Patient Request for Medical Record Corrections

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Interoperability Standards Workgroup Meeting
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Scope of the Problem
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.
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  - An incorrect or outdated dosage(s) of prescription medicine(s)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

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**

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.**

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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%)

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.

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.”

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
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.**”

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

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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.

8https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/correction.pdf
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.\(^\text{10}\)

\(^{10}\)https://www.healthit.gov/sites/default/files/facas/07_25_11_HITPC_Letter_PrivSecTigerTeam.pdf
§ 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.

12https://www.healthit.gov/sites/default/files/170%20315%28d%29%20Amendments.pdf
## Current Ability to Access vs. Ability to Correct

<table>
<thead>
<tr>
<th>Access Electronic Health Information</th>
<th>Request a Correction (current state)</th>
</tr>
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<tbody>
<tr>
<td>• Standards based</td>
<td>• No standards-based processes</td>
</tr>
<tr>
<td>• Modern technology – RESTful API</td>
<td>• Labor intensive, low tech workflows</td>
</tr>
<tr>
<td>• Interactive – innovative personal health record functionality designed for ease of use</td>
<td>• Outside of current EHR workflow</td>
</tr>
<tr>
<td>• Scalable across multiple settings</td>
<td>• Not interactive or scalable</td>
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<tr>
<td></td>
<td>• Lack of continuity &amp; fragmentation throughout</td>
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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 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!

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