1 and 2, older age groups have a higher concentration of Advance Directives, compared with those in lower age groups. For example, 93% of women 85+ and 79% of men 75-84 have an Advance Directive, while the 18-24 age group has the smallest share of respondents saying they have an Advance Directive for both genders. As was the case for the number of conversations and instances of health care agent agreement, the share of respondents reporting having an Advance Directive increases across age bands for both genders, though it is lower for men in all age groups.

Table 3: Most commonly cited barriers to Advance Directives

Top 5 Reasons for not having an AD
1. I haven't gotten around to it
2. I need more info to get started
3. Haven't figured out what type of care I would want
4. I don't know where to get one
5. I've never thought about it



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Identifying barriers to Advance Directives

Table 3 outlines the most common barriers to having an Advance Directive. The most common barrier identified in our survey is procrastination. 39% of all respondents indicated they simply “*haven’t gotten around to it.*” This represents 71% of respondents who did not have an Advance Directive at the time of our survey. The other most common reasons for not having an Advance Directive are “*need for more information*” (8% of full sample; 15% of restricted sample); “*haven’t figured out what type of care I would want*” (8% of full sample; 15% of restricted sample); “*don’t know where to get [an Advance Directive]*” (8% of full sample; 15% of restricted sample); and “*never thought about it*” (7% of full sample; 14% of restricted sample).

Advance Directive storage and accessibility by the health care system

We asked respondents who have an Advance Directive where they store the document (see Figure 6). Respondents could choose several options in the event that they have multiple copies of their directive, so



Figure 6: Percent of respondents indicating where they currently store their Advance Directive.

when interpreting the following percentages, it is important to consider that individuals may have stored their directive in multiple locations. 83% of individuals with an Advance Directive indicated that they store their directive in *their current home or residence*. The second most common response was *doctor's office or hospital* (52%), followed by *lawyer's office* (44%) and *a family member has it* (38%). Respondents also had the option to write in any other locations where they may have stored their Advance Directive; of these responses, the most common location was a *safe deposit box* (n=28). This represents roughly 4% of all individuals with an Advance Directive.

By observing respondents who stored their directive at their doctor's office, hospital, or, in the case of Vermont residents, the Vermont Registry (New Hampshire does not currently have a statewide registry), we constructed a measure for hospital system access to the directive. The importance of this measure lies in the fact that it is highly unlikely that a hospital system will honor a patient's wishes if it does not have access to the Advance Directive documenting preferences. Out of all the respondents that indicated they have an Advance Directive, only 52% have a directive that is accessible by a hospital system (see Figure 7).

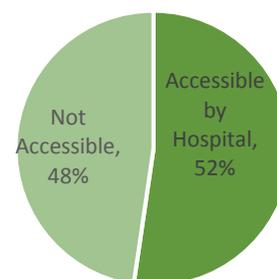


Figure 7: Percent of respondents who have an Advance Directive stored properly.

IV. THOUGHTS FOR FUTURE SURVEYS

- During the dissemination process, some of our community employer partners requested paper surveys. In addition, most of the social service agencies and volunteer groups requested paper. Of the 1850 surveys received, 283 were paper. During data entry, we noted that some of the paper surveys disseminated at senior luncheons contained internal inconsistencies—in the electronic survey, these inconsistencies were impossible because of the branching logic. For example, a survey respondent indicated that they had stored their Advance Directive with a family member when they had previously reported that they did not have an Advance Directive. During the entry process, these inconsistencies were smoothed out when possible.
- Additional outreach methods need to be piloted to capture responses from towns with no listserv and no resident volunteer group interested in ACP.



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- Additional avenues (beyond social service agencies) should be explored for reaching populations that are not employed/unlikely to respond to or unreachable by listserv or emailed appeals.

Survey Dissemination Channels

