



September 1, 2020

To: The Honorable Senator Floyd Prozanski, Chair  
Senate Committee on Judiciary

The Honorable Representative Janelle Bynum, Chair  
House Committee on Judiciary

From: Lillian Shirley, Director  
Public Health Division  
Oregon Health Authority

Re: Draft Oregon Advance Directive from

Dear Chair Prozanski, Chair Bynum and Members of the Senate and House  
Judiciary Committees:

ORS 127.532 establishes the Advance Directive Adoption Committee (ADAC) within the Oregon Public Health Division. The charge of the ADAC is to adopt the form of an Advance Directive to be used in Oregon, and to review the form at least once every four years. This letter serves to: present the final draft form that the ADAC recommends be approved by the legislature; review the process used to develop the form; bring to your attention unresolved issues; and outline next steps for the ADAC.

After a public process requesting applications to represent sectors outlined in the statute, ADAC members were appointed by Governor Brown. The list of committee members can be found below. The committee selected Stephanie Carter as Chair, and Woodruff English as Vice Chair. The committee was staffed by Katrina Hedberg, of the Public Health Division and moderated by Diana Bianco of Artemis Consulting. Ms. Carter, Drs. English and Hedberg, and Ms. Bianco served as a steering committee to ensure that ADAC discussions and feedback, and community input were incorporated into drafts. Decision-making by the ADAC was based on consensus.

The ADAC met seven times from June 2019 to August 2020. All meetings were open to the public, time for public comment was ensured at the end of each meeting, and the committee accepted and considered comments throughout the process. The draft Advance Directive form underwent multiple revisions based on community and public input as well as feedback from experts from the medical and legal fields (i.e., lawyers and other groups who help people fill out the form and medical providers who use the form to guide care). The ADAC reached out to groups that represented people with disabilities but was not able to fill the seat designated to represent people with disabilities. To ensure that the Advance Directive form is accessible to all adults in Oregon, the committee requested assistance from Lorena Sprager of The Next Door, an expert in health literacy and plain language, who reviewed the form and suggested edits.

At the first meeting, the ADAC discussed principles that would guide the work of drafting the new form. The ADAC agreed to the following principles.

The Advanced Directive should:

1. Provide guidance to the health care representative
2. Avoid unintended consequences
3. Preserve provider integrity
4. Ensure a patient's right to self-determination, to the furthest possible extent
5. Be readable, clear and understandable
6. Be short and simple (language should be simple; form should be easy to complete)
7. Meet legislative requirements.

The ADAC reviewed the current Advance Directive form in statute. Several sections are codified and not subject to revision by the committee; those are included in the draft form in gray. These include information about the person themselves (i.e., the principal) as well as the appointment of their health care representative.

As per the statute, the primary duties of the ADAC were focused on the Health Care Instructions for the health care representative. The draft form includes instructions in the following sections: 1) three situations for which the principal can express specific wishes about treatments; 2) quality of life and what makes life meaningful; 3) spiritual beliefs; 4) additional information, including preferred place of care; and 5) names of other people with whom the health care representative can discuss the principal's health care. In addition, the ADAC thought it important that the Advance Directive form include a brief overview and instructions at the beginning of the form.

Every effort was made to make the form clear and succinct. Nonetheless, the ADAC believes it very important that a User's Guide accompany the form. The ADAC developed a provisional guide, which the ADAC will finalize once the Legislature approves a new form. The ADAC unanimously agreed that the User's Guide should be linked to Advance Directive.

During ADAC deliberations, several issues arose with the existing form that were beyond the scope of the Committee, but which members believed were important to address.

1. There was significant feedback that the gray section of the form (codified in statute) is confusing, internally inconsistent, and requires clarification. This section also does not meet plain language requirements. Our plain language expert reviewed this section and provided appropriate edits; the committee is happy to share that document with you.
2. The statute states that the health care representative can accept the role by signature or other forms of verification. It is not clear what other acceptable methods for verification are (e.g., how should verbal acceptance be documented?).
3. The statute directs the committee to include the statement that "This document is the only valid form of an Advance Directive in Oregon per ORS 127.533(2)." However, the ADAC believes this is not legally accurate – there are a number of exceptions and it would be too complicated to explain all of the exceptions in the form. Given that, if that statement was included in the form, it would confuse and concern people. For those reasons, we did not include that statement in the form.
4. The statute directed the ADAC to include language in the form that the Advance Directive is not the same as a POLST. While we have noted that these are separate documents in the draft form, we recommend that a full explanation be in the accompanying User's Guide rather than the form itself. We believe it is confusing to have a detailed explanation of the differences in the form itself.
5. In section 4.D. Under *Inform Others*: We wanted to give those filling out the form the option of letting their health care representative and their health care providers discuss health status with other people (such as relatives). We recognize this might cause HIPAA issues. The ADAC doesn't have the expertise to make this determination, so we wanted to call the legislature's attention to this potential issue.

ADAC members recommend that the legislature approve the draft form. Committee members are available to provide testimony about the process and the outcome of

the discussions. After the legislature approves a final form, the ADAC has the following recommendations:

1. There is a final plain language review to ensure the form is accessible to all Oregonians;
2. The ADAC reconvenes to finalize the User's Guide that will accompany the form and the User's Guide also receives a final plain language review;
3. The form be formatted to be as understandable as possible;
4. The form be translated into Spanish (and available in other languages upon request);
5. There is a process by which the form is made widely available and an educational effort through which Oregonians learn about the new form.

Thank you for your consideration of the draft Advance Directive form which reflects the strong commitment and hard work of ADAC members.

## Advance Directive Adoption Committee Membership

<b>Name</b>	<b>ADAC Role</b>
Stephanie E. Carter	Member of Oregon State Bar with extensive experience in estate planning and end of life decisions
Woody English, II, MD	Health care provider with expertise in palliative or hospice care NOT employed by hospital or health care facility
Bill F. Hamilton	Health care consumer representative
Christopher D. Hamilton	Member of Oregon State Bar with extensive experience in advance directive
Barb Hansen	Health care provider with expertise in palliative or hospice care
Jen Hopping-Winn	Hospital representative
Nick Kockler, PhD, MS	Clinical Ethicist
Kellie Lapp	Representative with expertise advising or assisting consumers with end-of-life decisions
Eriko Onishi	Primary health care provider representative
Mike Schmidt	Member of Oregon State Bar with extensive experience in health law
Fred B Steele, Jr.	Long Term Care Ombudsman
Katrina Hedberg, MD, MPH, State Health Officer (Ret.)	Ex Officio
Cara Biddlecom	OHA Staff
Under recruitment	Represents individuals with disabilities