# Patient Request for Medical Record Corrections

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**Interoperability Standards Workgroup Meeting**

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# Scope of the Problem

# The Volume and Impact of Errors is Staggering

## Independent studies have found:

- Up to **95%** of medication lists had mistakes[1]
- **84%** of progress notes contained at least one documentation error[2]
- An average of **7.8 documentation errors per patient**[2]
- Errors and gaps in patient records may lead to medical errors. Medical errors are the **3rd leading cause of death** in US[3].

[1] https://www.wsj.com/articles/health-care-providers-want-patients-to-read-medical-records-spot-errors-1402354902
[2] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3797550/
[3] https://www.hopkinsmedicine.org/news/media/releases/study_suggests medical_errors_now_third_leading_cause_of_death_in_the_us

*"If we don't have accurate data **we can't take care of patients appropriately**," says Jonathan Darer, CIO at Geisinger. According to Darer, the aim is to move patients and doctors into a relationship of "**shared accountability**" and more effective medical care.*

[4] https://www.healthitoutcomes.com/doc/providers-encourage-shared-accountability-with-patients-0001

# Common Types of Errors in Patient Records

- Prescription & OTC medication inaccuracies:
  - An incorrect or outdated dosage(s) of prescription medicine(s)
  - Duplicate entries for prescriptions for brand-name and generic medications
  - OTC medications, vitamins, or supplements aren't listed
  - Incomplete or missing information about medication allergies
- Erroneous information about treatment outcomes
- Missing lab and pathology results
- Medical history & details about symptoms are missing or incorrectly noted
- Diagnoses are incorrect
- Missing information or updates from another provider
- Inaccurate patient demographics and social determinants of health
- Copying and pasting errors from previous visit notes & perceived errors

[1] https://www.wsj.com/articles/health-care-providers-want-patients-to-read-medical-records-spot-errors-1402354902

# OpenNotes Study: Frequency and Types of Patient-Reported Errors in EHR Ambulatory Care Notes

- **29,656** patients responded to survey
- **1 in 5** patients reported finding a mistake in their note
- **40%** perceived the mistake as **serious or very serious.**

Errors most commonly reported by patients as "very serious":

- incorrect or missing diagnoses
- medical history
- medications
- physical examination
- test results
- **wrong patient**
- **wrong sidedness**

[5] https://www.opennotes.org/research/frequency-and-types-of-patient-reported-errors-in-electronic-health-record-ambulatory-care-notes/

*The findings suggest that **inviting patients to report perceived mistakes in shared visit notes**, particularly those that patients believe are **very serious**, may be associated with **improved record accuracy** and **patient engagement in diagnosis.** **Developing efficient mechanisms to respond to such reports appears to be important.***

[5] https://www.opennotes.org/research/frequency-and-types-of-patient-reported-errors-in-electronic-health-record-ambulatory-care-notes/

# Inequity: Errors have greater impact on the most vulnerable

**Minorities or those with poorer health are less likely to speak up** to report errors

*"Participants who self-identified as Black or African American, Asian, "other," or "multiple" races, or those who reported poorer health were each less likely to speak up than White or healthier respondents."*

The most common barriers to speaking up were:

- not knowing how to report a mistake (61%)
- avoiding perception as a "troublemaker" (34%)

[6]https://academic.oup.com/jamia/article/28/4/685/6046150

*Patient records often have **mistakes** or are **missing sections of care**, which can result in **repeated or unnecessary tests and procedures** and make patients feel like they're playing a game of telephone with their providers.*

[7]https://www.healthit.gov/sites/default/files/playbook/pdf/ONC-Records-Request-Research-Report.pdf

# Problem is More Visible & More Widespread

- Information Blocking Rules are enabling more seamless access to patient data and health information.
- Patients, carepartners, and advocates are now able to see significant errors that could negatively impact care.
- Chaos ensues where standardized processes are not in place.
- There is an **urgent need for a standardized process for patients to request corrections** now more than ever.

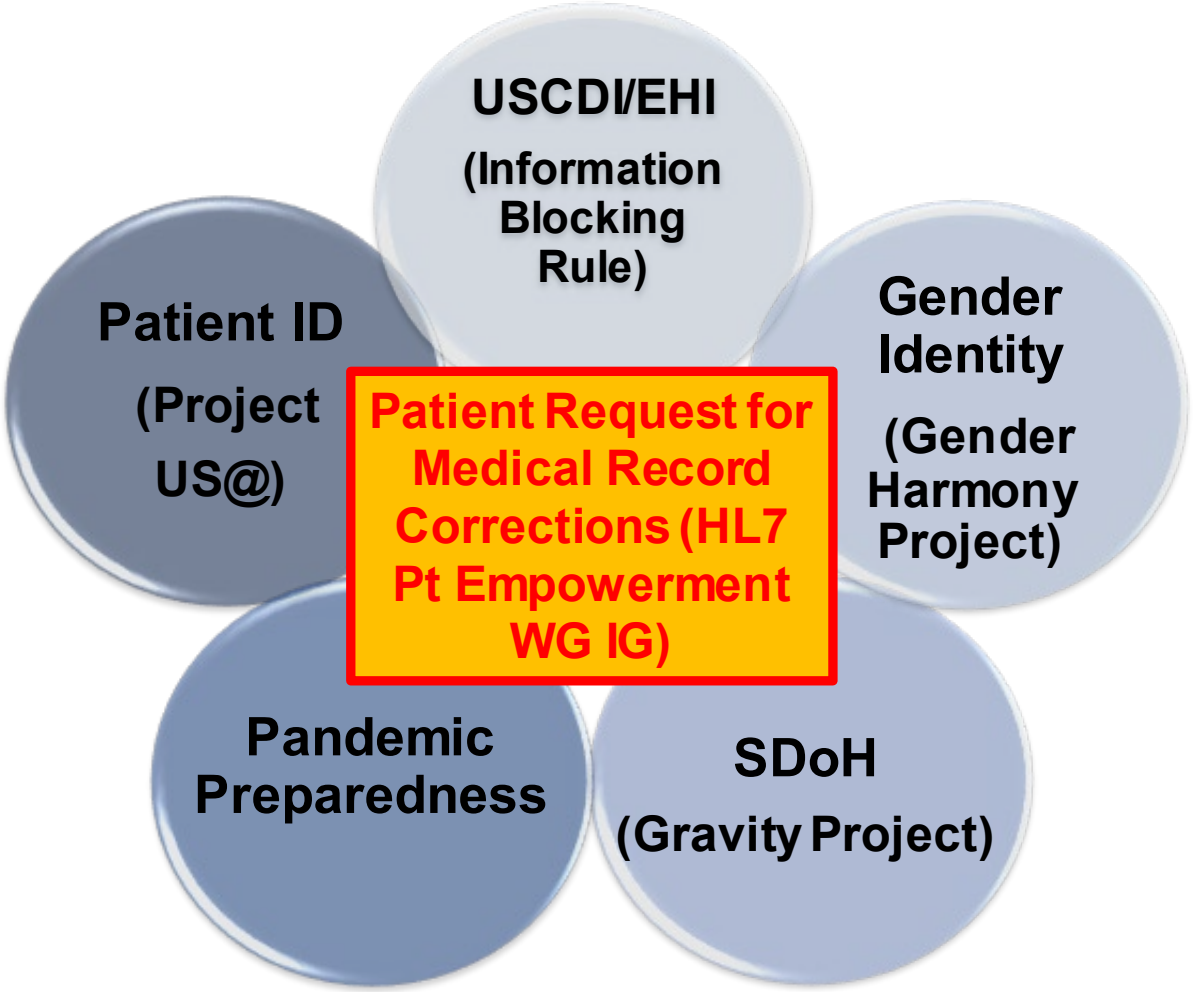
*"[65% of patients reviewing the volume of errors recommended]* ***reporting mechanisms include clear instructions about how to report a mistake*** *and* ***whom to report the mistake to****. Most participants wanted to report mistakes* ***online*** *using a fast and easy instrument and many preferred an* ***objective third-party reviewer*** *other than their own doctor. In addition to the convenience of online reporting, some respondents noted that* ***asynchronous reporting*** *was less anxiety-provoking."*

[6] https://academic.oup.com/jamia/article/28/4/685/6046150

# Data Integrity: Use of EHR Data in Research

- With the advancement of FHIR, many research organizations, including Public Health, are increasing their use of EHR data.
- Unless we provide an easy way for patients to make sure their data is correct, researchers will be using poor quality data.
- Research using **poor quality data** will result in **poor quality research,** eroding trust in health information technology and research in health care and public health arenas.


Data
Integrity,
Research, &
Public
Health


USCDI/EHI
(Information Blocking Rule)
Patient ID
(Project US@)
Gender Identity
(Gender Harmony Project)
Patient Request for Medical Record Corrections (HL7 Pt Empowerment WG IG)
Pandemic Preparedness
SDoH
(Gravity Project)

# POLICY LEVERS

# ONC Correction Principle (2008)

In its "Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information", ONC adopted the following principle on "Correction":

> *"Individuals should be provided with a timely means to dispute the accuracy or integrity of their individually identifiable health information (IIHI), and to* ***have erroneous information corrected or to have a dispute documented if their requests are denied.***"

[8] https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/correction.pdf

# 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.

> *"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. The covered entity must act timely, usually within 60 days, to correct the record as requested by the individual or to notify the individual the request is denied."*

[9] https://www.ecfr.gov/current/title-45/subtitle-A/subchapter-C/part-164/subpart-E/section-164.526
[8] https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/correction.pdf

*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.*

[8] https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/correction.pdf

# Health IT Policy Committee (2011)

- In 2011, the Health IT Policy Committee was tasked to give recommendations that will help **build public trust in health information technology** and electronic HIE and enable their appropriate use to **improve healthcare quality** and **efficiency**.
- Health IT Policy Committee recommended to ONC that they **establish certification criteria** to enable the HIPAA request for correction/amendment process[10].

[10] https://www.healthit.gov/sites/default/files/facas/07_25_11_HITPC_Letter_PrivSecTigerTeam.pdf

# 2015 Edition Health IT Certification Criterion

§ 170.315(d)(4) (Amendments) states:

- Enable a user to select the record affected by a patient's request for amendment and perform the capabilities specified in paragraph (d)(4)(i) or (ii) of this section.
- For an accepted amendment, append the amendment to the affected record or include a link that indicates the amendment's location.
- For a denied amendment, at a minimum, append the request and denial of the request in at least one of the following ways: (A) To the affected record. (B) Include a link that indicates this information's location.

[11] https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base

[12] https://www.healthit.gov/sites/default/files/170%20315%28d%29%284%29%20Amendments.pdf

# Current Ability to Access vs. Ability to Correct

## Access Electronic Health Information

- Standards based
- Modern technology – RESTful API
- Interactive – innovative personal health record functionality designed for ease of use
- Scalable across multiple settings

## Request a Correction (current state)

- No standards-based processes
- Labor intensive, low tech workflows
- Outside of current EHR workflow
- Not interactive or scalable
- Lack of continuity & fragmentation throughout

Interoperability mandates are improving the sharing of data between organizations.

Consequently, **errors getting shared and propagated** at an increasing rate.

# HL7 Patient Empowerment Workgroup: Patient Request for Corrections Project

**Project Leads:** Debi Willis and Virginia Lorenzi

**Began:** Summer 2020

**4 Connectathons:** January, May, Sept 2021, Jan 2022

- Strong feedback received on draft IG testing different resources
- IG balloted in May 2022 and is under reconciliation
- Currently have input from FHIR-I, Epic, Allscripts, and several other HL7 workgroups & members; Need more EHR involvement & policy support
- The Netherlands has mandated patient request for corrections be available by FHIR https://informatiestandaarden.nictiz.nl/wiki/MedMij:Vpoc/FHIR_Patient_Corrections

# RECOMMENDATIONS

# Recommendations for ISA

## ISA Structural Recommendations:

- Change “Specialty Care & Settings” menu to “Use Cases”
- Include Patient Request for Corrections as an ISA Use Case for standards development and implementation

## ISA Global Recommendations:

- Recognize that the HIPAA “right to request corrections to one’s medical records” Use Case broadly applies to all information in the designated record set and all EHI
- Encourage ONC to establish certification criteria to enable the HIPAA request for correction/amendment process via patient access FHIR API
    - FHIR resources exist that can be used to implement bi-directional communication.

# Recommendations for ISA

- Ensure that patients, at minimum, can make their corrections through the patient access API for all data available through the API
- ONC to collaborate with the HL7 Patient Empowerment Workgroup to help address gaps in standards, capabilities, and implementation of Patient Request for Medical Record Corrections

## ISA Granular Recommendations:

- Services/Exchange: Add Patient Request for Corrections to "Consumer Access/Exchange of Health Information" and corresponding terminology and exchange standards, where applicable
- Administrative: Add Patient Request for Corrections to "Administrative Transactions to Support Clinical Care" and corresponding terminology and exchange standards, where applicable

# QUESTIONS?

# JOIN US!

## Project Leads: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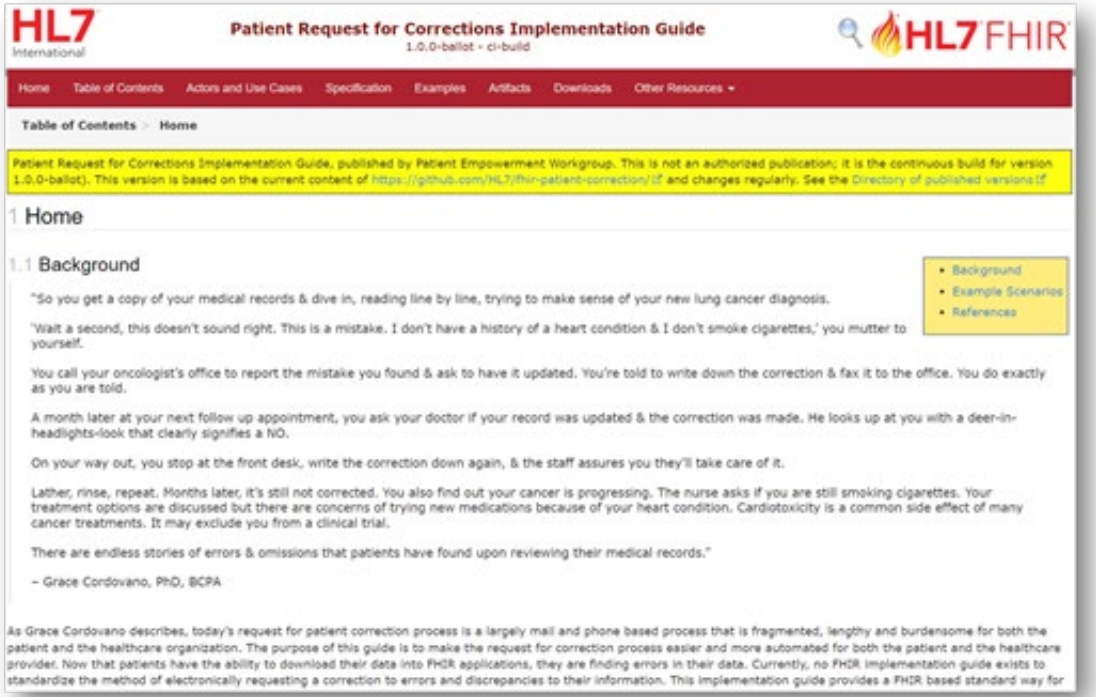

HL7 International

Patient Request for Corrections Implementation Guide

1.0.0-ballot - ci-build

HL7 FHIR

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Patient Request for Corrections Implementation Guide, published by Patient Empowerment Workgroup. This is not an authorized publication; it is the continuous build for version 1.0.0-ballot). This version is based on the current content of https://github.com/HL7/fhir-patient-correction/ and changes regularly. See the Directory of published versions

1 Home

1.1 Background

- Background
- Example Scenarios
- References

"So you get a copy of your medical records & dive in, reading line by line, trying to make sense of your new lung cancer diagnosis.

'Wait a second, this doesn't sound right. This is a mistake. I don't have a history of a heart condition & I don't smoke cigarettes,' you mutter to yourself.

You call your oncologist's office to report the mistake you found & ask to have it updated. You're told to write down the correction & fax it to the office. You do exactly as you are told.

A month later at your next follow up appointment, you ask your doctor if your record was updated & the correction was made. He looks up at you with a deer-in-headlights-look that clearly signifies a NO.

On your way out, you stop at the front desk, write the correction down again, & the staff assures you they'll take care of it.

Lather, rinse, repeat. Months later, it's still not corrected. You also find out your cancer is progressing. The nurse asks if you are still smoking cigarettes. Your treatment options are discussed but there are concerns of trying new medications because of your heart condition. Cardiotoxicity is a common side effect of many cancer treatments. It may exclude you from a clinical trial.

There are endless stories of errors & omissions that patients have found upon reviewing their medical records."

– Grace Cordovano, PhD, BCPA

As Grace Cordovano describes, today's request for patient correction process is a largely mail and phone based process that is fragmented, lengthy and burdensome for both the patient and the healthcare organization. The purpose of this guide is to make the request for correction process easier and more automated for both the patient and the healthcare provider. Now that patients have the ability to download their data into FHIR applications, they are finding errors in their data. Currently, no FHIR implementation guide exists to standardize the method of electronically requesting a correction to errors and discrepancies to their information. This implementation guide provides a FHIR based standard way for

**Details:** https://build.fhir.org/ig/HL7/fhir-patient-correction/index.html