

# Confidentiality in the Age of Open Notes

Authored by: Elizabeth Miller, MD, PhD and Jake Sese, MPH

## Introduction

The shifts toward telemedicine and newly expanded patient access to medical records, driven in part by the [21st Century Cures Act](#) (Cures Act), have brought significant changes to how health information is documented and shared. The Cures Act was put into place to address “information blocking” which can obstruct communication that could be used to improve patient care. Withholding data from electronic health records (EHRs) or failing to provide access to medical records can impact care coordination and can harm a patient. However, as more patients, including survivors of intimate partner violence (IPV), human trafficking (HT), and exploitation (E), gain access to their EHRs, the potential for breaches of confidentiality and harm increases. Specific attention is needed to protect confidentiality and privacy for survivors.

**This brief explores confidentiality policies and practices, safety considerations for survivors, methods for disclosing limits of confidentiality to patients, EHR adaptations, tracking IPV/HT/E measures in the Uniform Data System (UDS), and client-centered approaches to care.**

## Confidentiality is a Cornerstone of Clinical Care

Confidentiality is essential for building trust between patients and providers, and a cornerstone for high quality care.[1] Analysis of the studies shows that when patients trust their health care providers to protect their privacy, they are more likely to disclose sensitive information[1][2], follow treatment plans[3], and engage in preventive care.[4] For survivors of IPV/HT/E, breaches of confidentiality can have life-threatening consequences. Survivors may face retaliation, legal consequences, or further abuse if their personal health information is exposed.[5][6][7] Fear of such exposure can prevent them from seeking care or disclosing crucial information that could affect their safety and treatment.[8] Confidentiality is vital for survivors’ physical and emotional well-being.

Best practice is that health centers (HCs) establish clear confidentiality policies and practices that are consistent with laws, ethical standards, and best practices for protecting survivors. It is crucial to communicate the limits of confidentiality to patients while reassuring them of their privacy and safety within those boundaries. In U.S. states and territories that require reports on IPV and HT to authorities, patients should be made aware of these requirements. Mandatory reporting laws

related to child abuse and neglect vary state by state, thus HC practices and providers should be aware of their state's reporting requirements and clearly disclose these limits of confidentiality to patients with children before offering information and inquiring about exposure to IPV/HT/E.

Risks for breaches of confidentiality extend beyond mandatory reporting laws. For patients whose partners are monitoring their location and interfering with their care (such as keeping them from getting clinical care or withholding their medications and access to health insurance), evidence that they are seeking care can be used against them and increase their risk for harm. Partners may have access to an EHR and be able to see notes and laboratory results that have been released to the EHR.

Adolescent patients face unique challenges regarding confidentiality, including the involvement of parents or guardians in their care. Confidentiality is critical for adolescents to seek care.[9][10][11] Providers must balance legal and ethical considerations while ensuring the adolescent's safety and autonomy.[12][13]

## Open Notes and the 21st Century Cures Act

The introduction of the [Open Notes Mandate](#) was prompted by the need to enhance shared decision-making and promote patient-centered care. Patients' access to their medical records allows them to be more engaged in their care, improving outcomes and fostering trust. The Cures Act further expanded access to health records through the Open Notes Mandate, giving patients and their proxies the ability to view health information in real time. Although intended to increase patients' agency, this also increases risk for breaches of confidentiality if sensitive information is not properly protected. Providers should be aware that family members and partners, including those using violence and controlling tactics, may have access to the patient portal (as proxies, or by getting the patient to share their password).

### Key Resources:

- [Preventing Harm FAQs](#)
- [Exemption Webinar Slides](#)
- [Information Blocking Exceptions](#)
- [Confidentiality and Documentation of IPV and Exploitation: Balancing Safety with Data Collection](#)

Although the transparency of Open Notes supports informed decision-making, it is essential to strike a balance with the privacy needs of survivors of IPV/HT/E. Health care systems must develop practices that safeguard sensitive information without undermining the benefits of Open Notes (see this brief on [privacy principles for protecting survivors](#)). The key point is there are specific exceptions if sharing the information could cause harm to the patient.

Health providers and systems should consider any conversation about IPV/HT/E including universal education, screening or referrals as sensitive and should not automatically share it unless the patient requests it. Information should not automatically be populated in the patient's

portal without a patient's consent and request. This is especially important in pediatric health records where both parents/caregivers may have access to the child's health information, thus any documentation of IPV experienced by a parent/caregiver may be readily visible to the other parent. Studies have identified multiple ways in which abusive partners will use the child's health record and health visits to control and harm the other parent.[14][15][16]

## **Practical Considerations for Optimizing Electronic Health Records (EHR)**

One critical way to protect patient confidentiality in EHRs is to ensure sensitive notes are not shared with patients via Open Notes. Certain types of information, such as disclosures of abuse or exploitation, must be handled with extra care. Additional sensitive information may be related to sexual and behavioral health. Patients may need to have the entire confidential visit blocked (including that they even had an appointment) by using a 'confidential visit' code (not just blocking the notes and labs from the clinical encounter from being released to the portal).

A recommended practice is to make blocking sensitive notes the default setting in the EHR, rather than relying on individual providers to remember to block them. This ensures consistency and minimizes the risk of accidental exposure of confidential information. For more information on leveraging EHRs to promote patient safety and privacy, see [this recorded webinar](#).

## **Practical Considerations for Protecting Confidentiality in Telemedicine Visits**

Telemedicine, although critical for increasing access to care, presents additional challenges to protecting privacy and confidentiality. During telemedicine visits, it is important to assess the patient's environment to ensure their privacy is protected. Providers should ask patients about the safety of their surroundings and whether they are able to discuss sensitive topics freely. Patients should be encouraged to use headphones to increase their privacy. They may also use the chat function during the visit to reduce information being overheard by others who may be able to hear the encounter.

As with all clinical encounters, telemedicine visits should be conducted in a way that respects the patient's autonomy and comfort, offering options for them to control how much information is shared and with whom, especially when concerns about IPV/HT/E are involved.

## **Practical Considerations for UDS Tracking**

Accurate tracking of IPV/HT/E-related metrics in the [Uniform Data System \(UDS\)](#) is essential for quality improvement and for meeting federal reporting requirements. However, special care must be taken to ensure that sensitive information, such as diagnostic codes or treatment notes, is not

inadvertently shared or accessed by unauthorized individuals. HCs should implement safeguards, such as restricting access to IPV/HT/E-related codes and ensuring they are only viewable by those who need to know for treatment or reporting purposes.

## Conclusions

As HCs adapt to the evolving landscape of telemedicine and patient access to medical records, it is critical to implement policies and practices that protect the confidentiality of survivors of IPV/HT/E. By prioritizing patient safety, adopting client-centered approaches, and securing sensitive information in EHRs, HC staff can ensure that survivors continue to receive the care they need in a safe and confidential environment. Health care teams, including providers and administrators, can work together to define key practices and workflows that support confidentiality and privacy for survivors of IPV/HT/E in the EHR.

## More Resources

HCs can also provide support to survivors of IPV/HT/E by establishing partnerships with community based organizations including domestic/sexual violence programs in their communities. The tools on the right can be used to foster these relationships and promote bi-directional warm referrals between your organizations.

- [Addressing IPV and Exploitation in Health Centers \(CUES Infographic\)](#)
- [Partnerships Between Health Centers and Domestic and Sexual Violence Advocacy Programs \(Bi-directional Infographic\)](#)
- [Sample Memorandum of Understanding \(English/Spanish\)](#)
- [Sample Health Center Protocol \(English/Spanish\)](#)

Health Partners on IPV + Exploitation, a project of Futures Without Violence, offers health center staff training on building partnerships, policy development, and the integration of processes designed to promote prevention and increase the identification and referral to supportive services for individuals at risk for, experiencing, or surviving intimate partner violence, human trafficking, and exploitation.

**Email:** [\*\*healthpartners@futureswithoutviolence.org\*\*](mailto:healthpartners@futureswithoutviolence.org)

**Website:** [\*\*healthpartnersipve.org\*\*](http://healthpartnersipve.org)

This resource was developed with support from the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award to Health Partners on IPV + Exploitation (Futures Without Violence) totaling \$650,000 with 0 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more info visit [HRSA.gov](https://www.hrsa.gov)

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