

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.

Patient Request for Corrections Project

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

Patient Request for Corrections Project

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



Advance (ADI) w/FHIR Project Need

- 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)

Encounter-Centric Patient
Instruction
(practitioner-authored information)

Portable Medical Order for
Life-Sustaining Treatments
(practitioner-authored information)

Initial Focus Area for STU1 IG

STU1 Person-Authored 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

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)

Encounter-Centric Patient
Instruction
(practitioner-authored information)

Portable Medical Order for
Life-Sustaining Treatments
(practitioner-authored information)



STU2 Practitioner-Authored Portable Medical Orders for Life-Sustaining Treatment

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/

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.

USCDI V1 USCDI V2 USCDI V3 Draft USCDI V4 **Level 2** Level 1 Comment


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.

Submission Period

- Any -


Apply

Advance Directives

Advance Directive Observation 
Care Experience Preference 
Advance Directives

Allergies and Intolerances

Harmful or undesired physiological responses associated with exposure to a substance.

Substance (Non-Medication) 
Substance (Food)

Assessment

Incontinence

Assessment and Plan of Treatment

Health professional's conclusions and working assumptions that will guide treatment of the patient.

Health Insurance Information

Data related to an individual's insurance coverage for health care.

Payer Identifier
Coverage Period
Policy Number
Payer Name
Plan Name
Plan Identifier
Group Name

Health Status Assessments

Assessments of a health-related matter of interest, importance, or worry to a patient, patient's family, or patient's healthcare provider that could identify a need, problem, or condition.

Physical Activity Status 
Health Literacy Status

Immunizations

Pregnancy Information


Pregnancy Status
Gestational Age
Multiple Gestation
Corrected 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

USCDI Reflects the Drive to Empower Patients (Draft v4)

Clinical Test
Clinical Test Result/Report

Diagnostic Imaging

Tests that result in visual images requiring interpretation by a credentialed professional.

Diagnostic Imaging Test
Diagnostic Imaging Report

Encounter Information

Information related to interactions between healthcare providers and a patient.

Encounter Type
Encounter Diagnosis
Encounter Time
Encounter Location
Encounter Disposition
Encounter Identifier ★

Facility Information ★

Physical place of available services or resources.

Facility Name ★
Facility Identifier ★
Facility Type ★

Goals

Desired state to be achieved by a patient.

Patient Goals
SDOH Goals
Treatment Intervention Preference ★
Care Experience Preference ★

Analysis of clinical specimens to obtain information about the health of a patient.

Tests
Values/Results
Specimen Type
Result Status
Specimen Source Site ★
Result Interpretation ★
Specimen Identifier ★
Result Reference Range ★
Specimen Condition and Disposition ★
Result Unit of Measure ★

Medical Devices

An instrument, machine, appliance, implant, software or other article intended to be used for a medical purpose.

Unique Device Identifier - Implantable

Medications

Pharmacologic agents used in the diagnosis, cure, mitigation, treatment, or prevention of disease.

Medications
Dose
Dose Unit of Measure
Indication
Fill Status
Medication Instructions ★
Medication Adherence ★

Problems
Problems/Health Concerns
Date of Diagnosis
Date of Resolution

Procedures

Activity performed for or on a patient as part of the provision of care.

Procedures
SDOH Interventions
Reason for Referral
Time of Procedure ★

Provenance

Metadata, or data that describes other data.

Author Time Stamp
Author Organization

Vital Signs

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 Height
Body Weight
Pulse Oximetry
Inhaled Oxygen Concentration
BMI Percentile (2 - 20 years)
Weight-for-length Percentile (Birth - 24 Months)
Head Occipital-frontal Circumference Percentile (Birth - 36 Months)
Average Blood Pressure ★

Standard Personal Health Record (SPHR)

4/15/2023

Abigail Watson MITRE, Project Lead

MITRE Providing the Framework and Technical
Resources



SPHR Project Overview

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.