2020-07-16 Patient Empowerment Minutes

Chairs: Virginia Lorenzi, Debi Willis

Scribe: Dave deBronkart

Attendees

Present	Name	Present
Dave deBronkart	Dave deBronkart	x
Virginia Lorenzi	Virginia Lorenzi	
Debi Willis	Debi Willis	x
Lloyd McKenzie	Lloyd McKenzie	x
Rachel Richesson	Rachel Richesson	x
Mikael Rinnetmäki	Mikael Rinnetmaki	x
Nancy Lush	Nancy Lush	
Lisa Nelson	Lisa R. Nelson	x
Jan Oldenburg	Jan Oldenburg	x
Marie Moen	Maria D. Moen	x
Abigail Watson	Abigail Watson	x
John Moehrke	John Moehrke	
John Keyes	John Keyes	x
Terrie Reed	Terrie Reed	
Jose Costa Teixeira	Jose Costa-Teixeira	
Bart Carlson		
Casey Thompson	Casey R. Thompson	x
Didi Davis - VP @ Sequoia Project	Didi Davis	
Olivier Karasira		
Laura Bright (OneRecord)		
Michelle Barry		

Meeting Info:

HL7 Patient Empowerment   https://global.gotomeeting.com/join/322275573
United States: +1 (872) 240-3212,,,322-275-573

Agenda Outline	Agenda Item	Meeting Minutes from Discussion	
Updates (10 min)	Welcome newcomers	Newcomers: • Subscribe to the Patient Empowerment Listserve (patients@lists.hl7.org) • Create an account on confluence.hl7.org to get at our minutes, work docs etc in the Pt Empowerment space • If you're on Zulip, sign up to the Patient Empowerment stream	
	Announcement	Rachel Richesson has students in last semester of a 2 year nursing informatics program who may be able to help. Reach out to her.	
Organization	Approval of this Agenda	done	

	Prior call Minutes (7/9/20) approval	done	
10 min	It's HL7 election time - through end of July.	Virginia ~~will~~ was absent - was going to present her recommendation that our WG vote for Riki Ulrich for ASD Co-chair. Assuming we agree, she will now submit our vote. • Lloyd reviewed how this works in HL7. No objections to Riki were heard. ================== • **Vote to re-elect your Work Group chairs.** Watch your email for subject line **"Your Invitation to Vote"** by mid-day on July 1. If you have not received an invitation but feel you are eligible to vote, please contact Linda Johnson at Linda@HL7.org. (If you're a member of multiple groups you'll get one email for each, with a unique voter ID.) • These emails went to anyone on the WG's listserv. You can vote whether or not you're a paid member of HL7. • HL7 members can also vote for board members	
PE WG projects (30 min)	Instead of covering all 4 projects weekly, with a tiny time slot for each, your co-chairs decided we'll grant time slots each week to whoever has something to present. Default for now will be 1-2 projects each week, alternating as the need arises.		
	Updated WG priorities document is **here** - reformatted to clarify next steps for each. Please review! Co-chairs (led by Virginia) will be shepherding our two PSS's through the HL7 process		
	Corrections to the Record (Debi & Abigail)	We'd like to learn of various workflows, to support automating them in FHIR. Simple example with my (Dave deBronkart's) PCP: (just had this happen) • Patient declares something's wrong. • Provider & patient negotiate what should change, if anything • Provider gives it to someone in IT <u>Notes from the meeting:</u> Lisa Nelson tells us that some HL7 project proposals take the form of **patient stories ("user stories" ... which explain how the project will deliver value)**. My example above is a very condensed example or outline of one. **Need to find the HL7 page on user stories** Ultimately we figure this will lead to an implementation guide (IG) but Lisa warns it can be a big big project. Better to start with a smaller part of the elephant. Debi shared Patient requests to amend PHI implementation specs HIPAA and GDPR.docx (in our WG's Documents sidebar) - a visual representation of the sequence of events for the US "implementation sequence" - how the process works in the US, with notes on difference with GDPR. Possible patient examples cited: • Morgan Gleason's "no I have not been pregnant twice" (her DevDays talk) • LA Lupus Lady says she frequently has to correct her doc's notes because of important errors/omissions. Lloyd: 2 approaches to corrections - "please make this change in this record" vs "here is the full corrected record" ... we need to be clear about the difference, & different business processes. Abigail: also second opinion consultations, and import/export to/from a previous provider's system.	
	Did not get to this - carry forward to next week **Patient Contributed Data** (Jan & Maria) - continue where Jan left off in last week's minutes But add this from today's discussion of Corrections, above: *Jan notes that we should (in a white paper?) take into account the evolving practice of* **OurNotes** *(co-generated visit notes). (Dave thought: imagine the drafting and evolution of a visit note in the same way people collaborate on a Google Doc before its release ... or should this belong under patient CONTRIBUTED data below??)*	⊙ PSS-1655 - Create a white paper on patient contributed data. New note: Purpose suggested by Virginia in the PSS: "to define patient contributed data and the work done to standardize interoperability in the field up to this point as well as consideration of gaps and needs and recommendations)" • Jan & Maria to provide updates. • Update on **intersection of provenance and PCD** - see huge Zulip thread.	
Organization	HL7 process (if time allows)	~~See Virginia's email titled "HL7 101 Continued" re HL7 balloting process.~~	
Adjournment			

• Edit Label

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> ⓘ This is to approve minutes via general consent. *"You have received the minutes. Are there any corrections to the minutes? (pause) Hearing none, if there are no objections, the minutes are approved as printed."*

Agenda Topics

Agenda Outline	Agenda Item	Meeting Minutes from Discussion	Decision Link(if not child)
Management	Minutes Approval		
Methodology			
Management	Next agenda		
Adjournment		Adjourned at	

Supporting Documents

Outline Reference	Supporting Document
Minute Approval	

Tasks

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