Patient Empowerment Work Group

Wednesday April 19, 2023
HIMSS ‘23
WELCOME AND OVERVIEW

Patient Empowerment Workgroup

- Our Mission & Charter
- Our Community
- Our Initial Priorities
- Our Projects
Our Mission

The Patient Empowerment Work Group was formed to identify and define requirements for standards that enable individuals and caregivers to identify their personal needs, requirements and preferences for health information data exchange and accessibility.

Our mission is to represent, accommodate, and empower individuals and patients in HL7’s standards work to guide the design of a more inclusive healthcare system that serves the people it is intended to serve with HL7 standards as the mechanism for doing so.
Our Charter

This Work Group provides a forum for all interested parties who want to promote a person’s right to be represented when standards are developed to access, update, and exchange their health information whether for their own use or for transfer to other entities.

The recipients of care inevitably have a different perspective than those creating and working in the healthcare system, and that perspective needs to be included by direct participation of patients and caregivers in the HL7 standards process.

The focus of this group will be on the information content, secure and permitted access, and accuracy of people’s health information with an over-arching agreement that the subject’s health and device-initiated information needs to be permitted to be eligible for exchange of as the world becomes more and more inter-connected.

The WG will also work with and provide guidance and recommendations to other WGs that should be ensuring people can access, update, and be stewards of their own health information.
Our Community

- Patients
- Caregivers
- Patient Advocates
- Active project participants where patients and people are impacted by their work (vendors, implementers, interoperability SME’s, clinicians, providers, YOU)

United by the belief that standards-based interoperability can empower patients and caregivers
Our Initial Priorities and Focus

- Several areas we felt needed more direct attention:
  - Patient Contributed Data
  - Correction Requests
  - Consent from a Patient Perspective
  - Patient Voice in Care Plans
Current Projects

PE as a Sponsor

- Patient Request for Corrections
- Advance Directive Interoperability (ADI) w/FHIR (Patient Care, Orders & Observations, Community-Based Care and Privacy co-sponsor)
- Patient Contributed Data (PCD) White Paper
- Standard Personal Health Record (SPHR) (EHR co-sponsor)

PE as a co-sponsor

- International Patient Access (IPA)
- Problem-Oriented Health Record
- Personal Functioning and Engagement
- SMART Health Cards for Vaccine and Testing
- ePOLST CDA IG
Patient Request for Corrections

Ballot and Issue Review

Virginia Lorenzi & Debi Willis - Leads
04/2023
Problem and Opportunity

- **Problem:**
  - Many studies and patient stories describe the prevalence and severity of errors in medical records.
  - Current methods for requesting a record change are often paper based, fully manual, and opaque, and with little communication or status information provided during the process.

- **Opportunity:**
  - FHIR is now being used to share information between provider organizations and patients millions of times a day.
  - Patients are able to review their data and detect errors in their information.
  - *This presents a nice opportunity* for creating a standard way for patients to electronically request a correction/amendment to their health record via FHIR, including any back and forth communication and status tracking.
Goal: Create a FHIR Implementation Guide so patients/caregivers can use their apps to:

- Request corrections to their records
- Conduct back-and-forth conversations between Requester and Fulfiller
- Track the status through to resolution of their request.

Contact project leads:

- Debi Willis  debi@MyPatientLink.com
- Virginia Lorenzi  vlorenzi@nyp.org
**Project Status on IG**

**Began:** Summer 2020

**4 Connectathons:** January 21 – Jan 22

**Balloted:** May 2022, Passed

**In Process:**
- Ballot reconciliation is close to completion on STU1
- Getting ready to update the current draft
- Publication as early as Spring 2023

**Future:**
- New data types:
  - Amendment Decisions
  - Disagreements
  - Amendment Decision and Disagreement Data Types

**Needs:** More stakeholder participation, especially EHR vendors
WE NEED YOUR HELP!!

Read the Draft IG:
https://build.fhir.org/ig/HL7/fhir-patient-correction/index.html

Visit us on Confluence: https://confluence.hl7.org/display/PE/Patient+Corrections

Join our Weekly Calls: Mondays 4 ET/3PM CT
http://www.hl7.org/concalls/CallDetails.cfm?concall=57967

Needed:
Advocates to spread the word.
Stakeholders to provide their perspective.
IG developers and editors to help us with spec edits.
Implementers to test and make this a reality
Patient Contributed Data

Progress Report from the Patient Contributed Data project sponsored by the HL7 Patient Empowerment Workgroup

April 2023

Jan Oldenburg and Maria Moen, co-leads
(Many contributing authors)
Current status

- The team is revising the white paper:
  - Incorporating comments and suggestions from balloting
  - Updating recommendations
- Goal is full reconciliation by Summer 2023 WGM
- Goal is publication, not another ballot cycle
Plans and goals

- We are looking for opportunities to speak about the topic
- We currently have two publications from the white paper; we’re looking for further opportunities to publish
- Extensions of our work are required:
  - We will recommend additional subgroups
  - We will recommend additions to other IGs
Advance Directive Interoperability (ADI) w/FHIR

April 2023

Brian Meshell, Matt Elrod and Maria Moen, Project Leads

MITRE Providing the Framework and Technical Resources
Systems used to create and update patient-generated advance directives/advance care plans through a patient-directed process need a way for individuals to communicate information about their advance medical care goals, preferences, and priorities.

Individuals need a way to generate and update information related to their advance directives/advance care plans so that their current wishes can inform provider-generated care plans.

Interoperable exchange of the advance directive information supports more effective sharing of advance directive information across transitions in care and enables practitioners to create person-centered care plans that align with a patient’s values, goals of care, treatment preferences, and quality of life priorities when a patient cannot communicate for themselves.
Advance Directive Interoperability (ADI) w/FHIR IG Use Case Overview STU1

**Use Cases**

- Use Case 1: Create and store in digital form [Content]
- Use Case 2: Share [Content]
- Use Case 3: Query and access [Content]
- Use Case 4: Update (replace) [Content]
- Use Case 5: Verify Current version of AD [Content]

**Content**

- Advance Directive Information (person-authored information)
- Patient Encounter-Centric Instruction (practitioner-authored information)

Initial Focus Area for STU1 IG

Portable Medical Order for Life-Sustaining Treatments (practitioner-authored information)
STU1 Person-Authorised Advance Directive/PACP Information

- Currently in ballot reconciliation
- Open areas to shore up include:
  - Observations vs. Goals to Represent
  - Integration into Care Plan/Treatment Plan
  - Alignment with Personal Advance Care Plan (PACP) CDA IG R2.1
  - Various LOINC code discussions with proposed modifications to address this use case
**Advance Directive Interoperability (ADI) w/FHIR IG Use Case Overview STU2**

### Use Cases

<table>
<thead>
<tr>
<th>Use Case 1</th>
<th>Use Case 2</th>
<th>Use Case 3</th>
<th>Use Case 4</th>
<th>Use Case 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Create and store in digital form</td>
<td>Share</td>
<td>Query and access</td>
<td>Update (replace)</td>
<td>Verify Current version of AD</td>
</tr>
</tbody>
</table>

### Content

- **Advance Directive Information** (person-authored information)
- **Encounter-Centric Patient Instruction** (practitioner-authored information)
- **Portable Medical Order for Life-Sustaining Treatments** (practitioner-authored information)

**Initial Focus Area for STU2 IG**
First Testing Event - January 2023 HL7 Connectathon

• What was the track trying to achieve?
  • Create, exchange, update, and query/retrieve Portable Medical Order (PMO) information between disparate health IT (HIT) systems, in a consumable format for clinicians, patients, and family members
    • PMO document type
    • Order service requests
    • Completion information observations
  • Test the STU-2 draft version of the Advance Directive Interoperability (ADI) w/FHIR IG
    • [https://build.fhir.org/ig/HL7/fhir-pacio-adi/branches/STU2_draft/](https://build.fhir.org/ig/HL7/fhir-pacio-adi/branches/STU2_draft/)
USCDI Reflects the Drive to Empower Patients (Level 2)

With the publication of Draft USCDI v4, ONC is accepting feedback on its content until April 17, 2023. ONC plans on releasing a final USCDI v4 in July 2023.

In addition to "Comment" and "Level 1" criteria, Level 2 data elements demonstrate extensive existing use in systems and exchange between systems, and use cases that show significant value to current and potential users. These data elements would clearly improve nationwide interoperability. Any burdens or challenges would be reasonable to overcome relative to the overall impact of the data elements.

**Advance Directives**
- Advance Directive Observation
- Care Experience Preference
- Advance Directives

**Health Insurance Information**
- Data related to an individual's insurance coverage for health care.
- Policy Number
- Payor Name
- Plan Name
- Plan Identifier
- Group Identifier

**Pregnancy Information**
- Pregnancy Status
- Gestational Age
- Multiple Gestation
- Conception Estimated Due Date
- Last Menstrual Period (LMP)

**Problems**
- Condition, diagnosis, or reason for seeking medical attention.
- Date of Onset

**Procedures**
- Activity performed for or on a patient as part of the provision of care.
- Procedure Timing
- Location of Procedure
- Procedure Sequence

**Assessment**
- Incontinence

**Assessment and Plan of Treatment**
- Health professionals' conclusions and working assumptions
- Immunizations
# USCDI Reflects the Drive to Empower Patients

(Draft v4)

## Portable Medical Order for Life-Sustaining Treatments

- **Practitioner-Authored Information**

<table>
<thead>
<tr>
<th>Information Type</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical Test</strong></td>
<td>Clinical Test Result/Report</td>
</tr>
<tr>
<td><strong>Diagnostic Imaging</strong></td>
<td>Tests that result in visual images requiring interpretation by a credentialed professional. Diagnostic Imaging Test Diagnostic Imaging Report</td>
</tr>
<tr>
<td><strong>Encounter Information</strong></td>
<td>Information related to interactions between healthcare providers and a patient. Encounter Type Encounter Diagnosis Encounter Time Encounter Location Encounter Disposition Encounter Identifier</td>
</tr>
<tr>
<td><strong>Facility Information</strong></td>
<td>Physical place of available services or resources. Facility Name Facility Identifier Facility Type</td>
</tr>
<tr>
<td><strong>Goals</strong></td>
<td>Desired state to be achieved by a patient. Patient Goals SDOH Goals Treatment Intervention Preference Care Experience Preference</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td>Analysis of clinical specimens to obtain information about the health of a patient. Tests Values/Results Specimen Type Result Status Specimen Source Site Specimen Interpretation Specimen Identifier Specimen Reference Range Specimen Condition and Disposition Result Unit of Measure</td>
</tr>
<tr>
<td><strong>Problems</strong></td>
<td>Problems Health Concerns Date of Diagnosis Date of Resolution</td>
</tr>
<tr>
<td><strong>Procedures</strong></td>
<td>Activity performed for or on a patient as part of the provision of care. Procedures SDOH Interventions Reason for Referral Time of Procedure</td>
</tr>
<tr>
<td><strong>Provenance</strong></td>
<td>Metadata or data that describes other data. Author Time Stamp Author Organization</td>
</tr>
<tr>
<td><strong>Vital Signs</strong></td>
<td>Physiologic measurements of a patient that indicate the status of the body's life sustaining functions. Systolic Blood Pressure Diastolic Blood Pressure Heart Rate Respiratory Rate Body Temperature Body Weight BMI</td>
</tr>
</tbody>
</table>
Standard Personal Health Record (SPHR)

4/15/2023

Abigail Watson MITRE, Project Lead

MITRE Providing the Framework and Technical Resources
Patients on FHIR: Bring Your Own Health Record

Patient Empowerment invites participants to export a health record from their personal health record or electronic medical record of choice, and join us to learn more about review, discussion, and exchange. Inspired by the Physicians on FHIR sessions (historically held on Fridays of working group meetings), we want to give patients, patient advocates, and PHR/EHR vendors an opportunity to meet and exchange records.

In particular, we will be looking at longitudinal records, and how a patient's health history may be spread over multiple systems, with focus on things like how different systems bundle and export files, patient ID formats, code systems and value sets in use, loading records into other systems, deduplication, record reconciliation, and so forth.

Protected Health Information is not required to participate. Nor is programming experience required. We will accept sandbox and application data in any format (PDF, XML, JSON, FAX, JPEG, etc), although our long-term focus will be on mapping pathways to FHIR based formats.
SPHR Details and Testing Initiatives

Please join our calls Friday at 2PM ET.

Participants we’d like to engage:
- Patients who use any sort of digital record keeping for their health conditions.
- Patient advocates representing communities of patients with specific niche concerns.
- Personal Health Record (PHR) vendors who have developed software for tracking personal health.
- Electronic Medical Record (PHR) vendors who have obligations under 21st Century Cures Act to provide data to patients.
- Application and medical device vendors who develop software that may export health history for a patient.

Testing Scenarios:

Scenario 1. Export a health record.
The most basic testing scenario for Connectathon tracks is to explore whether your system or application can export a health record. Particular attention will be given to records exported in FHIR format, which satisfy 21st Century Cures Act requirements.

Scenario 2. Import a health record.
Interested parties may wish to go an additional step further, and attempt to import records that were exported by other systems. Systems that include both import/export functionality typically include some sort of File > Save As and File > Open functionality, although that is not strictly required. Vendors and developers with PHRs, EHRs, or applications that can import health records are highly encouraged to reach out.

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