

# Advance Care Planning in Rural Communities

## *A Report for MercyOne PHSO*

Authors: Jennifer McCleary and Christin Lindberg

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451 Lexington Parkway North | Saint Paul, Minnesota 55104  
651-280-2700 | [www.wilderresearch.org](http://www.wilderresearch.org)

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# Executive summary

Wilder Research utilized web and paper surveys as well as targeted interviews to learn about residents' barriers to participating in advance care planning and completing advance directives. The findings will be used to develop and implement outreach and methods to boost participation in advance care planning among residents in Ringgold and Appanoose counties in Iowa.

## Characteristics and background of respondents

A total of 449 individuals completed the survey and 12 respondents were invited to participate in individual interviews to provide depth and context for the survey results. People who completed the survey were predominantly white (98%), female (76%), age 50 and over (63%), and married (65%). They were also equally split between saying they received their health care in Appanoose (45%) and Ringgold (46%) counties. About 10% said they received their health care in a different county.

## Key findings

- Knowing someone with an advance directive appears to be a key factor in encouraging people to talk about their own advance care planning and complete advance directives.
- People want to talk with their doctors about advance care planning but report that their doctors don't ask about it or invite deeper conversations about it.
- Top barriers to completing an advance directive include:
  - A lack of information about advance directives or about how to complete one
  - The stress of thinking about end-of-life or medical crises
  - Doctors haven't asked about it or provided support
- People feel informed about advance directives but need help with concrete steps toward completing them, such as help filling out forms and deeper conversations with doctors.

## Recommendations offered by survey and phone interview respondents

- Show people how easy it is
- Educate people on cost
- Make information about advance directives more widely available, especially at medical clinics
- Use impactful messaging to build support
- Provide concrete help with forms
- Doctors should engage in deeper conversations about advance care planning and advance directives
- Explain the importance of ADs for medical crises beyond terminal illness

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# Background and introduction

Wilder Research was selected by MercyOne Population Health Services Organization (PHSO) to conduct a community survey and targeted interviews with residents in two rural counties—Ringgold and Appanoose—in southern Iowa. The purpose of the study was to understand the residents’ barriers to participating in advance care planning and completing advance directives. The findings will be used to develop and implement outreach and methods to boost participation in advance care planning among residents in the two counties.

MercyOne is a connected system of hospitals and clinics in southern Iowa providing comprehensive medical care to over 300,000 patients. In Ringgold County, residents receive care at Ringgold County Hospital and Mount Ayr Clinic; in Appanoose County, residents receive care at MercyOne Centerville Medical Center. Both counties were identified as medically underserved counties. Recognizing the importance of advance care planning in general, coupled with limited participation in advance care planning in these rural communities, MercyOne determined to broaden the reach of advance care planning in order to improve health outcomes for residents.

The following summary highlights the key information from the surveys and interviews. A complete set of data tables and detailed study methodology are located in the Appendix.

## Definitions

**Advance care planning** is a process of reflection and communication about medical care in the event one is unable to make decisions for themselves due to a medical crisis or end-of-life. Advance care planning specifically involves the process of making and sharing choices about one’s future medical needs with others, such as a doctor or loved one.

**Advance directives** are the official forms with documentation of these choices, which are shared with loved ones and health care providers.

## Methods

From April 6, 2023 to May 26, 2023, paper-and-pencil surveys were distributed to patients at MercyOne clinics as they waited for their appointments. During the same time period, an online version of the same survey was distributed via social media posts, radio advertisements, and flyers, with the goal of including residents of Appanoose and Ringgold counties who were not seen in the clinics during the study period or who did not receive

care through the MercyOne network. As an incentive to complete the survey, participants who turned in their paper surveys received a MercyOne-branded coffee mug.

On the survey form, participants had the option of indicating their interest in completing an additional phone survey about advance care planning. They shared their name, phone number, and email address for follow-up. Participants in the phone survey were offered a \$20 gift card to thank them for their time.

A full discussion of the methodology is located in the Appendix.

## Limitations

The study results should be interpreted within a set of limitations.

1. Participants for the survey were primarily recruited from patient waiting rooms at MercyOne clinics while patients and family members were waiting for scheduled appointments. This population of participants may be more likely to think about health care and advance care planning than the general population.
2. A noteworthy number of paper surveys were incomplete or had missing data and could not be included in the final analysis. It is possible that participants had limited time to fully complete the surveys while waiting for appointments or that distractions interrupted their ability to complete the surveys. As such, some data results are limited by smaller sample sizes and cannot be considered representative of the full set of participants. These variations are noted in the data tables in the Appendix.
3. A review of email addresses associated with both paper and web surveys indicated that many of the participants were affiliated with MercyOne clinics (for example, their email addresses ended in “mercyoneiowa.org”). This group of participants may also be more familiar with advance care planning and the purposes of the survey than the general population.

## Detailed results

A total of 449 individuals completed the survey, with most completing it on paper (84%) and the remainder completing it online (16%). Responses from the two versions were combined for analysis. Basic descriptive statistics were calculated for each of the survey questions. Crosstabs were calculated to compare responses to questions by age, gender, education, marital status, and whether or not the respondent had their own advance directive.

Twelve participants who completed surveys were asked to participate in individual interviews to provide depth and context for the survey results described above. Participants were selected to represent three different identities: participants who have their own advance directive (AD), participants who don't have an AD but know someone who does, and participants who don't have their own AD and don't know anyone else who has one. There were seven female and four male interviewees. One interviewee did not report their gender. Eight interviewees were over 50 years old.

Interviews were analyzed thematically and the findings are integrated with the survey findings to provide depth and context to the responses.

## Characteristics of participants

People who completed the survey were predominantly white (98%), female (76%), age 50 and over (63%), and married (65%). They were also equally split between saying they received their health care in Appanoose (45%) and Ringgold (46%) counties. About 10% said they received their health care in a different county. Other characteristics are presented below (Figure 1).

### 1. Participant characteristics

|               | N   | %   |
|---------------|-----|-----|
| <b>Gender</b> |     |     |
| Male          | 104 | 24% |
| Female        | 337 | 76% |
| <b>Age</b>    |     |     |
| 18–34         | 75  | 17% |
| 35–49         | 87  | 20% |
| 50–64         | 145 | 33% |
| 65+           | 133 | 30% |

Note. Percentages may not equal 100 due to rounding

## 1. Participant characteristics (continued)

|  | N   | %   |
|--|-----|-----|
| <b>Marital Status</b>                    |     |     |
| Married/domestic partnership             | 280 | 65% |
| Single, never married                    | 44  | 10% |
| Divorced/separated                       | 67  | 15% |
| Widowed                                  | 41  | 9%  |
| <b>Race</b>                              |     |     |
| White                                    | 433 | 98% |
| Biracial or person of color <sup>a</sup> | 14  | 2%  |
| <b>Education</b>                         |     |     |
| High school or less                      | 123 | 28% |
| Some college                             | 115 | 26% |
| College degree                           | 150 | 34% |
| Advanced degree                          | 51  | 12% |
| <b>Household income</b>                  |     |     |
| Less than \$40,000                       | 140 | 38% |
| \$40,000-\$55,999                        | 56  | 15% |
| \$56,000-\$69,999                        | 49  | 13% |
| \$70,000 or more                         | 125 | 34% |

Note. Percentages may not equal 100 due to rounding

<sup>a</sup>Racial identities were combined to protect privacy due to low responses

## Familiarity with advance care planning and advance directives

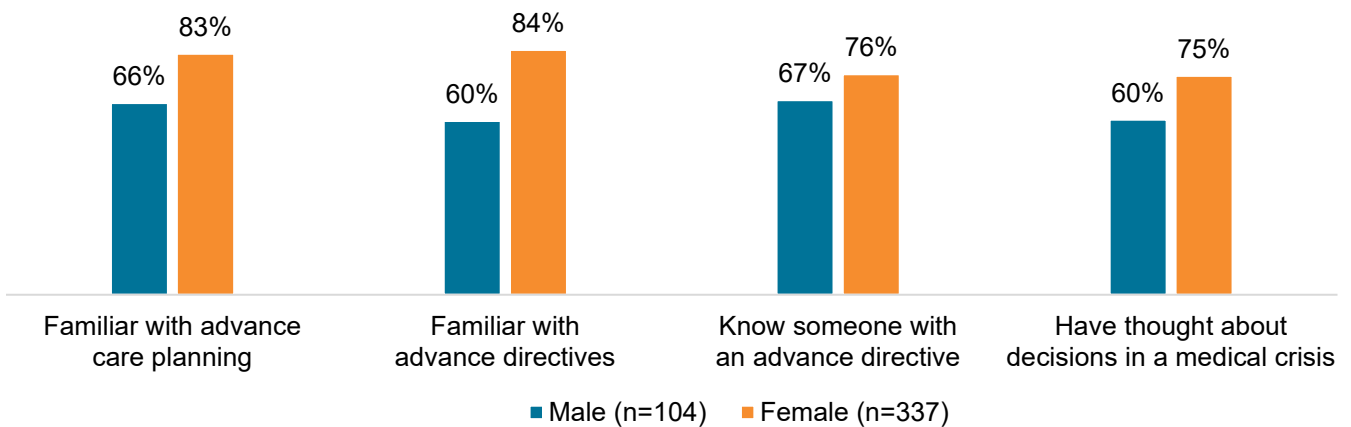
Most survey participants reported being familiar with the terms advance care planning and advance directive:

- 78% of participants reported that they were “somewhat” or “very” familiar with the term “advance care planning.”
- 78% reported they were “somewhat” or “very” familiar with the term “advance directive.”
- Nearly three-quarters (73%) reported they knew someone with an advance directive, most commonly their parent/guardian (33%), other relative (15%), spouse/partner (13%), and/or friend (10%).
- Of the participants without their own advance directive, just over half (54%) said they did not know or were unsure if they knew anyone with an advance directive.

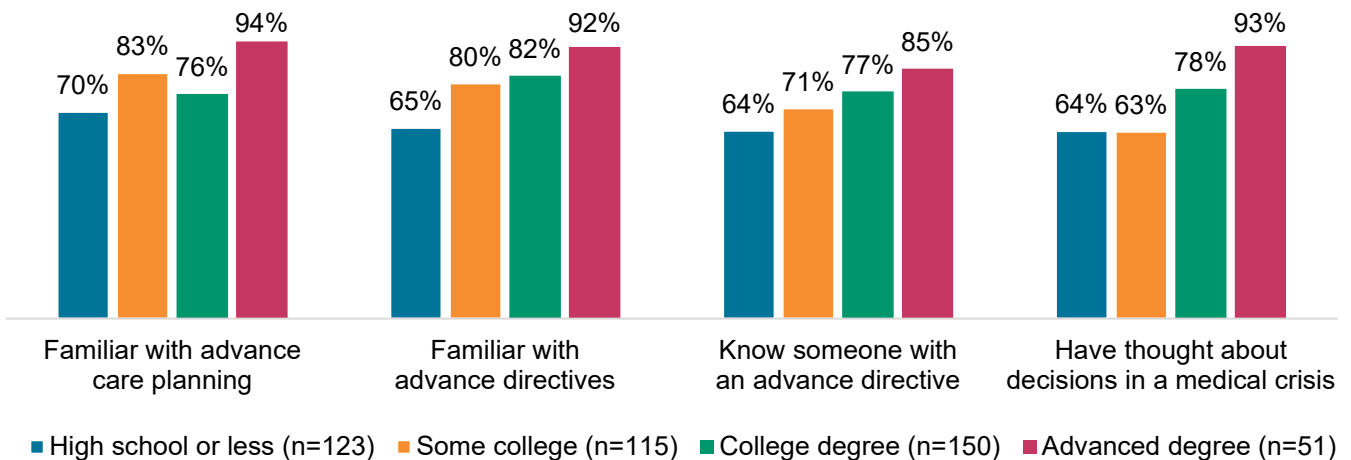
Several background characteristics or demographics appear to be related to being familiar with advance care planning and advance directives. Women were more likely than men to be familiar with advance care planning and advance directives and to have thought about their wishes in the event of a medical crisis (Figure 2). Men were more likely than women to talk with their doctors about advance care planning (23% vs. 16%).

Participants with advance degrees were more likely than those with a high school education or less to be familiar with advance care planning and advance directives, to know someone with an advance directive, to have thought about their own decisions in the event of a medical crisis, and to have talked with others about those decisions (Figure 3).

## 2. Gender and familiarity with advance care planning and advance directives



## 3. Education and familiarity with advance care planning and advance directives





## Participants with an advance directive

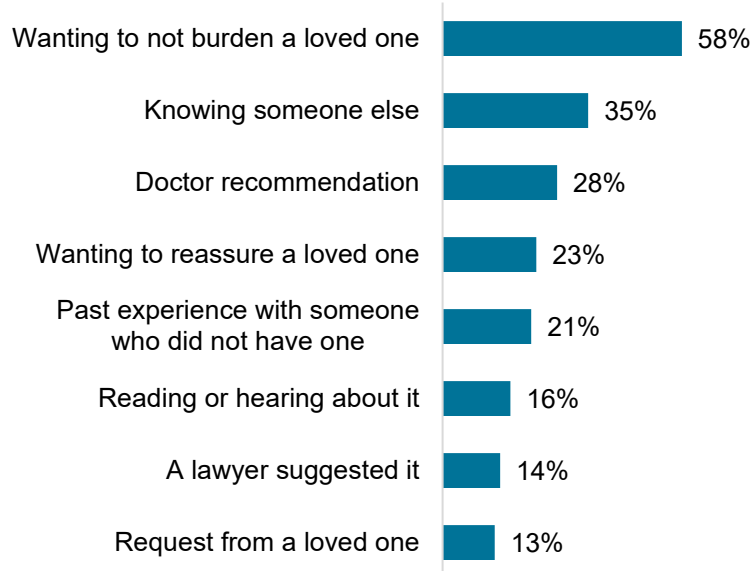
Eighty-one of 449 survey respondents reported they had their own advance directive. Key highlights for respondents with an advance directive include the following:

- They were more likely to be female (80%) vs. male (20%)
- They were more likely to be married (67%), followed by widowed (15%), divorced or separated (11%), and single or never married (6%)
- Over half were age 65 or older (53%), followed by age 50 to 64 (31%). Just 16% were under age 50.
- 47% had a college or advanced degree, 27% had attended some college, 27% had a high school degree or less

Respondents also reported getting their information about advance directives primarily from their doctors (45%), lawyers (44%), and friends/family (16%). Seventeen percent of respondents had completed their AD in the past year

The top three reasons respondents with an AD reported completing it included: not wanting to burden a loved one (58%), knowing someone else who had one (35%), and based on a doctor's recommendation (28%; Figure 4).

### 4. Reasons for completing an advance directive



Two people who completed the telephone interviews and had advance directives shared the following comments explaining further about not wanting to burden others:

*To me, the greatest gift, the last gift, you can give your child is to have your estate planning done, your advance directive, your will. It's a gift when you are going through so much anyway.*

*We have tried to do everything so that our children don't have it hard – have everything prepared when that time comes. We have lost some of our parents, and we certainly understand that it's not a good time.*

## Planning for medical crises or terminal illness

Almost half (47%) of participants who do not have an AD reported they have planned “some” or “a lot” for medical decisions in the event they are unable to make them for themselves. Sixty-eight percent of participants reported they are “somewhat” or “very” ready to talk to a doctor about advance care planning and 63% reported they are “somewhat” or “very” ready to complete an advance directive.

Eighty-four percent of participants who know someone with an advance directive reported thinking about how they wanted to be treated in the event of a medical crisis compared to 57% of participants who don't know anyone with an advance directive.

Interestingly, most of the interviewees who did not have an AD talked about advance care planning in the context of terminal illnesses (especially cancer) rather than a non-fatal medical crisis. Some participants said that if they had a terminal illness, they would complete an AD, or related ADs to terminal illness in some way. This differed from participants who have ADs and talked about them in the context of general medical crises, such as strokes or accidents, in addition to end-of-life.

When asked whether they had thought about their wishes in the event of a medical crisis, most participants *without* an AD talked about terminal illnesses:

*It would take a near-death experience for me to fill out an advance directive.*

*If I have a terminal illness, I just want to be kept comfortable – just make sure I am comfortable and don't treat for a terminal illness.*

*If I have a terminal illness, what I want will depend on my life expectancy.*

## Talking with a doctor about advance care planning

Of survey respondents without an AD, most (92%) reported seeing a doctor within the last year. In contrast, only 18% reported that they had actually talked to their doctor about advance care planning.

About 70% of survey respondents reported they had thought about how they want to be treated if they had a medical crisis. Another 68% of respondents reported being “very” or “somewhat” ready to talk with a doctor about advance care planning. In addition, many participants perceived their medical providers as a significant source of information about medical decisions.

Conversations with interviewees provided more depth to these responses. Two of the interviewees with their own ADs and all of the interviewees without ADs reported that their doctors “never asked” about advance care planning. Several participants reported that doctors asked if they have an AD, but did not engage in any further discussion.

One participant had the following to say:

*Medical staff and providers seem too busy to have these conversations. It would be helpful to have dedicated staff who can answer questions and help with the forms.*

## Talking with others about advance care planning

Respondents without an AD reported they did talk with other people besides their doctors about advance care planning. They most commonly reported talking with a spouse about advance care planning (71%), followed by their children (44%), a parent or guardian (25%), or a friend (15%).

This finding is mirrored by two interviewees without an advance directive, who said:

*I have talked with my family about what I want for a funeral and cremation. They know what I want.*

*We've [interviewee's husband] talked about it, not specifics, just general things, like not wanting anything heroic.*

For some respondents, this discussion was emotionally challenging. One participant said:

*I have talked about it with my fiancé – she knows the feelings I have about it. The discussion about it was difficult, uncomfortable; she wants to hang on to me as much as she can, and to tell her that if I have a terminal illness that is going to take my life and I don't say for myself to the doctors to go ahead and do whatever they can, then that is going to be very difficult for her.*

For other participants, the discussion felt easy:

*[Talking with my sons] was just a normal discussion, like we talk about everything in our family, so no big deal.*

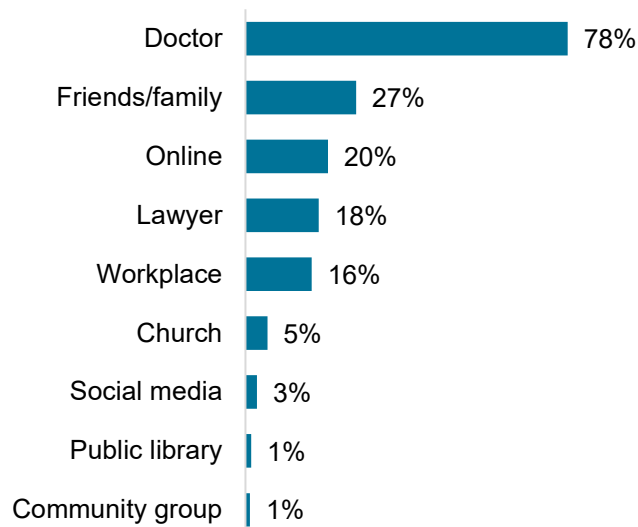
Interviewees without an advance directive, *but who know someone who has one*, reported talking fairly openly with family members about their wishes for medical crises or end-of-life, however these conversations appeared to be general, rather than specific. For example, one interviewee said “I haven't talked specifics, just general things.” And two interviewees said they have told their families they “just don't want heroic measures.” All interviewees *who don't know anyone with an AD* reported they had never talked with loved ones about advance care planning.

## Seeking information about advance care planning

Overall, 75% of participants without their own AD feel “somewhat” or “very” informed about advance care planning. However, 90% of participants who know someone with an advance directive report feeling informed about advance care planning compared to 60% of people who don’t know someone with an advance directive. Participants’ primary sources of information about planning for medical decisions were their primary care doctors (46%), friends/family without a medical background (20%), friends/family with a medical background (18%), and medical providers who are not primary care doctors (10%). Very few participants report getting medical information from the internet (3%).

Participants without ADs were asked about where they would like to learn more about advance directives and advance care planning. Top sources included their doctor (78%), friends or family (27%), and online (20%; Figure 5).

### 5. Preferred sources of information about advance directives



## Intention to complete an advance directive

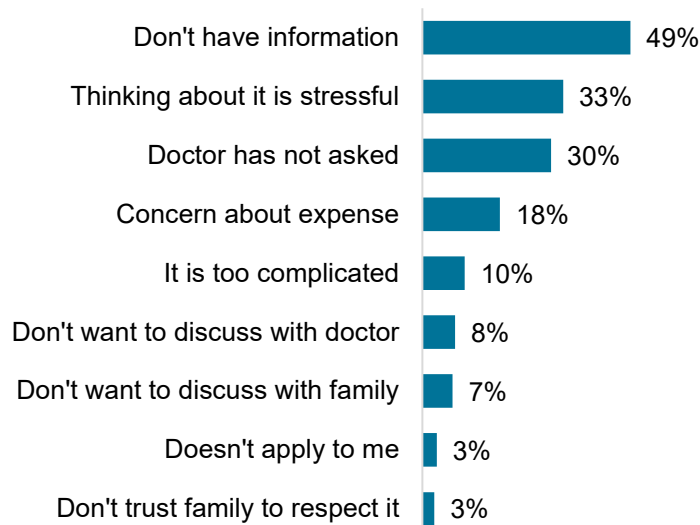
Nearly three-quarters of participants (73%) who said they knew someone with an advance directive reported being ready to complete their own advance directive, compared to about half (52%) of people who did not know someone with an AD.

Responses from interviewees supported this finding. While most of the interviewees without an AD said they would like to have one in the future, it appeared to be a low priority for all interviewees. One interviewee said he may do it in the future, when he is older.

## Barriers to completing an advance directive

Participants were asked about barriers to planning for medical crises and end-of-life. Top barriers included not having enough information about advance planning or knowing where to start (49%), stress around thinking about medical crises or end-of-life (33%), and doctors not asking about it (30%). Very few participants reported not wanting to talk about advance planning with family members (7%) or doctors (8%; Figure 6).

### 6. Barriers to completing an advance directive



Phone interview respondents provided additional details about these main barriers. They suggested that the barriers were largely due to being too busy, needing concrete help with the forms, doctors haven't asked about it, and not knowing where to start.

One interviewee explained their experience in the following way:

*If a doctor simply gives [me] some information about it, [I] will take it with [me], but put it on the back-burner and go on with [my] daily life.*

One interviewee whose husband is a cancer survivor, but resists getting an AD explained his resistance in this way:

*He would have to think about dying again... and he doesn't want to think about not being around for his kids.*

A lack of information as a barrier to getting an advance directive varied based on whether respondents said they knew someone with an advance directive. Less than one-third (30%) of participants who know someone with an advance directive reported that a lack of information was a barrier, compared to two-thirds (66%) of those who do not know someone with an advance directive.

## Respondents' recommendations

At the end of the survey and the telephone interviews, respondents were asked about recommendations they have for MercyOne or other organizations to promote advance care planning and advance directives. Their recommendations were grouped into the following themes:

- **Show people how easy it is.** Participants who have ADs recommended educating people about how easy it is to complete one. Participants who have an AD report that it was very easy to complete, but participants who do not have one report one barrier is believing it is too complicated.
- **Educate people on cost.** Several participants reported that cost is a significant factor preventing them from completing an AD. Some of these participants also believed that a lawyer needed to be involved, thus raising the cost.
- **Educate people on the use of advance directives.** Participants who do not have ADs report confusion about different aspects of advance care planning, including whether they are amendable, what age someone should have one, and whether they can be tailored to specific types of medical issues. For example, one participant reported that if she had a terminal illness what she wanted would depend on her life expectancy at the time.
- **Provide more accessible information.** Most participants said that more education on where to start would help people to complete ADs. Participants suggested information could be available at churches, workplaces, the driver's license bureau along with organ donor information, at schools when parents are present, at community events, and at medical clinics. One participant suggested having dedicated information on the internet that a doctor can point patients to.
- **Use impactful messaging.** One participant suggested emphasizing how an advance directive allows you to have a say in your life and make sure things happen the way you want them to. Another participant suggested targeting information to specific age groups. She cited an example of several young adults who were in a car accident and one was in critical condition without an AD, which made family decisions complicated.
- **Provide concrete help with forms.** Specifically, MercyOne should dedicate staff to encouraging and supporting people to complete the forms. Rather than simply offering information, doctors and medical professionals should be prepared to walk patients through the process in a clinic visit.
- **Doctors should engage in deeper conversations about advance care planning and ADs.** Many participants reported that their doctors ask about ADs, but rarely, if ever, engage in any kind of discussion about ADs, regardless of whether the patient has one or not. Participants without ADs said they would like to talk more deeply with their

providers about advance care planning, but want and need help navigating these conversations with a medical provider.

- ***Medical clinics should have accessible information.*** Several participants said that doctor's offices should have pamphlets, short videos/commercials, flyers, and other resources available in waiting rooms and exam rooms. Participants also suggested that clinics should have staff available for questions and to help with completing forms.
- ***Explain the importance of ADs for medical crises beyond terminal illness.*** Because many people without ADs appear to relate advance care planning only to terminal illnesses or being elderly, education materials should emphasize the importance of ADs beyond terminal illnesses or end-of-life.

# Appendix

## A. Methodology

This study had two parts:

- Web and paper survey
- Interviews with a selection of survey participants

### Surveys

A web-based and identical paper survey were created to survey participants about their experiences with advance care planning and advance directives. The survey had two parts – one for participants who did not have their own advance directive and one for those who did. Participants in both parts were asked questions about barriers and facilitators of advance care planning and completing an advance directive. Participants with their own advance directive were asked additional questions about their reasons for completing one and when they completed it.

The web-based survey was promoted by MercyOne’s marketing team and advertised via social media and radio. MercyOne administrative staff printed paper surveys for the clinics. Clinic front desk staff handed paper surveys out to patients as they checked in for their appointments to complete while they waited for their providers. Anyone age 18 and older was able to complete the survey. Participants who completed the paper-and-pencil survey received a MercyOne-branded coffee mug.

At the end of the survey, participants were asked if they were interested in participating in an in-depth, one-on-one interview about advance care planning. Interested participants gave their name, phone number, and email address. Twelve individuals were selected to participate in individual interviews. Four participants were chosen in each of three groups – those who had completed their own advance directive, those who had not completed their own AD but knew someone who had, and those who neither knew anyone with an AD nor had their own AD.

Interviews were conducted via telephone and lasted approximately 30 minutes. Participants were offered \$20 gift cards after completing the interview to thank them for their time. The interviewer took detailed notes during the interviews and these notes were analyzed using a basic thematic analysis.



## B. Data tables

### *Respondents' background and characteristics, by advance directive status*

#### B1. Gender

| Gender  | Total (N=449) | Have an advance directive (N=80) | Don't have an AD, but know someone who does (N=153) | Don't have an AD/don't know anyone with one (N=160) |
|---------|---------------|----------------------------------|---|---|
| Female  | 75%           | 83%                              | 84%   | 64%   |
| Male    | 23%           | 18%                              | 16%   | 36%   |
| Missing | 2%            | --                               | --  | --  |

Note: Percentages may not total 100 due to rounding.

#### B2. Marital status

| Marital status               | Total (N=449) | Have an advance directive (N=79) | Don't have an AD, but know someone who does (N=150) | Don't have an AD/don't know anyone with one (N=156) |
|------------------------------|---------------|----------------------------------|---|---|
| Married/domestic partnership | 62%           | 67%                              | 68%   | 63%   |
| Divorced/separated           | 15%           | 11%                              | 17%   | 17%   |
| Single, never married        | 10%           | 6%                               | 11%   | 12%   |
| Widowed                      | 9%            | 15%                              | 3%  | 9%  |
| Missing                      | 4%            | --                               | --  | --  |

Note: Percentages may not total 100 due to rounding.

#### B3. Age

| Age range   | Total (N=449) | Have an advance directive (N=80) | Don't have an AD, but know someone who does (N=153) | Don't have an AD/don't know anyone with one (N=159) |
|-------------|---------------|----------------------------------|---|---|
| 19 or under | >1%           | 0%                               | 1%  | 1%  |
| 20-34       | 16%           | 5%                               | 26%   | 15%   |
| 35-49       | 19%           | 11%                              | 28%   | 19%   |
| 50-64       | 32%           | 31%                              | 33%   | 34%   |
| 65 or older | 30%           | 53%                              | 12%   | 32%   |
| Missing     | 2%            | --                               | --  | --  |

Note: Percentages may not total 100 due to rounding.

#### B4. Race/ethnicity

| Race/ethnicity                     | Total<br>(N=449) | Have an advance<br>directive<br>(N=78) | Don't have an<br>AD, but know<br>someone who<br>does<br>(N=153) | Don't have an<br>AD/don't know<br>anyone with one<br>(N=161) |
|------------------------------------|------------------|--|---|--|
| White                              | 96%              | 100%                                   | 99%   | 100%   |
| Bi-racial/BIPOC/other <sup>a</sup> | 3%               | 0%                                     | 2%  | 0%   |
| Missing                            | 2%               | --                                     | --  | --   |

Note: Percentages may not total 100 due to rounding.

<sup>a</sup> Racial categories were combined because of small numbers

#### B5. Education level

| Education           | Total<br>(N=449) | Have an advance<br>directive<br>(N=79) | Don't have an<br>AD, but know<br>someone who<br>does<br>(N=152) | Don't have an<br>AD/don't know<br>anyone with one<br>(N=160) |
|---------------------|------------------|--|---|--|
| High school or less | 27%              | 27%                                    | 15%   | 38%  |
| Some college        | 26%              | 27%                                    | 26%   | 28%  |
| College degree      | 33%              | 34%                                    | 41%   | 29%  |
| Advanced degree     | 11%              | 13%                                    | 18%   | 5%   |
| Missing             | 2%               | --                                     | --  | --   |

Note: Percentages may not total 100 due to rounding.

#### B6. Income level

| Income range         | Total<br>(N=370) |
|----------------------|------------------|
| Less than \$40,000   | 38%              |
| \$40,000 to \$55,999 | 15%              |
| \$56,000 to \$69,999 | 13%              |
| \$70,000 or over     | 34%              |

Note: Unable to link all income responses to individual records; only cumulative data is reported for available responses. Percentages may not total 100 due to rounding.

## B7. History of doctor visits

| Last time visited the doctor                          | Total (N=393) | Have an advance directive (N=79) | Don't have an AD, but know someone who does (N=153) | Don't have an AD/don't know anyone with one (N=161) |
|---|---------------|----------------------------------|---|---|
| Within the last year                                  | 94%           | 98%                              | 92%   | 94%   |
| More than a year ago, but less than 3 years ago       | 4%            | 3%                               | 6%  | 3%  |
| Three or more years ago                               | 1%            | 0%                               | 1%  | 1%  |
| I don't remember                                      | 1%            | 0%                               | 1%  | 1%  |
| I don't go to the doctor unless there is an emergency | 1%            | 0%                               | 1%  | 1%  |

Note: Percentages may not total 100 due to rounding.

## B8. County that receive medical care in

| County/location   | Total (N=449) | Have an advance directive (N=75) | Don't have an AD, but know someone who does (N=146) | Don't have an AD/don't know anyone with one (N=156) |
|---|---------------|----------------------------------|---|---|
| Appanoose   | 45%           | 44%                              | 48%   | 46%   |
| Ringgold  | 46%           | 45%                              | 39%   | 48%   |
| <i>Adjacent counties: 24</i><br>Adams, Davis, Decatur (3), Mahaska, Marion, Monroe, Taylor (3), Union (5), Wapello, Wayne (4) | 10%           | 15%                              | 18%   | 6%  |
| <i>Non-adjacent locations: 9</i><br>Linn County, Polk County (5), Missouri, Nebraska  |               |                                  |   |   |

Note: Percentages may not total 100 due to rounding.

## Respondents' familiarity with advance care planning and advance directives

### B9. Familiarity with terms

| Terms                         | Very familiar | Somewhat familiar | Not very familiar | Not at all familiar |
|-------------------------------|---------------|-------------------|-------------------|---------------------|
| Advance care planning (N=443) | 29%           | 49%               | 14%               | 7%                  |
| Advance directive (N=442)     | 37%           | 41%               | 15%               | 7%                  |

Note: Percentages may not total 100 due to rounding.

## B10. Know someone with an advance directive

| Response | N=323 |
|----------|-------|
| Yes      | 73%   |
| No       | 22%   |
| Unsure   | 5%    |

## B11. Relationship with person with advance directives

| Relationship to person with the advance directive | N=234 <sup>a</sup> |
|---|--------------------|
| Self  | 35%                |
| Parent/guardian                                   | 33%                |
| Other relative                                    | 15%                |
| Spouse/partner                                    | 13%                |
| Friend  | 10%                |
| Children  | >1%                |
| Someone else (e.g., clients, patients)            | 5%                 |

Note: Percentages may total >100. Multiple responses possible.

<sup>a</sup> Respondents who know somebody with an advance directive

## Respondents without an advance directive

### B12. How informed respondents feel planning for medical decisions

|                     | N=360 |
|---------------------|-------|
| Very Informed       | 26%   |
| Somewhat Informed   | 49%   |
| Not very informed   | 16%   |
| Not at all informed | 8%    |

Note: Percentages may not total 100 due to rounding.

### B13. Extent of planning for medical decisions

|            | N=334 <sup>a</sup> |
|------------|--------------------|
| A lot      | 12%                |
| Some       | 35%                |
| A little   | 29%                |
| Not at all | 24%                |

Note: Percentages may not total 100 due to rounding.

<sup>a</sup> Respondents who said they were very, somewhat, or not very informed

## B14. Primary source of information for medical decisions

| Source  | N=328 <sup>a</sup> |
|---|--------------------|
| Primary care doctor                             | 46%                |
| Friends or family who are not medical providers | 20%                |
| Friends or family who are medical providers     | 18%                |
| Other medical provider                          | 10%                |
| Other community professionals                   | 6%                 |
| Internet/social media                           | 3%                 |
| Member of the clergy                            | 1%                 |
| Other   | 8%                 |

Note: Percentages may total >100. Multiple responses possible

<sup>a</sup> Respondents who said they were very, somewhat, or not very informed

## B15. Planning ahead for medical treatment

|   | Yes | No  | Unsure |
|---|-----|-----|--------|
| Have talked to doctor about how you want to be treated if you can't make medical decisions for self (N=358) | 18% | 78% | 5%     |
| Have thought about how you want to be treated in a medical crisis (N=365)                                   | 71% | 23% | 6%     |
| Have thought about how you want to be treated if you have a terminal illness (N=364)                        | 70% | 26% | 4%     |

Note: Percentages may not total 100 due to rounding.

## B16. People have discussed personal wishes with

| Person             | N=243 |
|--------------------|-------|
| Spouse or partner  | 71%   |
| Children           | 44%   |
| Parent or guardian | 25%   |
| Friend             | 15%   |
| Other relative     | 11%   |
| Someone else       | 3%    |

Note: Percentages may total >100. Multiple responses possible

## B17. Barriers to planning for a future medical crisis

| Barriers   | A barrier | Know someone else with an AD (N=92) | Don't have an AD/don't know anyone with one (N=98) |
|--|-----------|-------------------------------------|--|
| I don't have enough information or know where or how to start      | 51%       | 35%                                 | 71%  |
| Thinking about a medical crisis or the end of my life is stressful | 34%       | 37%                                 | 31%  |
| My doctor or provider has not asked me about advance directives    | 23%       | 25%                                 | 22%  |
| I am concerned that it is too expensive                            | 19%       | 15%                                 | 21%  |
| I don't want to bring this up with a doctor                        | 6%        | 4%                                  | 7%   |
| I don't want to discuss this with family members                   | 8%        | 9%                                  | 7%   |
| The forms seem too complicated                                     | 10%       | 12%                                 | 7%   |
| I do not trust my family members to respect my wishes              | 1%        | 1%                                  | 2%   |
| This kind of medical planning does not apply to me                 | 2%        | 3%                                  | 1%   |
| I do not trust doctors to respect my wishes                        | 1%        | 1%                                  | 1%   |
| Something else   | 20%       | 24%                                 | 16%  |

Note: Percentages may total >100. Multiple responses possible

## B18. Where you would like to learn more about advance directives

| Source               | N=356 |
|----------------------|-------|
| Doctor               | 78%   |
| Friend/family member | 27%   |
| Online               | 20%   |
| Lawyer               | 18%   |
| Workplace            | 16%   |
| Church               | 5%    |
| Social media         | 3%    |
| Other                | 2%    |
| Community group      | 1%    |
| Public library       | 1%    |

Note: Percentages may total >100. Multiple responses possible

## B19. Degree of readiness for next steps

|  | Very ready | Somewhat ready | Not too ready | Not at all ready |
|--|------------|----------------|---------------|------------------|
| Discuss advance care planning with your doctor or another medical professional (N=364) | 22%        | 46%            | 21%           | 10%              |
| Complete paperwork for an advance directive (N=363)                                    | 19%        | 44%            | 25%           | 12%              |

Note: Percentages may not total 100 due to rounding.

## Respondents with an advance directive

### B20. Primary source of information about medical care, beside medical provider

| Source of information           | N=75 |
|---------------------------------|------|
| Family member                   | 39%  |
| Online websites or social media | 25%  |
| Lawyer                          | 21%  |
| Friend                          | 20%  |
| Television or radio news        | 7%   |
| Newspaper or newsletter         | 5%   |
| Something or someone else       | 19%  |

Note: Percentages may total >100. Multiple responses possible

### B21. Source of information about advance care planning

| Source of information | N=80 |
|-----------------------|------|
| Doctor                | 45%  |
| Lawyer                | 44%  |
| Friend/family member  | 16%  |
| Workplace             | 16%  |
| Online website        | 8%   |
| Social media          | 1%   |
| Church                | 1%   |
| Public library        | 0%   |
| Community group       | 0%   |
| Salon/barber shop     | 0%   |
| Other                 | 6%   |

Note: Percentages may total >100. Multiple responses possible

## Advance directive background

### B22. Length of time since completed advance directive

| Time  | N=79 |
|---|------|
| Within the last month                           | 3%   |
| Within the last year                            | 14%  |
| More than a year ago, but less than 5 years ago | 38%  |
| Five or more years ago                          | 44%  |
| I don't remember                                | 1%   |

Note: Percentages may not total 100 due to rounding.

### B23. Factors that led to completing advance directive

| Factors  | N=80 |
|--|------|
| Doctor or medical provider suggested it  | 28%  |
| Reading or hearing about it  | 16%  |
| A loved one requesting this  | 13%  |
| Wanting to reassure a loved one  | 23%  |
| Wanting not to be a burden to loved ones                                       | 58%  |
| My lawyer suggested it   | 14%  |
| Past experience with someone who did <u>not</u> have an advance directive      | 21%  |
| Knowing someone else with an advance directive                                 | 35%  |
| Something else (e.g., through work/job, including nursing, other medical work) | 10%  |

Note: Percentages may total >100. Multiple responses possible

### B24. Person respondent knows with an advance directive

| Person            | N=26 <sup>a</sup> |
|-------------------|-------------------|
| Spouse or partner | 27%               |
| Child(ren)        | 12%               |
| Parent/guardian   | 54%               |
| Other relative    | 19%               |
| Friend            | 12%               |
| Other             | 4%                |

Note: Percentages may total >100. Multiple responses possible.

<sup>a</sup> Respondents who said knowing someone with an advance directive was a factor that led them to complete theirs.



## Advance directive location and contents

### B25. Location of advance care directive

|   | Yes | No  | Unsure |
|---|-----|-----|--------|
| Doctor or medical provider has a copy of advance directive (N=79) | 57% | 25% | 18%    |
| Have a copy of advance directive in another location              | 92% | 3%  | 5%     |

Note: Percentages may not total 100 due to rounding.

### B26. Location of advance directive, respondents who answered “another location” above

|  | N=71 |
|--|------|
| Safe deposit box                                       | 28%  |
| Somewhere in home                                      | 66%  |
| With another person                                    | 16%  |
| Another place (e.g., medical records, hospital, purse) | 11%  |
| Would rather not say                                   | 0%   |

Note: Percentages may not total 100 due to rounding.

### B27. Advance care directive contents

|   | Yes | No | Unsure |
|---|-----|----|--------|
| Advance directive names a person or group of people who can make medical decisions for you (N=79) | 98% | 0% | 3%     |
| The person/people are aware they are named in document (N=74)                                     | 95% | 1% | 4%     |

Note: Percentages may not total 100 due to rounding.

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451 Lexington Parkway North  
Saint Paul, Minnesota 55104  
651-280-2700 | [www.wilderresearch.org](http://www.wilderresearch.org)

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