PUBLIC HEALTH DIVISION
Office of the State Public Health Director
Kate Brown, Governor

Oregon Health Authority

800 NE Oregon Street, Suit 930
Portland, OR, 97232

Meeting Summary: Advance Directive Adoption Committee

Monday, June 3, 2019
9:00 am-12:00 pm

BACKGROUND, CONTEXT AND SCOPE

The Advance Directive Adoption Committee (ADAC) came together for their first meeting on June 3, 2019. Committee members introduced themselves and described the perspective that they hope to bring to the committee and the revision of the Advance Directive (AD) form.

Katrina Hedberg of the Public Health Division reviewed the details of HB 4135, the legislation that established the Committee, and outlined the Committee's scope and task: to update the Advance Directive form (but not the part that designates a health care representative). The Committee will draft a proposed Advanced Directive form, along with instructions, that will be sent to the Oregon Legislature for review and ratification. Although the Advance Directive includes both the health care representative designation and the instructions, the Committee only is looking at the instructions, not the health care representative designation. The Committee cannot change that form.

To avoid confusion, for the purposes of Committee discussions, when we refer to the Advance Directive in meetings, we will be talking about the instructions, not the health care representative designation.

We discussed the scope of the Committee's charge and affirmed the following:

- The designation of the health care representative is out of scope.
- The Committee's work may include clarifying how the AD and the POLST work together.
- The Committee does not have a mandate to provide education around end-of-life decisions and OHA does not have a budget nor the expertise for that work. However, the Committee can make recommendations about what needs to happen to make the AD form accessible and usable by Oregonians, which could include public education.

We clarified that if an issue arose that was out of scope, the Committee could flag the issue(s) for the legislature in a cover memo, but we would not spend time debating the merits of out-of-scope topics.

GROUP AGREEMENTS, DECISION MAKING AND CHARTER

We reviewed draft group agreements and affirmed the decision-making process outlined in statute. The committee will strive for consensus. If we do not achieve consensus, as required by the legislation, we will vote; Committee decisions must be approved by the majority of committee members. The ADAC requires a chair, and after some discussion, the group decided that Stephanie Carter would be chair and Woody English would be vice chair. The Committee unanimously approved these appointments. The Committee reviewed the charter, added the quorum requirement from the legislation and voted to approve.

REVIEW OF CURRENT FORM

HB 4135 protects the health care representative designation by pulling it out as a separate section which we cannot change.

Even though the health care designation form is coupled with the AD, for purposes of our discussion, we separated the two forms. We will later revisit whether they should remain separate and what the instructions will say. We discussed the challenges of having two separate forms that would require witnesses and notary for both.

The group decided to start a new AD form from scratch, rather than revising and editing the existing form.

UPDATING THE FORM

We discussed the challenges with the current form:

- Instructions for completing the form aren't clear.
- The current form doesn't create an opening/opportunity to have difficult end-of-life discussions.
- The form requires prose, which can be hard for people.
- The document is intimidating and onerous.
- There is a lot of room for interpretation.
- The current form is too narrow.
- The form doesn't serve people across the life span.
- The form doesn't necessarily serve a multi-cultural community.

We need both a *structure* for the form (e.g. Likert scale, visuals) as well as *content*. We can start with either. Instructions for completing the form also are very important. Instructions should educate the owner of the form and can script the conversation the owner will have with their health care representative. The form is in service to what the health care representative needs to make decisions. As we revise the form, we need to ensure that the form, through its structure and content, educates and informs the health care representative.

The purposes of the form are to:

- Educate: The owner of the form, the health care representative
- Instruct: The health care representative, providers, family, facilities
- Prepare: Patient, the health care representative

Content of the form

- We need both general content (e.g., value statements) and specific content (e.g., medical interventions).
- General content will stay more current than specific medical interventions, which may change over time.
- If we broaden the circumstances in which an advance directive is applicable, the array of medical interventions expands.
- One idea is that expressing value statements on the form is required while stating preferences around medical interventions would be optional.

As we revise the form, we should keep in mind that the content has to:

- Meet legislative requirements.
- Avoid unintended consequences.
- Clarify difference between AD and POLST.
- Preserve provider integrity.
- Protect vulnerable persons:
    - Could use statutory definition
    - Address concerns that this might make someone more vulnerable to inappropriate or inadequate treatment (e.g., people with developmental disabilities or dementia)
- Be readable, clear and understandable.

For the parking lot: A common issue in ethics consultation is when a patient presents with an advance directive and family overrides it. Often, this has to do with the advance directive's relevance to the medical situation. We may want to think about this as an issue that needs to be addressed.

Public comment

- None

NEXT STEPS

- Before our next meeting, Committee members should do the following:
  - Familiarize themselves with the POLST to differentiate it from the AD.
  - Gather ideas for content that should be included in the form, ideally with specific language (e.g. Conversation Starter kit).
  - Gather ideas for format and structure (e.g. Likert scale).
- Committee members will share with their networks that there are two open positions on the Committee.
- We decided we will ideally have two meetings by the end of 2019 and come up with a draft tool in that time.
  - We will vet the tool with stakeholders once we have a draft. Public Health Division staff will lead this work.
  - We will re-convene in 2020 and share progress with legislature/interim committee during the short session to get feedback.
  - We will finalize the form in 2020, incorporating feedback we've received.

Attendees

ADAC Members
Stephanie Carter
Woody English
Bill Hamilton
Christopher Hamilton
Barb Hansen
Jen Hopping-Winn
Nick Kockler
Eriko Onishi
Mike Schmidt
Fred Steele

Public Health Division Staff
Katarina Moseley
Katrina Hedberg

Consultant
Diana Bianco, Artemis Consulting