

Patient Requested Restrictions

ONC's Proposal in HTI-1

HIPAA provides patients the right to *request* restrictions of certain uses and disclosures.

ONC's proposed "patient requested restrictions" in HTI-1 would require developers of certified health information technology to create functionality:

1. For a patient to **make a request to restrict data** through an Internet-based method (e.g., via patient portal).
2. [If approved,] for a user (e.g., providers, HIM staff) to **flag restricted data**.
3. **Prevent flagged data from being included in subsequent use or disclosure.**

Data Segmentation

Limiting the use or disclosure of sensitive patient data.

Data Segmentation

Limiting the use or disclosure of sensitive patient data.








Data Segmentation

Limiting the use or disclosure of sensitive patient data.





Medication Warnings for Amberley, Mary

New Warnings (1 unfiltered, 1 filtered) ☐ Show filtered (1)

 Drug-Drug: lithium and lisinopril Pharmacologic effects of lithium may be increased by ACE inhibitors. Elevated lithium serum concentrations with toxicity may occur. Details	<input type="text" value="Override reason"/>   <input type="button" value="Don't Show This Warning Again"/>	lisinopril (PRINIVIL,ZESTRIL) 10 mg tablet  Prescription. New. Long-term. <input type="button" value="Remove"/>	lithium (ESKALITH) 450 mg CR tablet  Prescription. Active. Long-term. <input type="button" value="Discontinue"/>
--	--	--	---

Immediately override all warnings:

☒ Overall override reason  

Data Segmentation

Limiting the use or disclosure of sensitive patient data.



CLINICAL CONCERNS

CARE TEAM MISSING DATA



Maria requested restrictions on her reproductive health information, including her pregnancy. Her OB/GYN agrees.

During pregnancy, she develops gestational diabetes. Other **members of her care team, such as her endocrinologist and PCP, are unable to see this important information.**

CLINICAL CONCERNS

DRUG-DRUG INTERACTIONS

Sally chooses to restrict use and disclosure of her mental health information, including the SSRI she takes to treat depression.

Because of her hx of OUD, her surgeon prescribes an antidepressant off-label post-op as part of pain management to avoid opioids.

She may receive too high a dose and be at risk for serotonin syndrome.



CLINICAL CONCERNS

PREVENTABLE HARM

Jose has previously placed a restriction on his cardiology information. He arrives at an urgent care facility and is prescribed Levaquin for community-acquired pneumonia.

The provider doesn't receive a drug-interaction warning that could cause QT prolongation, putting Jose at **risk of a fatal ventricular arrhythmia**.

In addition to the safety risk, **the provider loses trust in the EHR**.



CLINICAL CONCERNS

INAPPROPRIATE MEDICAL PROCEDURES

Marcus is sensitive about his use of semaglutide to lose weight and restricts that information. This drug slows gastric emptying.

His surgical team is unaware of that prescription and doesn't take appropriate precautions prior to surgery to prevent **pulmonary aspiration**.

Approximately 5 million people were prescribed semaglutide in 2022.



STAFF IMPACT

UNEXPLAINABLE BEHAVIOR



Racquel's OB/GYN prescribes an antidepressant off-label to treat premenstrual symptoms. Racquel has previously requested that her mental health information be segmented, and antidepressants are automatically siloed.

After signing the prescription, it immediately “disappears” from view, confusing the provider.

A pharmacist dispensing the antidepressant may also be restricted from checking drug interactions.

STAFF IMPACT

BURDEN OF TAGGING DATA



Misoprostol is commonly used in chemical abortions, but it is also FDA approved to prevent NSAID-induced ulcers.

There is no algorithm to reliably categorize data. Every time a provider documents in the chart, they must discretely tag “why” that information is entered to ensure segmentation is accurate.

Clinicians using Epic document 200,000 allergies, 1,260,000 problems, and 85 million orders **weekly**.

STAFF IMPACT

UNDERMINING EVIDENCE-BASED DECISION SUPPORT



The proposed rule will **weaken the application of evidence-based decision support** that makes recommendations to avoid preventable harm.

Last year, decision support alerts of a contraindication led clinicians using Epic to **change their planned care 75 million times.**

STAFF IMPACT

BURDEN OF REDACTING DATA

A patient has asked their provider, Dr. Smith, to restrict uses and disclosures of their information relating to alcohol dependency.

Dr. Smith now must go through all her notes regarding the patient and look for information that could relate to their alcohol use. **This process takes significant time.**



STAFF IMPACT

CONFUSION



With interoperability, each vendor will use different rules to silo data. Data will be restricted inconsistently.

Patients will perceive this as broken promises.

Providers will be confused by the inconsistency.

PATIENT IMPACT

BROKEN PROMISES

Roy has a hx of OUD and is being prescribed a controlled substance. He's previously chosen to have his SUD information restricted.

His provider checks the state PDMP, which is not certified HIT and therefore does not comply with his request to segment data.

His provider receives information that Roy had been promised would be kept restricted,
decreasing his trust in the healthcare system.



PATIENT IMPACT

INFERRED DATA

A patient has asked to restrict HIV from their problem list.

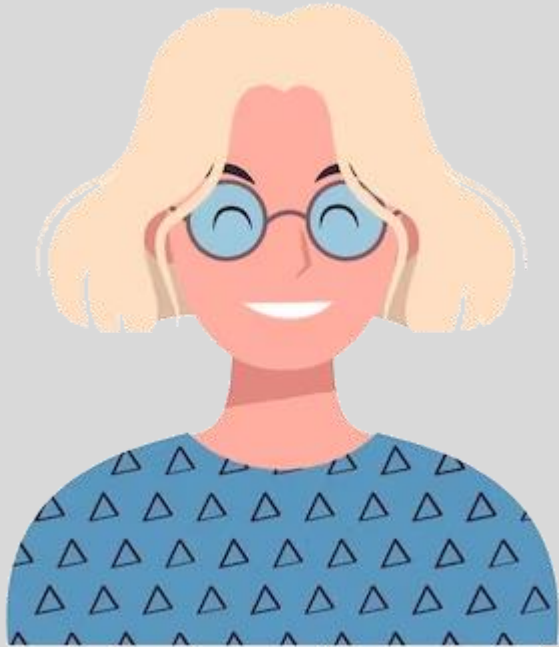
Their medication list still includes maraviroc, a medication used with other antiretrovirals to treat HIV infection. Even though the problem entry was hidden, **a physician can still infer their HIV status.**

Hiding the medication would be unsafe because it can cause hepatotoxicity and interacts with 100+ other medications.



PUBLIC SAFETY

EMPLOYMENT CHECKS



Margaret has restricted her hx of epilepsy. She's seeking employment as a commercial pilot, and during her physical, her physician is unaware of the restriction and cannot accurately assess her physical fitness as outlined by the FAA.

This puts the public at risk of harm.

NON-CLINICAL PROBLEMS

PUBLIC HEALTH



Dr. Joy, a public health physician, is investigating an infectious disease outbreak.

Because patients have restricted their data, she cannot evaluate the geography and socioeconomic status of affected citizens.

As a result, **public health resources are not equitably allocated, and disparities are increased.**

PUBLIC SAFETY

HEALTH DATA AGGREGATION

Stephen receives the mpox vaccination, as indicated by his recent sexual activity. He asks for that information to be restricted, and his provider agrees.

His provider can no longer report these immunizations to state vaccination registries.

When vaccinations aren't reported, **policymakers lack critical data about public health.**



UNSTRUCTURED DATA INFEASIBLE TO FILTER

Discrete data uses codes to structure information.

Narrative information, such as notes, comments, and medication instructions are not discrete. These data are unstructured, and it will be infeasible to build algorithms that reliably identify whether they match the filtering criteria.

The result will be even more manual labor by healthcare staff to review and redact information.

LIMITED REACH OF ONC RULE

ONC jurisdiction is limited to certified systems. Many other systems have patient data: insurer, pharmacy, patient-facing apps.

If ONC's goal is to protect patients' privacy, then this rule will be ineffective because of how many other places hold patient information.

EPIC'S PROPOSED SOLUTIONS

The issue **cannot be solved through technical standards alone.**

In finalizing its proposal, ONC should:

1. Advance point-of-care authorization to **empower patients** to choose with whom they'll share their chart.
2. Add certification requirements for **segmentation of sensitive notes.**
3. **Granular controls on proxy access** in patient portals.