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ABSTRACT

Most people would prefer to die at home rather than at a hospital, yet only 23% of deaths in Massachusetts in 2009 occurred at home. One cause of this disparity is that only about a third of US adults have written advance care plans. An advance care plan is a written document specifying a person's wishes for their end of life, and can help guide medical decisions when a person is no longer able to make his or her own decisions due to incapacity.

Luminat is an online advance care planning tool designed to help patients consider and document their wishes for end of life care. Ideally this tool will eventually be incorporated into the electronic medical record, so that it can be accessed by providers in an emergency situation. The program has been piloted in several clinics already but response rates have been low. With this project we used a survey to identify barriers to using the website, which included reluctance to commit to decisions, discomfort with thinking about the topic, and a lack of medical literacy. Survey respondents described the site as helpful and easy to use.

We recommend following up with patients by email and at annual visits with providers. Additionally, in order to improve response rates, the website could include more information about the legal status of these documents, as well as information about why people should complete advance care plans.

"Thinking about death clarifies your life."
- C. Chang-TED Talk

POPULATION FRAMEWORK

HOSPICE service is for patients with a terminal illness with a prognosis of 6 months or less, and is considered a shift in care from curative treatment to comfort care.

Mortality in Massachusetts:

- In 2011, 44.6% of deaths occurred under the care of hospice services

Hospice Statistics

- Primary diagnosis:
 - cancer - 36.5%
 - dementia - 15.2%
 - heart disease - 13.4%
 - lung disease - 9.9%

Length of Stay on Hospice Service

- Average - 72.6 days
- Median - 18.5 days
- 48.8% died or were discharged within 14 days

Demographics of Hospice

- 54.7% female
- 93.2% non-Hispanic
- 80.9% white/Caucasian

Responsibilities of the interdisciplinary hospice team

- Understand individual goals of care
- Pain and symptom management
- Provide personal and wound care
- Provide medications, medical supplies and equipment
- Teach and advise family/friends caring for the patient
- Provide transition to short-term inpatient care when pain/symptoms are unable to be managed at home
- Bereavement counseling
- Connect to community resources

SERVICE PROJECT: Challenges in Advance Care Planning

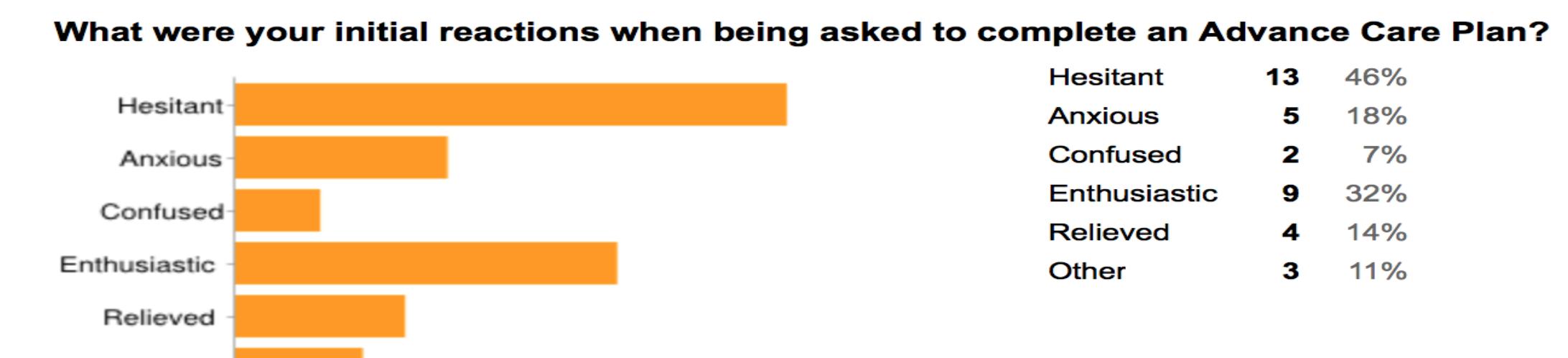
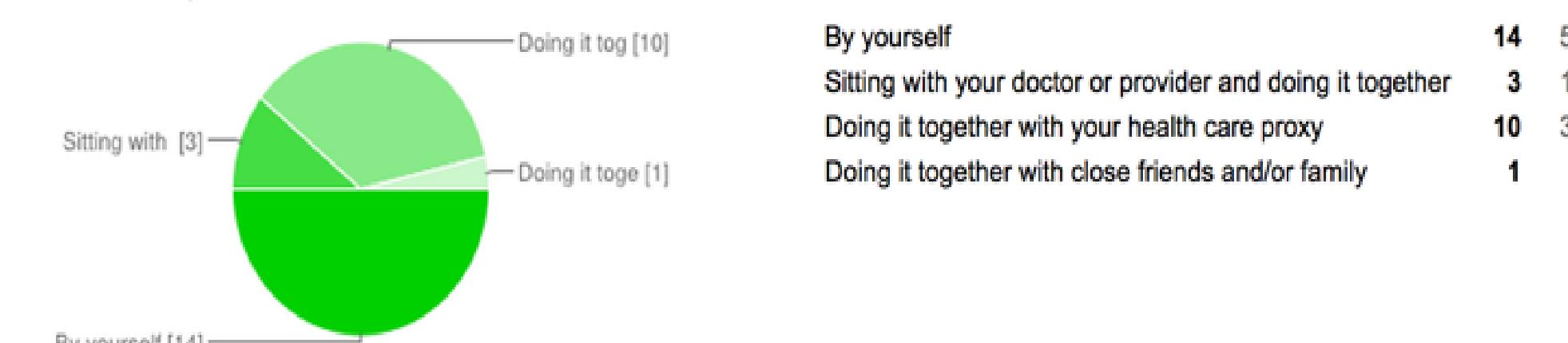
Objective: Determine the barriers individuals experience with using Luminat to create an Advance Care Plan.

Survey Population:

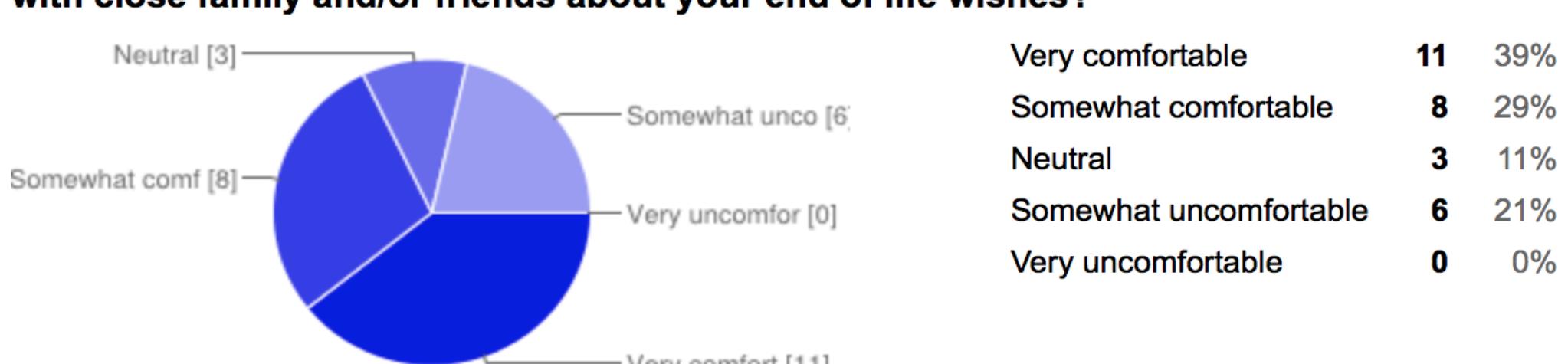
28 total participants

- 18 female, 10 male
- 61% ages 18-29
- 79% described themselves as "completely healthy without any chronic illness"
- 93% completed all four sections of Luminat

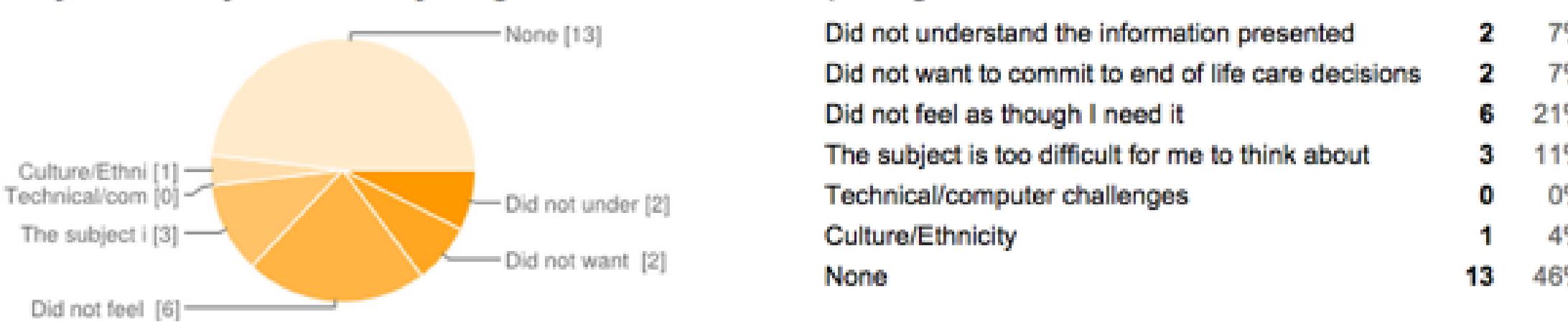
How would you prefer to complete the Advance Care Plan?



After completing the advance care plan, how comfortable do you feel about having a conversation with close family and/or friends about your end of life wishes?



If any, what did you feel was your greatest barrier to completing an Advance Care Plan?



Recommendations:

- Follow-up should be pursued via email and link.
- Advance care planning should be brought up at all annual visits with providers. Creating a more routine schedule for these discussions encourage people to make an advance care plan and reminds people to re-visit/re-think their choices.
- Make it more obvious on the website that Luminat is a not legally recognized document.
- Provide a link on the website to make a legally recognized document.
- Explain on the website homepage why registration is important.
- Have the option to forward a copy of your advance care plan to your health care proxy agent.
- Address lack of medical literacy by utilizing multi-media resources (i.e videos).

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Interprofessional Network Schematic – Hospice care is a model system for providing comprehensive healthcare. Central to the model is the interdisciplinary team meeting which allows for maximal communication between the team members regarding care of the patient.