

Patient Request for Corrections

A New Track at the HL7 January 2021 Connectathon

January 13th – 15th

Brought to you by: The Patient Empowerment Workgroup

Join Us

Thursday 1pm ET

patients@lists.hl7.org

Patient
stream

Our Three Current Projects:

- [Patient Request for Corrections to Errors IG](#) (Debi Willis, Virginia Lorenzi)
- [Patient-Contributed Data white paper](#) (Jan Oldenburg, Maria Moen)
- [Advance Directives Interop](#) (Maria Moen working with PACIO)

Dashboard

Patient Empowerment Home

Created by Joshua Prociuous, last modified by Dave deBronkart on May 26, 2020

Mission

Approved Jan 30, 2020

bit.ly/hl7patients

The Patient Empowerment Work Group promotes and amplifies the viewpoint of patients and their caregivers in HL7's standards work, in support of the HL7 mission.

Co-Chairs



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The “right health data” is Really Important



About	Standards	Membership	Resources	Events	Training	Certification
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HL7 Vision

A world in which everyone can securely access and use the right health data when and where they need it.

"The reason we're here is that when 'the right health data' arrives, it BETTER be right ... or bad things can happen." e-Patient Dave

Wall Street Journal, June 2014

Look in Your Medical Record, Odds Are You'll Find a Mistake

BY LAURA LONARDI

Health-care providers are giving patients more access to their medical records so they can help spot and correct errors and omissions.

Studies show errors can occur on as many as 95% of the medication lists found in patient medical records.

Errors include outdated data and omissions that many patients could readily identify, including prescription drugs that are no longer taken and incorrect data about frequency or dosage.

Patients also are being asked to fill in the blanks about pain relievers and other over-the-counter medications, as well as supplements and vitamins, all of which can interact with prescription drugs.

Technology is giving the efforts a boost: More than half of doctors use electronic medical records, compared with just 17% in 2008, according to the federal government, which offers financial incentives to providers tied in part to giving patients access to their health information online.



Mary Ellen Sexton, left, found outdated data in her husband Lynn's, center, medical record. Patients' checking 'only helps me,' says their physician, Richard Martin, right.

Several large medical providers, including Cleveland Clinic, Mayo Clinic, the Veterans Health Administration, Geisinger Health System and Kaiser Permanente, are giving patients direct online access to their

doctors' notes. And they are experimenting with different ways to solicit feedback and allow patients to correct or add to their records.

"If we don't have accurate data we can't take care of patients appropri-

ately," says a spokeswoman at Geisinger. The aim is to move patients and doctors into a relationship of "shared accountability" and more effective medical care, he says.

While studies have shown that immediate harm to a patient because of faulty medical records is rare, such errors can lead doctors to miss important information, such as whether patients aren't taking their drugs as prescribed, which can lead to worsening of a disease or condition. In an emergency, it's critical to know what drugs are in a patient's system, as hospital staff may prescribe new drugs that conflict with them.

Even when gaps in the medical record are a result of the patient's failure to provide updated or complete information, providers might still face legal liability in the event of an adverse or allergic reaction or a prescription that doubles something the patient is already taking. The risk is especially high for older patients, who often take several medications for one or more chronic diseases and may not recognize that, say, a brand-name drug and a generic-name drug are the same.

medical information are more likely to ask questions, identify inaccuracies and give additional information that might affect data in their records, according to research conducted by research organization NORC at the University of Chicago, under contract with the federal Office of the National Coordinator for Health Information Technology.

In a pilot study that the Chicago researchers conducted with Danville, Pa.-based Geisinger, patients with chronic diseases like diabetes and heart failure were invited to go online between November 2011 and June 2012 to update the medications in their electronic health records before a doctor's visit. They had the option to indicate which meds they were no longer taking, which they were taking differently than described and which they were taking that weren't listed. Geisinger pharmacists followed up with the patients to update their records and notify doctors and case managers about changes.

In nearly 90% of cases, patients requested changes to their medical records. Please turn to the next page.



THE WALL STREET JOURNAL.

By LAURA LANDRO

CONNECT



THE INFORMED PATIENT

Health-Care Providers Want Patients to Read Medical Records, Spot Errors

The aim is to move patients and doctors into a relationship of "shared accountability"

- Up to 95% of medication lists were found to have mistakes
- ~90% of patients requested changes to their records.
- ~80% were accepted by the doctors
- Geisinger doctor:
"If we don't have accurate data we can't take care of patients appropriately"

HIPAA: right for correction



The HIPAA Privacy Rule and Electronic Health Information Exchange
in a Networked Environment

CORRECTION

CORRECTION AND THE HIPAA PRIVACY RULE

The Privacy Rule provides individuals with the right to have their protected health information (PHI) amended in a manner that is fully consistent with the Correction Principle in the Privacy and Security Framework. See 45 C.F.R. § 164.526. Both the Privacy Rule and the Correction Principle recognize that individuals have a critical stake in the accuracy of their individually identifiable health information and play an important role in ensuring the integrity of that data. Under the Privacy Rule, individuals have the right to have a covered entity amend their PHI in a designated record set, as defined in § 164.501, for as long as the entity maintains the records.

GDPR: Right to rectification



What should we do if we refuse to comply with a request for rectification?

You must inform the individual without undue delay and within one month of receipt of the request about:

- the reasons you are not taking action;
- their right to make a complaint to the ICO or another supervisory authority; and
- their ability to seek to enforce this right through a judicial remedy.

You should also provide this information if you request a reasonable fee or need additional information to identify the individual.

Our Strategy – Follow HIPAA

HIPAA provides very specific Implementation Specifications for a Patient's Request to Amend their Record.

Our goal is to create a solution that works in the global context, but utilizing detailed HIPAA implementation specifications as a guide.

Workflows and data elements we need to consider:

- **Patient identifies:**
 - Where the error is found (could be structured or not)
 - Actions requested
 - Reason they want the change (optional)
 - Who they want notified (optional)
- **Covered entity must respond** within 60/30 days with: **Accepted, Denied, Time Extension.**
 - **HIPAA**: The entity must respond within **60 days**, which may include an **extension of 30 days** with a reason for the delay and date they will complete its action on the request.
 - **GDPR**: The entity must respond within **1 month**, which may include an **extension of 2 months** if the request is complex or you have received a number of requests from the individual.

HIPAA (continued)

Time Extension and Accepted Requirement

Request more time:

- o The covered entity must provide the individual with:
 - The reasons for the delay
 - The deadline the entity will complete its action on the request

Accepted:

- o Entity notifies patient the amendment is accepted
- o Entity obtains list of who the amendment needs to be shared with

HIPAA (Continued)

Denied Workflow More Complex

Denied:

- o The Entity must provide the individual with a denial in plain language and contain:
 - The **basis** for the denial
 - The **individual's right to submit a written disagreement**
 - A **statement** that the individual may request the covered entity provide the individual's request for amendment and the denial with any future disclosures of the protected health information that is the subject of the amendment
 - A description of **how the individual may complain** to the covered entity.
- o The patient may submit a statement of disagreement.
- o The entity may prepare a rebuttal and must provide a copy to the individual who submitted the statement of disagreement.

Patient Empowerment Connectathon Track

Patient Request for Corrections to their Record



Our ultimate goal is to build a FHIR Implementation Guide to provide a standard way to communicate information required to support a patient's request for corrections.

The purpose of this Connectathon is to test a draft Implementation Guide that uses the Task Resource to see if this is the best resource to accomplish our goal.

Track co-Leads: Virginia Lorenzi and Debi Willis

Testing Three Scenarios

- Patient requests change and **change is accepted**, covered entity makes requested change, notifies patient.
- Patient requests change, **change is denied**, reason and recourse information is sent to patient (among other things).
- **Patient disagrees** with denial. (optional: entity sends rebuttal response)

ACCEPTED

DENIED

I disagree!

RESPONSE

Overview of Guide and Test Plan

Implementation Guide:

- Contains 2 profiles on Task.
- <https://build.fhir.org/ig/HL7/fhir-patient-correction/index.html>

Test Plan:

- Contains 3 scenarios.
- Includes Bonus tests
- Trying to see if and how Task resource can work.
- <https://confluence.hl7.org/download/attachments/97456948/Patient%20Request%20for%20Correction%20Test%20Script.docx?api=v2>

Actors

Actor	Description
CorrectionRequester	The CorrectionRequester represents a patient's application, such as a personal health record. A patient or their caregiver uses the application to request a correction to their medical record.
RequestFulfiller	The RequestFulfiller represents a provider system such as an EHR. A Medical Records professional or clinician uses the provider system to review and process the correction request.

Profiles

Task Profile	Purpose
Patient Correction Request	Used to communicate information about a patient's request for correction and the associated process
Patient Correction Disagreement	Used to communicate information about a patient's disagreement with a correction rejection and the associated process

The Patient Correction Request Task Profile

Key Fields - Requester

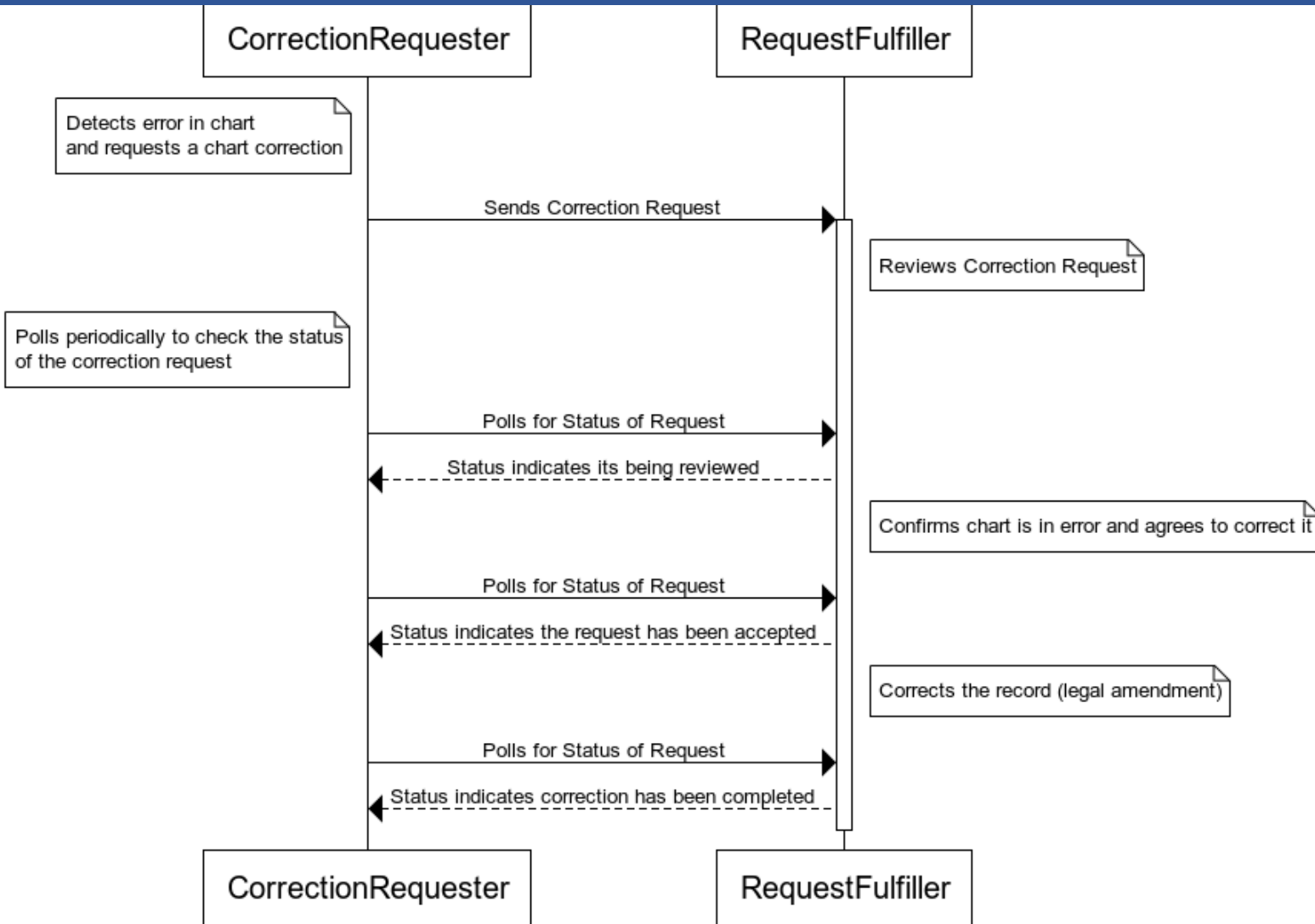
- Which record is being corrected? `Task.for`
- Who is asking for the correction? `Task.requester`
- Who is being asked? `Task.owner`
- When was the request made? `Task.authoredOn`
- What is the correction requested? `Task.description`
- Additional optional information `Task.input`
 - Encounter containing error
 - Attachments – Images
 - DocumentRef
 - CommunicationRequest for who to notify
 - Specific Resources representing resources in error or suggested corrections

The Patient Correction Request Task Profile

Key Fields - Fulfiller

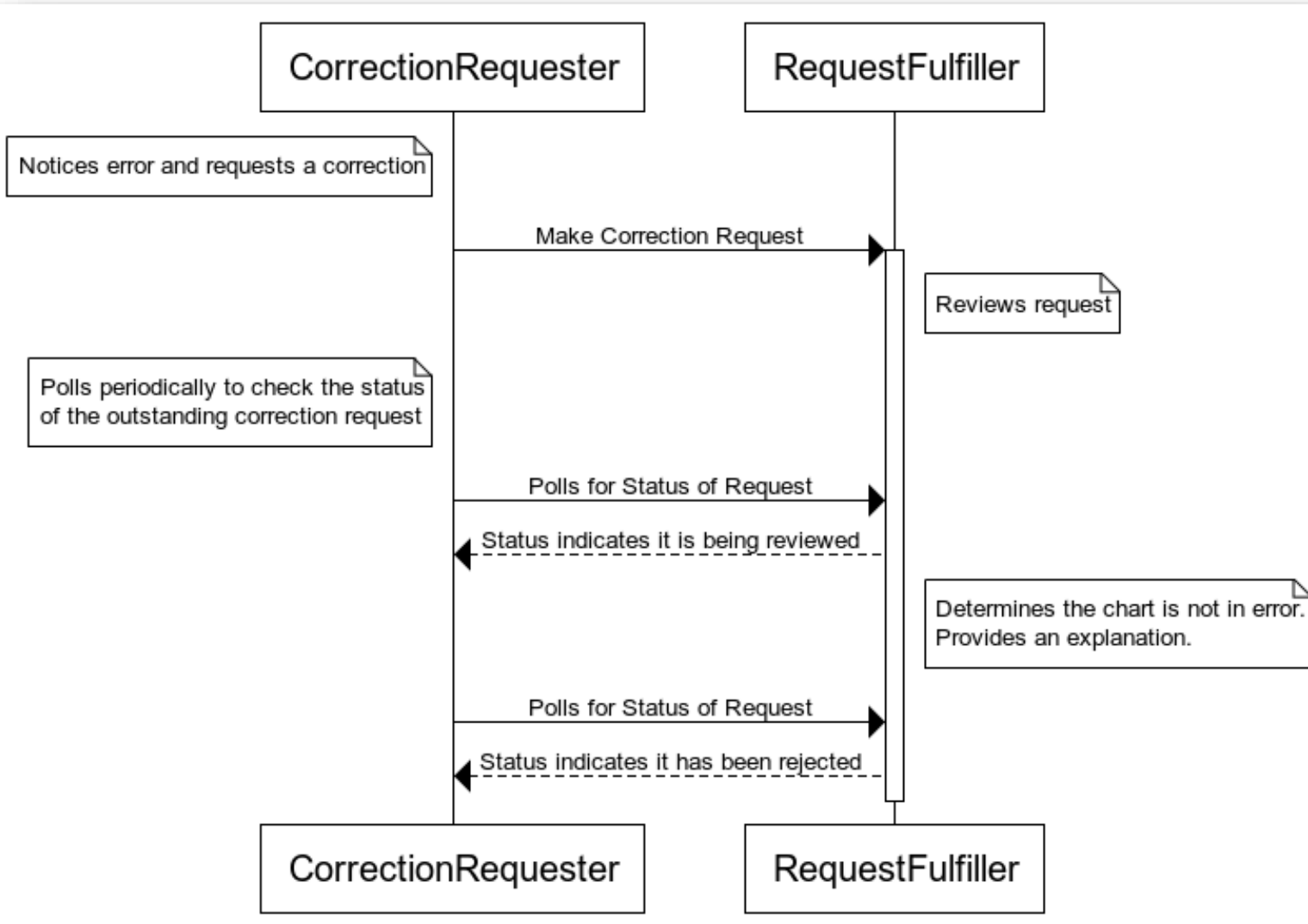
- What is the current status? `Task.status, Task.businessStatus`
- More understanding on status. `Task.statusReason`
- The fulfiller can log notes on the task. `Task.note`
- Responses back to patient `Task.output`
 - When task is accepted, patient is asked to identify who they want informed of the correction.
 - When task is rejected, patient is provided with an explanation of the rejection and informed that they can log a formal disagreement.

Scenario 1: Patient Requests a Correction to Their Record and Request is Accepted



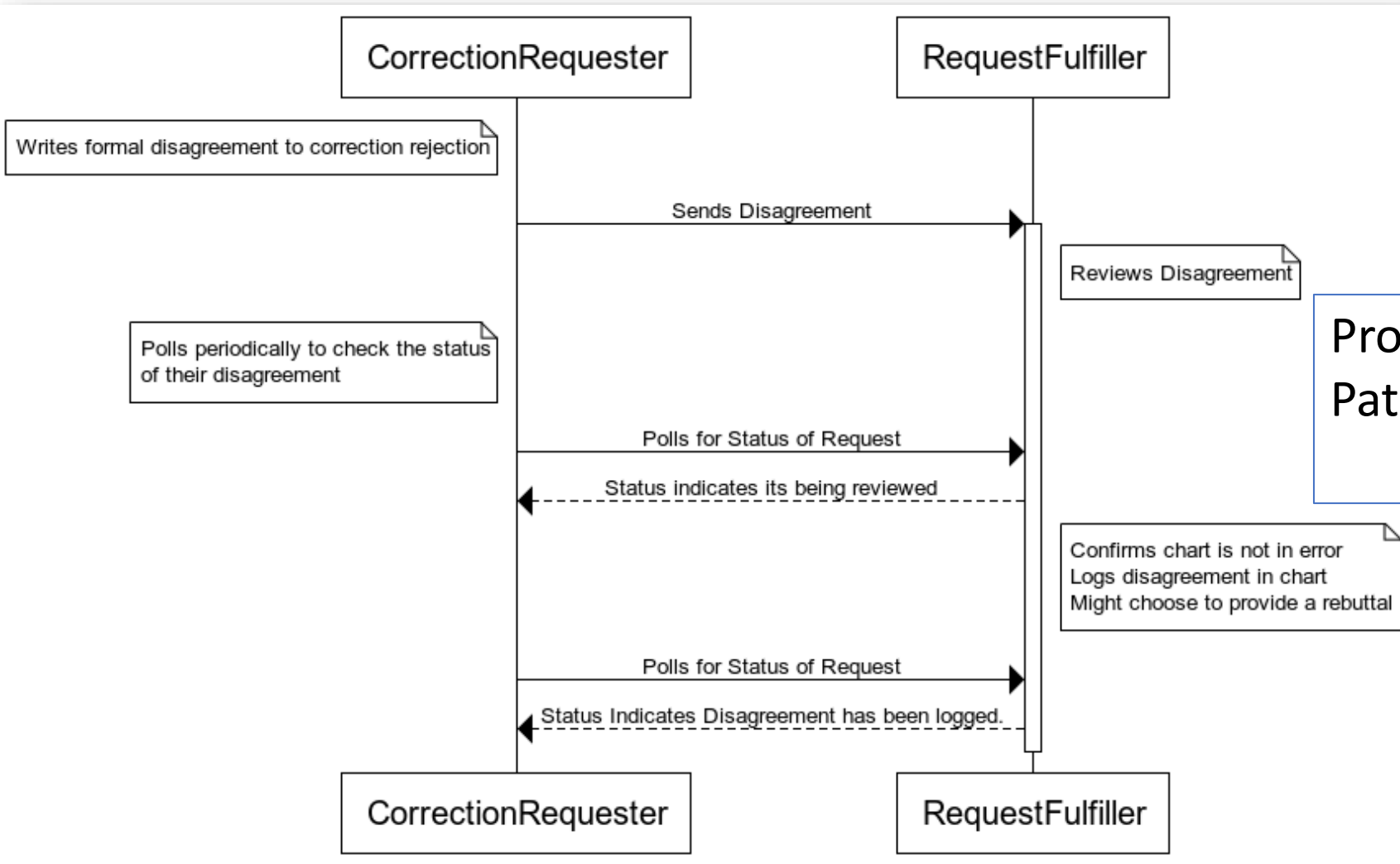
Profile: Patient Correction Request

Scenario 2: Patient Requests a Correction to Their Record and Request is Denied



Profile: Patient Correction Request

Scenario 3: Patient Disagrees With Denial



Profile:
Patient Correction Disagreement

The Patient Disagreement Request Task Profile

If a patient disagrees with a rejection, a new Task is sent with a reference to the previous task.

- Pointer to Request for Correction Task: **Task.reasonReference**

Sign Up Today! Two Steps

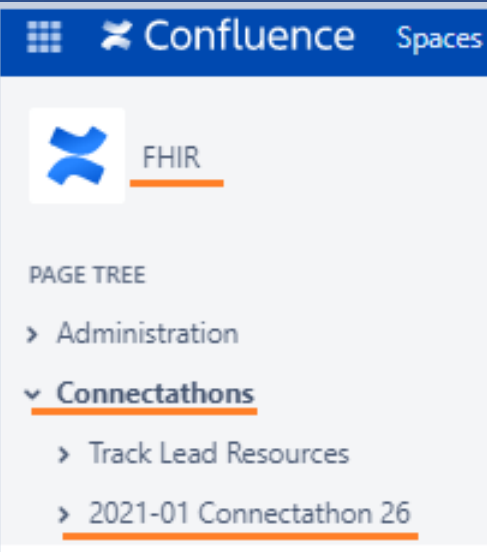
1. Register for the Connectathon:

- By December 31st for Early Bird Rate: \$150 HL7 members, \$250 non-members
- <http://www.hl7.org/events/fhir-connectathon/index.cfm?ref=nav>

2. Sign up for the “Correctathon” Track:

- <https://confluence.hl7.org/display/PE/Connectathon+26+Patient+Request+for+Corrections+Participation+Sign-Up>

Where to sign up for this track:



1. Go to Confluence FHIR page (<https://confluence.hl7.org/display/FHIR/Home>)
2. Go to Connectathons, then 2021-01 Connectathon 26
3. Go to 2021-01 Patient Empowerment track
4. Click link in “Expected participants” row

- 2021-01 Patient Empowerment: Patient Request for Corrections to their

Expected participants

Sign up here: [Connectathon 26 Patient Request for Corrections Participation Sign-Up](#)

Connectathon 26 Patient Request for Corrections Participation Sign-Up

What actor role (if known) will your system play?

- ☐ Patient App
- ☐ EHR
- ☐ Server (non-EHR)
- ☐ Patient Participant
- ☐ Provider Participant
- ☐ Observer

(select all that apply)

Prepare: Our Connectathon Prep Sessions

- **Monday Jan 4th at 3 PM ET**
- **Monday Jan 11th at 3 PM ET**
- **Use this for both sessions:**
 - <https://global.gotomeeting.com/join/322275573>
You can also dial in using your phone.
United States: +1 (872) 240-3212
Access Code: 322-275-573

Prepare: HL7 Connectathon Prep Sessions

- **General: Tuesday December 8th, 4 PM ET Connectathon26 Track Overview**
 - <https://www.youtube.com/watch?v=bo5YDQKLxrY&feature=youtu.be>
- **General: Tuesday December 15th, 4 PM ET Connectathon26 Prep**
 - Register and you will be taken to the recording -
 - <https://register.gotowebinar.com/register/5634777600894062605>
- **General: Tuesday January 12th, 4 PM ET Whova for Connectathon Participants**

Participate: General Connectathon Schedule

Connectathon Schedule

[Correction: dates are 13-15 not 12-14]

Wednesday, January 12, 4:00 PM Connectathon 26 Kick Off
5:00 PM Intro to FHIR

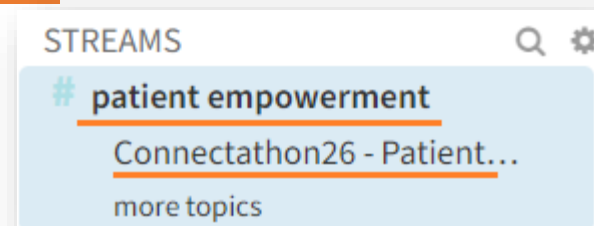
Thursday, January 13, 9:00 AM – 7:00 PM Connectathon

Friday, January 14, 9:00 AM – 4:00 PM Connectathon
4:00 – 4:30 Wrap Up Session
4:30 – 5:30 Virtual Happy Hour

Patient Request for Correction Track Schedule and Logistics

- Track Kickoff: Wednesday, January 13th, 6 PM ET
- Track Work:
 - Thursday, January 14th, 9AM -7PM ET
 - Friday January 15th, 9AM - 5PM ET
- Status Check Ins:
 - Thursday, January 15th 10 AM and 2 PM ET
 - Friday, January 15th 10 AM and 2 PM ET
- Expert Guest Panel: Thursday January 14th, 5 PM ET
- Report Out: Friday, January 15th, 3:30 PM ET
- Connectathon Track Chat:

- <https://chat.fhir.org/#narrow/stream/179262-patient-empowerment/topic/Connectathon26.20-.20Patient.20Request.20for.20Corrections>



Questions?



Additional Information

- **All Details on the “Correctathon” Track can be found here:**
 - <https://confluence.hl7.org/display/FHIR/2021-01+Patient+Empowerment%3A+Patient+Request+for+Corrections+to+their+Record>
- **More Questions?**
 - **Contact us our connectathon chat stream:**
 - <https://chat.fhir.org/#narrow/stream/179262-patient-empowerment/topic/Connectathon26.20-.20Patient.20Request.20for.20Corrections>
 - **Or reach out to the Track Leads:**
 - Debi Willis debi@MyPatientLink.com
 - Virginia Lorenzi vlorenzi@nyp.org