2020-05-28 Patient Empowerment Minutes

Chair: Debi Willis Virginia Lorenzi

Scribe: Dave deBronkart

Attendees

Present	Name	Present
Virginia Lorenzi	Virginia Lorenzi	y
Debi Willis	Debi Willis	y
LLoyd McKenzie	Lloyd McKenzie	y
Rachel Richesson	Rachel Richesson	y
Mikael Rinnetmäki	Mikael Rinnetmaki	y
Nancy Lush	Nancy Lush	
Lisa Nelson	Lisa R. Nelson	
Dave deBronkart	Dave deBronkart	y
Jan Oldenburg	Jan Oldenburg	y
Marie Moen	Maria D. Moen	y
Abigail Watson	Abigail Watson	y
John Moehrke	John Moehrke	
John Keyes	John Keyes	y
Terrie Reed	Terrie Reed	
Jose Costa Teixeira	Jose Costa-Teixeira	
Bart Carlson		

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	
	Approval of this Agenda	yes
	Prior call Minutes approval	yes
	co-chair nominations and elections	Send nominations to: Linda@HL7.org by June 15.
	Other updates:	• Dave: Final status of Patient Innovator Track at Virtual DevDays • Debi - job opening: The Assistance Fund in DC is looking for a Director of Pt Advocacy. • Virginia confirmed that our mission & charter are approved • Jan: the PACIO demo (post-acute care plan) from the Connectathon is being polished and will be out soon - we should all see it. (Connects also to Gravity (SDOH) and Care Plan)

	CARIN "My Health Application" project announcement (all FHIR using apps)	Jan: CARIN has published a curated list of patient facing apps that have attested to the CARIN Code of Conduct. Here's Virginia's Zulip post with the following links: • The CARIN app project website: https://MyHealthApplication.com • CARIN's announcement PDF: https://www.carinalliance.com/wp-content/uploads/2020/05/CARIN-Blog-05.27.2020.pdf • The gallery of apps: https://myhealthapplication.com/health-apps/gallery Note: ALL APPS IN THE GALLERY SUPPORT FHIR, according to Ryan in that thread.
PE WG projects	Patient Corrections project	• **Our proposal for Patient Corrections** has been accepted! Next step: Project Scope Statement. *Leads: Debi, Abigail* • "Given that Patients have access to the data in an EHR, when the Patient discovers an error in the medical record, then the patient needs a method of communicating the error so that it can be addressed, so that the medical record can be corrected to prevent future health and safety concerns."
	Patient-Contributed Data project *Leads: Maria D. Moen and Jan Oldenburg*	For more efficient layout I'm moving these lengthy notes to below this table.
Our projects	Future call: John to present CBCP for Consents *or* Lisa to present Care Planning	John will present on Consents 6/4/2020
Other WGs' project proposals that we might follow	DID NOT GET TO THIS - carry it forward: Others' project proposals: example from Debi - "Account, Payments, and Statements" - Accounts, Payments and Statements Project Scope Statement See heading 2a, "Primary /Sponsor WG" Note, this is a **project SCOPE statement,** not the brief Project Proposal	Which should we be following? How do we spot them and what do we do? How do you-all do this in other groups?
Adjournment	2:13 pm	

Discussion of Patient-Contributed Data

Now we need to create something similar for **Patient-Contributed Data.** Starter text from our Priorities document:

- "This is intentionally distinct from existing terms such as PGHD (patient-generated health data). Patient-contributed data can include observations, preferences, goals, anything that comes from the patient side of the clinical relationship."
- We had quite a lively discussion but were unable to determine what the project scope statement should contain or what the project would consist of. Will continue to work on determining the project purpose. See discussion details below:

Discussion:

Maria: Jan & she (co-leads) suggest starting with the existing ONC definition of PGHD, and adding the other use cases we're talking about. It seems as though we build upon, and expand the existing standards to accommodate the use cases our group is focused on rather than potentially creating redundancy or re-inventing the wheel.

Lloyd: Hm. CDA documents too often get accepted and set aside, rather than being put where they need to be in the EHR so they'll be seen by the HCP. In the FHIR world we're trying to get away from a "document" paradigm to a standard that isn't so rigidly structured.

(Dave needs a summary of this from someone (Maria? Jan? anyone?) more knowledgeable about the particulars, e.g. CDA-vs-FHIR and Lloyd prefers to "avoid documents," etc. What do these minutes need to say for future others to read, to understand what discussed?)

Lloyd re prior art: "Don't be bound by what exists, but do be informed by it."

Lloyd: appeared to recommend a generic specification that focused on those requirements that apply to all patient contributed data. Mentioned clinician "distrust".

Virginia: It seems that maybe two projects are needed:

1. a white paper which defines the concept and provides an environmental scan of all HL7 related patient contributed data specifications so we understand what is out there and what is not (gaps).
2. a FHIR IG that constrains/defines requirements common to all patient contributed data. For example, it might clearly define and constrain "provenance data"

Mikael in chat:

- Patient-generated health data does have some FHIR implementation guides too, right? Like http://hl7.org/fhir/uv/phd/2019May/.
- And there's an IHE profile https://wiki.ihe.net/index.php/Personal_Health_Device_Observation_Upload

Debi in chat: FHIR IG for PRO's (patient reported outcomes): http://www.hl7.org/fhir/us/patient-reported-outcomes/2018Sep/

Jan: We want to move away somehow (to the extent a standard can do this) from the paradigm that data is only legit when it's been validated by a physician. **Lloyd:** "validity" is a cultural thing ... there will always be a need to know "where did this come from?" (provenance)

(Note that aside from writing specs, HL7 can write position papers etc on items like the paradigm of physician approval. HL7 **can** remove the technical barriers to *doing* what needs to be done. Getting it so such things *can* get in there is the first step.)

Debi: get anything from a pt and into an EHR. **Lloyd:** yes but in a way that they can get *integrated* into the EHR. **Jan:** Not all genuinely useful data may exist in forms that may not exist in discrete elements in EHRs. e.g. for her own asthma, her peak flow readings aren't that useful but the trends are.

Note again that the enabling specification is a separate issue from the change-management process. HL7 position papers as above may be ONE source of encouraging change but is not sufficient.

Mikael in chat:

> Jan, I think so. And that was justified before, and that's why we want a broader term.
>
> Regarding what we want to achieve:
> If I'd have the magic wand, I'd swing it at least twice:
>
> **1. EHR's and clinicians are somewhat reluctant to take in patient provided data.** This may be due to policies of organizations and risk/liability for information that is in their EHR (which they are responsible for) and how to reflect patient-sourced information. However, **having a spec for this might encourage adoption.** Setting clear compartments in EHR's would be a step forward. I know clinicians do have the need for the data in some use cases.
>
> **2. Also, patient-facilitated transfer** of official clinical data. **How it should be signed by a healthcare org in order to be accepted by another system?** I could imagine a technical approach for this. Would there still be interest? Would it be adopted?