Patient Request for Corrections

A New Track at the HL7 January 2021 Connectathon

January 13th – 15th
Join Us
Thursday 1pm ET
patients@lists.hl7.org

Dashboard
Patient Empowerment Home
Created by Joshua Procius, last modified by Dave deBronkart on May 26, 2020
Mission
Approved Jan 30, 2020
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.

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)

Brought to you by:
The Patient Empowerment Workgroup

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The “right health data” is Really Important

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

BY LAURA LOUGHO

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Errors include outdated data and omissions that many patients could readily identify, including prescription drugs that are no longer taken and incorrect data about frequency or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 2000, according to the federal government, which offers financial incentives to providers tied in part to giving patients access to their health information online.

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 appropriately. 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 researchers 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 opportunity to indicate which meds they were no longer taking, which they were taking differently than described, and which they were removing that wasn’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 medication.
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.”
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.
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:
  o Where the error is found (could be structured or not)
  o Actions requested
  o Reason they want the change (optional)
  o Who they want notified (optional)

• Covered entity must respond within 60/30 days with: Accepted, Denied, Time Extension.
  o 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.
  o 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.
Time Extension and Accepted Requirement

**Request more time:**
- 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:**
- Entity notifies patient the amendment is accepted
- Entity obtains list of who the amendment needs to be shared with
Denied:

- **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.

- The patient may submit a statement of disagreement.
- The entity may prepare a rebuttal and must provide a copy to the individual who submitted the statement of disagreement.
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)
Overview of Guide and Test Plan

Implementation Guide:
- Contains 2 profiles on Task.

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](https://confluence.hl7.org/download/attachments/97456948/Patient%20Request%20for%20Correction%20Test%20Script.docx?api=v2)
## Actors

<table>
<thead>
<tr>
<th>Actor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CorrectionRequester</td>
<td>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.</td>
</tr>
<tr>
<td>RequestFulfiller</td>
<td>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.</td>
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</tbody>
</table>
### Profiles

<table>
<thead>
<tr>
<th>Task Profile</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Correction Request</td>
<td>Used to communicate information about a patient’s request for correction and the associated process</td>
</tr>
<tr>
<td>Patient Correction Disagreement</td>
<td>Used to communicate information about a patient’s disagreement with a correction rejection and the associated process</td>
</tr>
</tbody>
</table>
# The Patient Correction Request Task Profile

## Key Fields - Requester

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

2. Sign up for the “Correctathon” Track:
   • [https://confluence.hl7.org/display/PE/Connectathon+26+Patient+Request+for+Corrections+Participation+Sign-Up](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](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=bo5YDQLxrY&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
## Connectathon Schedule

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>Wednesday, January 12,</td>
<td>4:00 PM</td>
<td>Connectathon 26 Kick Off</td>
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<tr>
<td></td>
<td>5:00 PM</td>
<td>Intro to FHIR</td>
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<tr>
<td>Thursday, January 13,</td>
<td>9:00 AM – 7:00 PM</td>
<td>Connectathon</td>
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<tr>
<td>Friday, January 14,</td>
<td>9:00 AM – 4:00 PM</td>
<td>Connectathon</td>
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<td></td>
<td>4:00 – 4:30</td>
<td>Wrap Up Session</td>
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<td></td>
<td>4:30 – 5:30</td>
<td>Virtual Happy Hour</td>
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**Correction:** dates are 13-15 not 12-14
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:**
Questions?
• 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