

Meeting Minutes

HL7 CDA Personal Advance Care Plan Document Implementation Guide Project

Prepared by: Lisa Nelson

Industry Team

September 15, 2015

Addendum 01

RECORDING:

<https://youtu.be/WfOWwa-fLTw>

(Please report issues with accessing the recording to LisaRNelson@cox.net)

ATTENDANCE:

Present		Not Present
Bob Fine	Lisa Nelson	Dan Morhaim
Brian Scheller	M'Lynda Owens	Fred Mirarchi
Dan Hanfling	Remington Johnson	Jacob Reider
David Tao	Scott Brown	Joseph Schneider
Douglas Renfield-Miller	Stephen Chu	Jude Gallagher
Evelyn Gallego	Swapna Bhatia	Leslie Kelly-Hall
Jeff Zucker	Taima Gomez	Mike Wasserman
John Derr	Terry O'Malley	Monica Murphy
Judy Peres	Tony Chou	Paul Coyne

AGENDA:

Industry Team Introductions – 10-15 mins

Role of the Industry Team

Project Overview – 5 mins

Goal, purpose, tasks and timeline

Project Use Case Review – 15 mins

Functional Requirements – 20 mins

Content required to support functional requirements of in scope use cases

Vocabulary strategy

HL7 Process - optional participation for non-members (not required, but possible) – 2 mins

Open discussion of other guiding considerations for the project

DISCUSSION NOTES:

I. Introductions

The role of the industry team was reviewed, and it was clarified that this group was not a governing body for the project. The industry team creates a forum to provide input that will help

guide the project to ensure the solution is on target. Governance is through HL7 Structured Documents Work Group (SDWG).

Introductions were valuable and inspiring. The team shares a high level of commitment to seeing advance care planning information shared in a standard digital format so that clinicians can have the information they need to care for patients and people can feel confident their goals, preferences, and priorities will be heard. The group agreed that the term “advance care plan” was appropriate to describe the informational content that is the focus of this project. David Tao noted he hopes to see an increase in the “liquidity” (i.e., the transportability) of advance care plan information. John Derr requested clarification that information about a person’s goals, preferences, and priorities includes the person’s expression of his or her thoughts about “quality of life.”

II. Project Overview

The project goal, purpose, guiding principles, tasks and timelines were reviewed and accepted as described.

III. Project Use Case Review

The use cases were reviewed, and the group confirmed these five scenarios as within the scope of this project. The importance of establishing the right set of use cases to guide the project was discussed. Lisa Nelson gave the example of not including privacy-related use cases and Use Cases showing user consent to show how including too few use cases can cause problems because the resulting solution fails to possess key capabilities at its foundation. This makes for a less optimal solution as the functionality associated with the missing foundation begins to be addressed. Stephen Chu identified an additional use case developed through the CHOW Health Care Group covering children with special health needs. He offered to send the description, as well as a list of other edge-case use cases that could be considered for possible inclusion.

IV. Functional Requirements and the Content to Support these Capabilities

The group reviewed the functional capabilities. Terry O’Malley questioned organ donation and whether organ donation and autopsy choices belonged in scope, given that they focused on events that occur following death. Stephen Chu, Robert Fine, Judy Peres, and Lisa Nelson described a number of benefits associated with having advance planning information about these areas available, including improved care planning, respect for religious beliefs, and improved family communication to know and understand these wishes. The members of the group ultimately agreed that issues related to events occurring after death remain in scope. Additional items such as burial plans and wishes may also be relevant. It was noted that the Functional Capabilities need to address ways to support “substitute judgement.” Also noted, clarity needs to be included to distinguish situations involving organizations versus individuals as legal representatives for healthcare decision-making.

The group briefly reviewed the list of sample advance directives. Lisa Nelson explained that the project aims for the set of guiding documents to include high quality examples of current advance directives which represent a full spectrum of perspectives. The team was encouraged

to review the list of sample documents in greater detail and notify Lisa Nelson of any concerns regarding the current set. Additional samples that diversify the mix of guiding documents will be appreciated. Judy Peres offered to send some additional examples for the assessment.

V. HL7 Process

Lisa Nelson explained the process for non-HL7 members to join the HL7 listserv discussions for the Structured Documents Work Group. The process for non-members to participate in an HL7 ballot was also reviewed. An additional document describing balloting for non-members will be distributed with the minutes.

VI. Open Discussion

Lisa Nelson shared her e-mail address and phone number and encouraged team members to contact her with any additional thoughts or questions. Scott Brown expressed appreciation for the group’s willingness to support the project. Jeff Zucker reiterated the importance of including Use Cases that demonstrate consumer-centered care planning and functional capabilities that permit a person to create and control the sharing of advance care planning information that expresses his or her goals, preferences, and priorities. Judy Peres expressed interest in participating in the HL7 ballot for this project. She also questioned if additional forms of digital communication, such as video content, would be considered in scope for this project. Terry O’Malley pointed out that Consolidated CDA R2.0 included work on templates for advance directives and suggested that a review of that prior work should be included in the scope of this project.

SUMMARY OF ACTION ITEMS:

Responsible	Action
Lisa Nelson	Distribute minutes, presentation slides, link to recording, list of sample advance directive documents, and instructions for non-members to participate in the HL7 ballot.
Steven Chu	Send Use Case for Child with Health Issue, and list of other edge-case Use Cases for consideration.
Judy Peres	Send additional sample advance directive documents which may offer additional perspectives.
All	Let Lisa Nelson know if you see any gaps or issues with the use cases, functional capabilities, or content samples given the scope of this project.

ADJOURNMENT:

The meeting ended at 6:00pm ET.

Next meeting will be scheduled for Tuesday, October 20th at 5:00pm ET.

ATTACHMENTS:

1. Meeting slide deck.
2. Instructions for HL7 non-members to participate in the ballot process.
3. List of current sample documents being assessed. (Use this link then scroll down.)
http://wiki.hl7.org/index.php?title=Personal_Advance_Care_Plan_Document)

ADDENDUM 01:

Date	Type	Description
9/17/2015	Addition	<p>Additional possible source document sample submitted by Brian Scheller</p> <p>http://www.healthwise.org/insights/healthwiseblog/mmettler/october-2013/2097.aspx</p> <p>National Hospice and Palliative Care Organization: http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1 [Includes links to state specific Advance Directives]</p> <p>MedlinePlus: https://www.nlm.nih.gov/medlineplus/advancedirectives.html [on Advance Directives]</p>
9/19/2015	Addition	<p>Introduction from Fred Mirarchi</p> <p>My involvement with this group is my hope to raise awareness to safety issues surrounding the advance care planning process. There is a growing body of research supporting that these documents are not as simply as we think they are and are not very well understood in the medical community with all the various disciplines (EMT.'s, Paramedics, RN's, Residents, Doc's and APP's.). My specific research (TRIAD Series) looks at how these documents get interpreted and understood in the setting of critical illness and soon will be evaluating this concern with respect to their use in pandemic and disaster preparedness type situations. A specific area of concern is a lack of safe guards to ensure the patient's wishes and adherence to nationally published guidelines.</p> <p>As we all work together to create, develop or trouble shoot issues, I am hoping to learn from you regarding this world of IT and how HL7 would enable the use of easy but effective safe guards to minimize both over and under resuscitation.</p>

9/20/2015	Addition	Additional Gap Issue from Fred Mirarchi The functional capability of easy but effective safe guards to minimize both over and under resuscitation.
9/20/2015	Addition	Additional sources from Fred Mirarchi http://www.npsf.org/blogpost/1158873/200782/A-New-Nationwide-Patient-Safety-Concern-Related-to-Living-Wills-DNR-Orders-and-POLST-Like-Documents http://www.medscape.com/viewarticle/835645 http://www.medscape.com/viewarticle/842419 https://m.youtube.com/watch?v=S6XKv7MOuts health IT article on pros and cons http://www.healthitoutcomes.com/doc/the-pros-and-cons-of-emr-in-end-of-life-care-0001
9/20/2015	Consideration for removal	Possible Source Removal from Judy Peres Judy noted possible inappropriateness of the Good-to-go Tool Kit produced by Compassion and Choices.
9/20/2015	Addition	Additional Sources from Judy Peres 1) Supportive Care Coalition ... a coalition of large Catholic health care systems that developed a "Spirituality in Goals of Care" system: http://supportivecarecoalition.org/ . I think we might be interested in the questions captured at the end of Step 10. 2) PREPARE for you Care web sit. Designed to help people and their loved ones prepare for medical decision making by guiding the user through five steps of preparation for decision-making with the help of multiple video aids. The result is a printable action plan. www.prepareforyourcare.org . 3) The Conversation Project: an initiative developed by Ellen Goodman and others dedicated to helping people talk about their wishes for end-of-life care. Resources include the Conversation Starter Kit, which includes the type of questions we want to capture: http://theconversationproject.org/starter-kit/intro/ The Conversation Starter Kit is translated into different languages. 4) Caring Conversations Workbook ... by the Center for Practical Bioethics ... is both a workbook and an advance directive which can be downloaded for free: https://www.practicalbioethics.org/resources/caring-conversations

		<p>5) I think we need to consider addressing cultural sensitivity in some way ... while there may be no specific documents ... there are some thoughtful assessment questions that have been developed along the way. The link to the article on Cultural Relevance near the end of life: https://ethnomed.org/clinical/end-of-life/cultural-relevance-in-end-of-life-care includes the questions developed for the Kleinman and Campbell Patient Explanatory Assessment Model ... I think we should consider some of those questions for inclusion.</p>
9/21/2015	Addition	<p>Additional Gap Issue from Stephen Chu</p> <p>The issue of “managing disputes” should be considered in our functional capabilities area. (I believe that the version content and dateTime informational content that will be included will help with addressing this issue.)</p>
9/21/2015	Consideration - but out of scope for the initial ballot	<p>Topic Identified by Stephen Chu – but suggested to be out of scope</p> <p>“Assisted suicide” – this is a very common scenario in patients with advanced debilitating disorders such as advanced multiple sclerosis, or in many cases of end stage diseases (including cancers). Many patients may want to include an “assisted suicide” option in their advanced directives. Information may include at what stage of the condition/disease this option would be considered, who can authorise for this to go ahead if the patient is unable to give instructions, what mechanism(s) is/are preferred, what are the guard-rails or safeguard mechanisms, ... etc</p> <p>This is legal in some countries.</p> <p>But assisted suicide is illegal in many countries that I know of. It has generated tremendous amount of extremely heated debates within the realms/communities.</p> <p>This is a very thorny issue and probably may worth considering as out of scope.</p>
9/21/2015	Consideration	<p>Stephen Chu suggested that we meet with the HL7 Child Health WG to discuss the possibility of including a Use Case for Children with severely disabling or terminal Health Conditions.</p> <p>A discussion has been planned for Wed Oct 7th Q2 at the HL7 F2F.</p>
9/21/2015	Consideration – but may be out of scope for initial ballot.	<p>Additional Gap Issue from Lisa Nelson</p> <p>The issue of “available translations” should be considered in our functional capabilities area. Providing Advance Directives in different languages is a “content issue”.</p> <p>Possible additional languages: Spanish, French, Mandarin, others? What are the most common languages for providing translated materials in the nation? By state?</p>

9/22/2015	Addition	Thomson Kuhn recommended that resources available from the American College of Physicians be considered in the assessment of available sources. http://www.acpinternist.org/archives/2015/09/advanced-directive.htm