



Documenting ICD Codes and Other Sensitive Information in Electronic Health Records:

Guidelines For Healthcare Professionals Who Encounter Patients With A History Of Human Trafficking Or Other Forms Of Violence

JANUARY 2021

Contributing Authors and Reviewers: Jordan Greenbaum, MD, International Centre for Missing and Exploited Children/Children's Healthcare of Atlanta; Robert C. McClure, MD, MD Partners, Inc., Scott Stare, MBA, PMP, Office of Minority Health, Centers for Medicare and Medicaid Services; Wendy Barnes, CommonSpirit Health; Claire E. Castles, Jones Day; Elise R. Culliton, Jones Day; Holly Austin Gibbs, CommonSpirit Health; Ashley Garrett, National Human Trafficking Training and Technical Assistance Center; MaryBeth Burrell, RN, MS, CommonSpirit Health; Hanni Stoklosa, HEAL Trafficking.

Introduction

In 2018, the Centers for Disease Control and Prevention adopted new ICD codes to describe human trafficking (HT). These specific HT codes allow healthcare professionals and others to optimize continuity of care for trafficked persons, determine health needs and effective treatments for HT-related health conditions, track cases of HT to assist in ensuring adequate resources are provided to communities, and inform local and national prevention and intervention policies. However, in some cases use of violence-related codes (e.g., HT, intimate partner violence, child sexual abuse) could pose a threat to patient and staff safety, and patient confidentiality. In response to these and other concerns, the International Centre for Missing & Exploited Children (ICMEC), HEAL Trafficking and the HHS Office on Trafficking in Persons (OTIP) co-hosted a national convening to discuss the safe use of the codes. The convening was facilitated by the National Human Trafficking Training & Technical Assistance Center (NHTTAC) and attended by those with lived experience of human trafficking, healthcare professionals (HCPs) and representatives from healthcare organizations, key government agencies, the technology industry, and non-governmental organizations.

The following guidelines were developed by a subcommittee of stakeholders, including survivors of labor and sex trafficking, and were written to reflect a trauma-informed, rights-based approach (please see Resources at the end of this document for information on trauma-informed care). The guidelines aim to educate HCPs about how to work with trafficked/exploited/abused patients when making decisions about use of ICD codes and documentation of sensitive information in the electronic health record (EHR).

The information in these guidelines may be used to develop a short HCP learning module on EHR documentation or be embedded within existing general presentations on human trafficking and other types of violence. Much of the information below may already be covered in training materials addressing a trauma-informed approach.

Please note: Healthcare systems, facilities, and HCPS are strongly advised to have their legal counsel review the use and application of any recommendations provided in this document.

The section titled, "Background Information for HCPs" includes essential information and tips for HCPs, and provides the clinician with a foundation of knowledge on which to draw when determining how to engage a particular patient in a discussion of documentation. It is NOT intended to be a list of items that an HCP <u>must</u> discuss with each and every patient. Flexibility is the key: *The depth and detail of conversations with patients about documentation will necessarily vary, based on the patient's developmental level and emotional state, and the clinical context.* Following the section on "Background Information" is a series of sample scenarios with scripts that demonstrate potential ways of responding to a variety of situations involving documentation of sensitive information and mandatory reporting.

Background Information for Healthcare Professionals (HCPs)

In order for HCPs to effectively work with their patients regarding documentation issues, healthcare facility support is needed. This includes implementing protocols/guidelines for human trafficking, providing support for compliance with guidelines and ensuring adequate time and resources are available to clinicians.

For additional information about the ICD-10-CM codes for classifying labor and sex trafficking among children and adults, please see the American Hospital Association (AHA) factsheet titled, *ICD-10-CM Coding for Human Trafficking*. In short, the ICD codes include classifications for confirmed or suspected cases of labor or sex trafficking among adult or child patients, as well as encounters for examinations and observations of victims following trafficking and a personal history of trafficking or exploitation. For additional information about human trafficking or related terms, and the need for ICD codes defining human trafficking, please see the Resources section at the end of this document.

There are several conditions under which sensitive health information may be accessed by persons outside of the immediate healthcare team:

- Patient portal (proxy or other person [e.g., trafficker] may have access to portal)
- After visit summaries (may be viewed by trafficker or others)
- Explanation of benefits documents (may be viewed by trafficker or others)
- Access to information by
 - Billing and coding staff
 - Insurance company staff
 - Professionals with access to information obtained through releases e.g., disability claims, legal subpoenas
 - Other care providers with access to EHR information, but whom the patient may not wish to have knowledge of the sensitive information (e.g. patient wants to share with some of their clinicians, but not with all)

 There may be inadvertent exposure of sensitive information during a visit (e.g., companion of patient sees the computer screen as a clinician is entering information; companion of patient overhears conversations between clinicians)

Health systems need to promote compliance with applicable law, policy and procedure and to employ trauma-informed care practices to protect the confidentiality of all sensitive health information, including ICD codes and references to risk factors, indicators and presence of human trafficking (HT) and other forms of violence, and other sensitive information that may be associated with the exploitative experience (e.g. medications, current or past history of substance abuse, pregnancies and abortions). Operational flexibility and innovative strategies built into EHR systems may further protect patient confidentiality. An example of such a strategy involves data segmentation, whereby specific types of clinical information are given restricted access. All HCPs need to be trained on, and thoroughly familiar with, confidentiality protection strategies in order to maximize compliance.

Healthcare professionals need to be familiar with the policies and procedures, software capabilities, and other strategies employed at their facility to protect sensitive information and make use of these strategies when appropriate.

No one should be accessing EHR materials if such access is not required for the staff member to perform their roles and responsibilities. Those accessing EHR materials must be extremely vigilant about privacy of this information.

Providers should document complete and accurate information needed to support medical decision making and treatment, while also considering and respecting patient's desires/preferences related to how sensitive information is documented. (Legal and administrative policies or the professional judgment of the practitioner may dictate decisions, however.)

The bottom line

A practitioner cannot guarantee and does not have absolute control over who may access confidential information with any of the commonly used EHR strategies. Even sophisticated protection systems may be designed to allow sensitive information to be shared on the patient portal or to outside actors (e.g. payors, legal) and to medical staff pursuant to applicable law or policy. **Patients need to know about this limitation, and about use of ICD codes** so they can make informed decisions about the sensitive information they share. When deciding on the approach to patient confidentiality in use of ICD codes and inclusion of sensitive information in the records, the provider should consider three basic tenets of trauma-informed care:

The depth of conversation about documentation needs to be feasible, relevant, and appropriate to the patient and context. 1. Safety of the patient from harm by those gaining access to information in the record. Failure to document may also pose a risk to patient safety in that future providers may lack important information to guide treatment and referrals.

2. Respect for the patient's autonomy, as well as their concerns and wishes regarding confidentiality, in the context of their culture and history of trauma.

3. Informed consent: patients need counseling on how their health information is created, protected, handled, maintained, and accessed. Patients need to be empowered to participate in making decisions about documentation (under the limits of relevant laws/policies). This counseling also provides further opportunity to build trust between the patient and practitioner

and may encourage the patient to continue to access necessary care and resources. The following list of 'pros' and 'cons' regarding documentation of sensitive information is helpful for an HCP to know, but it is not expected that they will review each of these items with a patient. Again, the depth of conversation about documentation needs to be feasible, relevant, and appropriate to the patient and context.

Important considerations and affirmative need for including sensitive information in the EHR:

Patient factors

Documentation of relevant sensitive information helps to ensure continuity and optimization of the patient's care with future clinicians. It may assist providers in obtaining relevant resources for the patient now and in the future, as patient needs change. Appropriate documentation may help keep the patient (as well as staff and visitors) safe in the hospital if there are concerns that the trafficker/abuser will come to find them. Finally, it helps HCPs to recognize the prevalence of HT, which can help decrease bias and stigmatization, especially among disenfranchised populations (e.g., transgender).

Criminal justice factors

Documentation of information may help with an investigation, especially if the trafficked/abused person chooses to seek criminal justice in the future.

Resources

Tracking patients who have been trafficked or abused helps to ensure that the local community has data to support requesting the resources they need to serve these populations. The government needs to know where trafficking and other types of violence occur in order to direct resources appropriately.

Epidemiology

Research and epidemiology will lead to improved access to, and quality of care for populations that are disenfranchised/under-recognized.

Key concerns regarding inclusion of sensitive information in the EHR:

Patient factors

- If information appears in the patient portal, a proxy (typically the guardian) or trafficker/abuser may obtain access to the information and may harm the patient.
- Staff reading sensitive information may exhibit bias/discrimination in their treatment of the patient.
- A patient may feel shame or other negative emotions regarding the information. This may be exacerbated if an HCP mentions some sensitive information to the patient in a manner that seems abrupt, unexpected, or out of context.
- Ability for the information to be used against a patient in a legal proceeding (e.g., child custody hearing, criminal case, immigration proceeding.)
- Information may be used by the trafficker to blackmail, threaten or otherwise manipulate the patient.

Given the unique limitations and features of each EHR system, providers need to understand and consider confidentiality limitations prior to documenting sensitive information that may not be redacted in the future. Providers should keep in mind that ICD codes and other forms of documentation allow for occasions when the provider is not certain HT or other types of violence have occurred. They can indicate 'suspected' or even indicate their level of concern in a note (mild, moderate, strong).

Patient Concerns:

- Harm by trafficker
- Shame, stigma
- Discrimination by staff
- Legal ramifications

In some situations, it may be possible to convey necessary information to future providers using text that is less specific and worrisome to the patient. Some examples include:

- Use of an abbreviation (preferably one known to coders and other clinicians): HT: human trafficking; CST: child sex trafficking; CSEC: commercial sexual exploitation of child, CSA-child sexual abuse; DV/IPV-domestic violence/intimate partner violence.
- "There are multiple vulnerabilities for labor/sex HT, high level of concern"
- "Risk factors for exploitation discussed and resources offered; recommend f/u with further discussion and resources in future"
- "Administered HEA<u>DS</u>S screen and discussed positive components (underlined), with resources provided."

Documentation of sensitive information is only one aspect of the comprehensive care needed to support these patients. The information in this document should be linked to response protocols and resources to support clinicians' understanding and familiarity with processes to recognize and to respond to suspected trafficking/exploitation/violence using a trauma-informed approach.

- Prioritizing patient safety first. If a provider decides to document information about trafficking/exploitation/other violence in the record, they need to make sure there is a proactive documentation plan in place that maximizes patient safety, including security and confidentiality protocols.
- If the clinician is mandated to report suspected trafficking or abuse but does not know much about what will happen after police or child/adult protective services are notified, they may consider consulting staff members with relevant expertise (e.g., social workers), who are familiar with interdisciplinary collaboration in child/adult protection situations. Consultation with social workers is extremely helpful even if reporting is not mandated, given the knowledge and experience of these professionals in working with outside agencies and organizations.

Sample Scenarios

Following is a series of sample scripts and scenarios for HCPs to consider when documenting ICD Codes and other sensitive information.

Remember, this conversation should be sensitive to the patient's level of stress and developmental capabilities. It may range from a comprehensive conversation of options to a brief discussion with only essential information shared with the patient, with the HCP making some or all decisions on their own about documentation. The depth of conversation about documentation needs to be feasible, relevant, and appropriate to the patient and context.



SCRIPT 1

At the beginning of the conversation with a lucid adult/child patient able to engage in conversation:

"Usually, I include many of the things we talk about in your health record so other healthcare providers can best care for you in the future, or in case you need this information in the future. This includes sensitive information if it is relevant to your health. While the clinic/hospital does its best to keep records confidential so that only staff who are helping to care for you have access, there are certain circumstances where others may gain access so I cannot guarantee that no one else will ever see your record. If there is something sensitive you'd like to tell me but you don't want it in your record, we can talk about it. Do you have any questions about this?"

SCRIPT 2

At the beginning of the conversation with a lucid adult/child patient when mandatory reporting laws apply:

Summarize text in Script 1 and add, *"In addition, if you tell me that you may hurt yourself or someone else, or that someone else has, or may hurt you or your children, I'll need to contact other professionals so they can help me to help you. Do you have any questions about that?"*



SCRIPT 3

After the clinician has completed the history and sensitive information has been disclosed by a lucid adult/child patient:

"We've talked about a lot of important things that can affect your health now and in the future. Is there anything we've discussed that you do not want documented in your health record?"

Patient says "No." Clinician moves on to next step of routine care.

SCRIPT 4

• • •

After the clinician has completed the history and discussed the patient's possible exploitative situation, the patient tells you s/he does not want any information about human trafficking included in the record:

Important Points for the HCP to remember regarding documentation in the EHR:

- This conversation should be sensitive to the patient's level of stress, and their developmental capabilities. It may range from a comprehensive conversation of options, to a brief, 'bare-bones' discussion of any key items the patient wants to omit from documentation, with the provider needing to make some decisions on their own about documentation.)
- If there is a legal or policy requirement to document certain information, or you believe it is essential for continuity of care, you need to explain this to the patient. Transparency is critical.
- Discuss options and respect the patient's desires as much as possible while protecting patient safety and health and complying with relevant laws.

Clinician says, "As we discussed a little while ago, I'll need to include some documentation of your visit in the health record so providers you have in the future will be better able to care for you. The hospital/clinic tries hard to keep your records private, accessible only to those who provide care or otherwise are involved with your health services. Your records are not available to just anyone, and certainly not posted on social media. I hear your concerns about documenting our discussion of exchanging sex for drugs, but I'd like to understand more. What do you fear will happen if this information is included in your health record? What worries you the most about this?"

Patient explains fears, which clinician may or may not be able to allay.

Then provider says, "I see. Well, let's look at our options. I think it's important for your primary care doctor to know that you may need frequent testing for HIV and sexually transmitted infections, that you may have concerns about drug use and that you may have had some pretty difficult experiences trying to survive when living on the streets. Your experiences can affect your health and your mental health. Your doctor needs to be aware of what you've been through so they can offer you the best treatment and resources. Can you think of a way I can communicate your health needs in the record while still addressing your concerns?"

NOTE: The clinician is engaging the patient to be part of the solution and empowering them.

Patient says, "No."

Clinician says, "I have a few ideas. Would you like to hear them?"

If the patient agrees, the provider can say, "Maybe I can make the message clear to your primary care doctor but keep it general, so we don't go into the details that are uncomfortable for you. So, maybe I can write, 'We discussed adolescent health issues; HEADSS screen was positive for D and S_1 . Resources were discussed; recommend f/u and monitoring.' What do you think? Would that be okay?" (Provider explains the abbreviations to the patient.)

NOTE: Another option may be for the provider to use EHR protection strategies such as 'sensitive notes' if these are available, and the circumstances are appropriate per policies and relevant laws.

The provider goes on to explain ICD codes: "Now, in the health record, we are required to write codes that summarize your health. For example, if you have asthma, or you've been hurt in a car accident there are codes we use to indicate that. For your visit today, the code I would use is called "child sexual exploitation". 'Child' just means you are under 18 years old. In this case, "sexual exploitation" refers to a person exchanging sex for something they need. It sounds very technical, doesn't it? This code will be listed in scattered places in your health record. Are you okay with me using this code?"

NOTE: If more elaboration is appropriate, the HCP could explain the reason for the use of codes, *"This allows experts to track how many people in an area have a given health condition so that resources can be directed to treat that group of people. It's a way of making sure the government gives resources to the people who need it. The tracking is completely anonymous; the experts don't know who is in the group; they only know the size of the group."*

If the child says, *"No"* then do not use the HT ICD code and instead use a code(s) for associated diagnoses (e.g., STI) or a more general code, perhaps for social determinants of health (e.g., Z62-problems related to upbringing, or Z59-problems related to housing and economic circumstances).

SCRIPT 5

...

After the clinician has completed the history and discussed the patient's possible exploitative situation, a mandatory report to authorities is required:

"Do you remember earlier when we talked about how I might have to speak with other professionals if you tell me something that makes me worried about your safety? Well, I'm worried about your safety. When you tell me you've had to exchange sex with people on the street in order to get food or drugs, I worry that you are being taken advantage of by people, and may get hurt. I'm very concerned about you. Because of this, I'm going to need to call child protective services, so that they can help me to help you. You and I don't have a choice about this. But we can control **how** we make the reports to authorities. Let's think about this: Would you like me to call them from another room? Would you like to be in the same room while I call? Would you like to help me call, have us both be on speaker phone so you can make sure they understand your concerns? What feels best to you?"

"And afterwards let's talk about what you think might be helpful to you in your life after you leave this clinic today. We can talk about possible services and organizations in the community and online that might interest you and make your life easier. I'd like to get your thoughts about it...."

NOTE: The clinician may want to have this discussion of resources prior to advising the patient about mandatory reporting, if they are concerned the patient may leave against medical advice prior to finishing the conversation.

If the patient is reluctant, anxious or fearful about contacting authorities, it is important to acknowledge their feelings (don't dismiss them) and explore the reasons behind their reaction. The provider may be able to allay fears based on misinformation, and also may learn information that will be critical for authorities to know in order to protect the safety of the patient and their family. Work with the patient, and authorities to address the patient's concerns.



What should a clinician do about documentation decisions if the patient is unable to participate in a conversation due to developmental capabilities, emotional state or clinical condition?

- Typically, there will be no extended discussion with the patient so they will not be sharing sensitive information. However, sensitive information may be available from others (e.g., police who brought patient to the emergency department). In the latter case the clinician needs to think about immediate and longer-term safety of the patient and make the documentation decision accordingly.
- **Example:** A patient is brought to the emergency department with a gunshot wound (he was shot by his trafficker). There is the possibility that the trafficker will come to the hospital, jeopardizing the safety of patient and staff. The clinician could write, "Patient with gunshot wound to right upper extremity, offender location unknown. Concern for staff and patient safety is high; confidential admit recommended." When the patient is no longer incapacitated, the provider should discuss privacy and documentation issues.

• **Example:** Police bring an adolescent to the local hospital for evaluation. She was found in a motel room during a 'sting' related to suspected sex trafficking; she is intoxicated upon admission. A possible note from the clinician may include, "16 year old female presents with acute intoxication of unknown duration. She was brought to the ED immediately upon discovery. By history, was awake but poorly communicative when discovered; on admission is able to focus intermittently, but slurs words. Admit and address circumstances surrounding intoxication when patient is able. Concern for assault, exploitation or other harm."

Resources

For more information about the healthcare response to human trafficking and the new ICD 10 codes on trafficking and exploitation, please see the following resources:

American Hospital Association: ICD 10 CM Coding for Human Trafficking (information and codes): <u>https://www.aha.org/icd-10-cm-coding-human-trafficking-resources</u>

Greenbaum J, & Stoklosa H. (2019). The healthcare response to human trafficking: A need for globally harmonized ICD codes. PLoS Med, 16(5), : e1002799. https://doi.org/1002710.1001371/journal.pmed.1002799.

Substance Abuse and Mental Health Services Administration. (2014). SAMHSA's concept of trauma and guidance for a trauma-informed approach. Substance Abuse and Mental Health Services Administration. Available at https://ncsacw.samhsa.gov/userfiles/files/SAMHSA_Trauma.pdf.

HEAL Trafficking: www.healtrafficking.org

A global network of multidisciplinary professionals, including people with lived experience, in 35 countries, who are dedicated to ending human trafficking and supporting survivors through a focus on health, health care, and equity. The website provides resources and training opportunities for health systems and health professionals.

SOAR to Health and Wellness: <u>https://nhttac.acf.hhs.gov/soar</u>

The SOAR to Health and Wellness Training Program is a nationally recognized, accredited training program designed to help you identify and respond to those who are at risk of, are currently experiencing, or have experienced trafficking and connect them with the resources they need.

Resources

National Human Trafficking Training and Technical Assistance (NHTTAC) https://nhttac.acf.hhs.gov/

NHTTAC delivers training and technical assistance to inform and enhance the public health response to human trafficking. NHTTAC's training and technical assistance is survivor informed, interactive, collaborative, available in-person or remotely, and is customized to meet the unique training needs of the requesting organization. NHTTAC services are free.