



Health IT Policy Committee

A Public Advisory Body on Health Information Technology to the National Coordinator for Health IT

Patient Perspective - Hearing Questions

Responses in bold from Panel Member Karen M. Wyatt, MD – 11/15/2013

- What has your experience been with advance directives?

My mother had an advance directive when she died. The existence of this document was very helpful to my brother and me as we made decisions for her care at the end-of-life. Our burden of responsibility was relieved by the fact that we knew we were following her wishes, rather than making our own decisions on her behalf. When a loved one is dying there are many conflicting and confusing emotions, which are difficult to sort out in the middle of a crisis. The presence of an advance direction provides a clear and consistent guideline to follow. It might have been difficult to honor Mom's wish to remain at home had we not had a written copy of her choices available to us when her condition began to deteriorate rapidly. The presence of the AD also prevented any disagreements between my brother and me, who saw her situation very differently and might have struggled to reach consensus without the guidance provided by the AD.

- If you have an advance directive, when was it created? How often do you update it?

I created an advance directive 4 years ago (2009) before traveling abroad. I have not updated it.

- If you have an advance directive, how did you share your advance directive with multiple organizations/providers?

My advance directive is on file with my estate attorney but I have not shared it with any organization or provider (I do not have a physician.)

- As to advance directives, what is working? What is needed?

Advance directives work well when they exist and are honored. But, in my experience, many patients who complete them do not inform their care provider of the existence of the AD, which is true in my own case. What is needed:

- 1. Rapid access to the details of the AD during an emergency.**
- 2. Portability from state-to-state for those of us who travel a great deal.**
- 3. Universal access by healthcare workers in any facility. Many patients no longer have one long-term primary care physician, but receive episodic care from many different providers.**



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- Can you please comment on the structure of an advance directive, such as the importance of readability, individual preferences including culturally-sensitive considerations, etc.?

Readability is an essential quality of any AD, including the avoidance of medical and technical jargon, with clear and understandable explanations of options. 5 Wishes is laid out very nicely, offers options, and has language that was decipherable for my elderly mother. The inclusion of other “wishes” in addition to physical care is a very nice added touch to 5 Wishes that helps remove some of the clinical “coldness” of the document. Cultural sensitivity is also a must, since many groups have specific preferences for end-of-life care (and after-death care, for that matter) that should be honored.

- Would it be helpful for the status of your advance directive to show in a patient portal?

Yes, I believe this would be very helpful as it might trigger conversations between the care provider and patient about the AD. It should also include the date last updated so that any recent changes in health status might also trigger a review of the AD.

- Would the inclusion of the status of a patient’s advance directive in a care summary at transitions of care ease the burden of having to share this information with multiple organizations?

Yes.

- What information should be shared? The status (e.g., you have one or you don’t)? The actual directive? Instructions on how to obtain it? Any other information (a POLST/POST/MOSLT form care planning notes, etc.)?

The actual advance directive should be shared so that it can be referenced quickly in case of an emergency. Anyone who bothers to create an AD should want the information shared since that it is the only hope for it to be followed. POLST/POST/MOSLT form should be included, as well as care planning notes so that continuity of care can be ensured.

- If sharing the advance directive in the care summary is something you find helpful, do you have advice on how to make sure it’s the latest version?

If the AD is part of the electronic record then each time a new version is created, the previous version should be deleted. If previous versions are saved then the most recent version should have an electronic marker attached to identify it as the latest version.



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- As part of advance care planning, what information should be included in or with a patient's advance directive? A POLST/POST/MOSLT form, care planning notes, other?

Include the POLST/POST/MOSLT form and care planning notes for continuity of care.

- In consideration of the previous question, how could the meaningful use measure for advance directives be improved (*Record whether a patient 65 years old or older has an advance directive*)? Additionally, please comment on the potential effects of removing or changing the age threshold.

Yes I think the presence of an AD should be recorded. There should be an age threshold (65 is fine) AND/OR any diagnosis of chronic or life-threatening illness, at any age, should trigger the necessity of an AD. Removing the age threshold might result in too many healthier individuals "slipping through the cracks" and then being uncovered during an unexpected health emergency.

- Should providers be required to be more responsible for patient's advance care planning (e.g., asking patients about whether they have an advance directive or educating them about advance care planning)?

Yes and providers should WANT to be more involved in patient's advance care planning since the presence of an AD can simplify end-of-life care decisions for the provider. This requirement emphasizes the importance of end-of-life decision-making, and elevates the status of end-of-life care, which is a much-needed change.