



Adolescent Health & Confidentiality in the Age of Open Notes and Telemedicine

Webinar - June, 1 2022

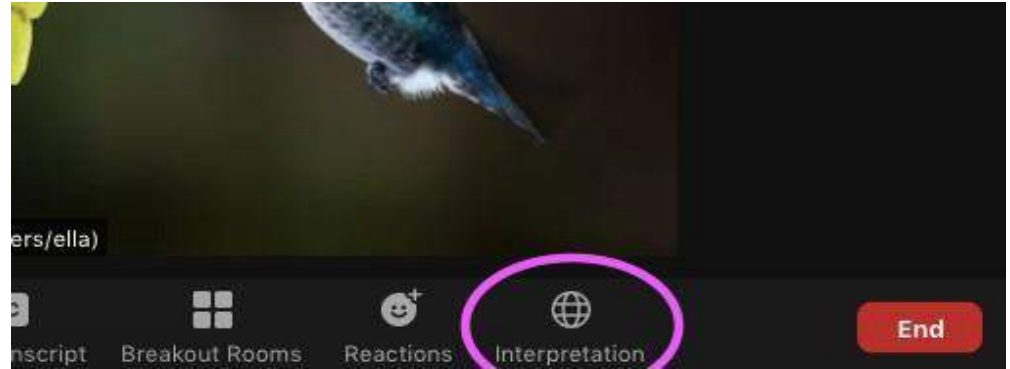
Spanish and American Sign Language interpretation will be provided
Se proporcionará interpretación en español y ASL



How To
Access
Language
Interpretation
on Zoom

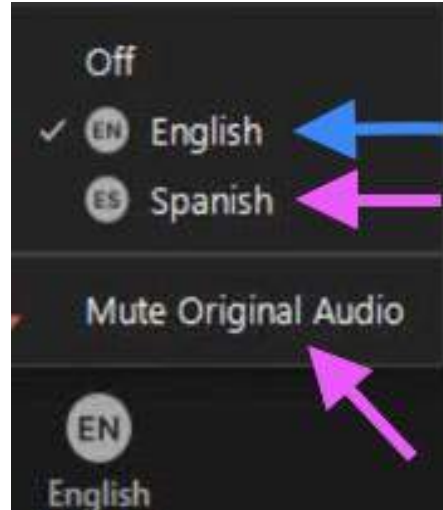
Cómo Activar la
Interpretación
de Idiomas en Zoom

On your computer, find the Interpretation Globe Icon at the bottom of your screen

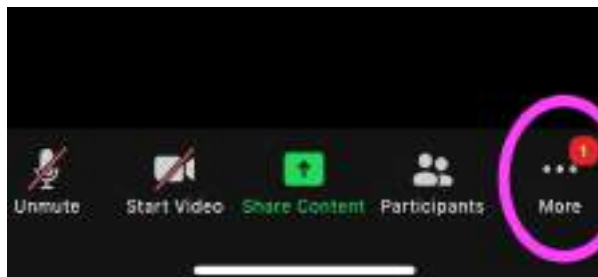


En su computadora, busque el globo terráqueo que dice Interpretación en la parte inferior de su pantalla.

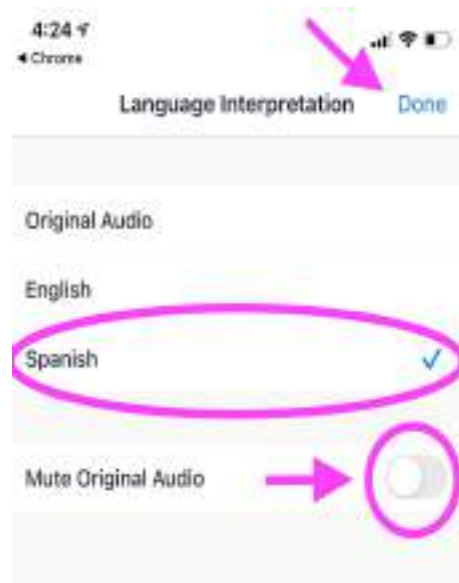
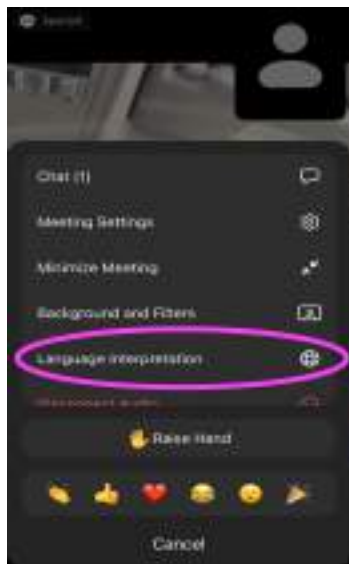
Choose English as your language. Make sure to **NOT** mute original audio so that you can hear the main room



Seleccione Español. Asegúrese de Silenciar Audio Original, si solo desea escuchar al intérprete



If you are on a smart device, look for the three dot menu and choose Language Interpretation. Then, select English.



Desde un dispositivo inteligente, busque el menú de tres puntos y elija Interpretación. Después, escoja “Español” y silencie el audio original.

OTHER USEFUL TIPS:

- Mute your mic unless you are speaking.
- Spanish is 15 to 30% longer than English. Don't rush when speaking.
- Expand acronyms every time you say them.
- Interpretation is not available from a Chromebook or if you dial into Zoom.

OTROS CONSEJOS ÚTILES:

- Silencie su micrófono si no está hablando.
- No se apresure al hablar.
- No utilice acrónimos al hablar.
- No podrá acceder a la interpretación a través de un Chromebook o si marca por teléfono a la reunión de Zoom

If you have any questions regarding interpretation, please post them in the chat so that a facilitator can help you.



Si tiene alguna pregunta o dificultad para acceder a la interpretación, escriba en el chat para que le ayude un facilitador.

About Health Partners on IPV + Exploitation

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Health Partners on IPV + Exploitation is led by Futures Without Violence (FUTURES) and funded by HRSA BPHC to work with community health centers to support those at risk of experiencing or surviving intimate partner violence, human trafficking, or exploitation and to bolster prevention efforts.

We offer health center staff ongoing educational programs including:

- ✓ Learning Collaboratives on key topics for small cohorts
- ✓ Webinars + archives
- ✓ Clinical and patient tools, an online toolkit, evaluation + Health IT tools

Learn more: www.healthpartnersipve.org



Today's Presenters

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Disclosures

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- Elizabeth Miller receives royalties for writing content for UpToDate Wolters Kluwer.
- Abigail English receives royalties for editing content for UpToDate Wolters Kluwer.
- David Bell does not have anything to disclose.



Learning Objectives

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1. Describe how protecting adolescent confidentiality in the health care setting is critical for promoting adolescent health, especially regarding sensitive topics such as substance use, mental health, sexual health, and relationships.
2. Explain the legal framework for confidential adolescent health care in state and federal law
3. Identify three challenges for protecting adolescent confidentiality in clinical practice
4. Adopt systems- and practice-level strategies to mitigate against risk for breaches of confidentiality



What is confidentiality?

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As a legal term, *confidentiality* refers to a duty of an individual to refrain from sharing confidential information with others, except with the express consent of the other party.

Ref:

<https://legaldictionary.net/confidentiality/>



Why is confidentiality important for adolescents?

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Short Term Goal:

- Create a safe space to talk candidly about sensitive issues.

Long Term Goal:

- To keep adolescents safe and healthy, avoiding unhealthy consequences of behaviors that may be considered shameful or "immoral" by some segment(s) of society, or allow disclosure of unsafe circumstances that an adolescent feels "trapped."



Why is confidentiality important for adolescents?

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Adolescents are more likely to obtain care, disclose sensitive information, and return for future care if clinicians address confidentiality.

KEY RESEARCH

Cheng TL, Savageau JA, Sattler AL, *et al.* Confidentiality in healthcare. A survey of knowledge, perceptions, and attitudes among high school students. *JAMA* 1993; 269:1404–1407.

Ford CA, Millstein SG, Halpern-Felsher BL, *et al.* Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future healthcare. A randomized controlled trial. *JAMA* 1997; 278:1029–1034.

Ford CA, Thomsen SL, Compton B. Adolescents' interpretations of conditional confidentiality assurances. *J Adolesc Health* 2001; 29:156–159.



Areas usually covered by confidentiality

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- Substance Use
- Mental Health
- Sexual Health
- Relationships

KEY RESEARCH:

Bearinger LH, Sieving RE, Ferguson J, *et al.* Global perspectives on the sexual and reproductive health of adolescents: patterns, prevention, and potential. *Lancet* 2007; 369:1220–1231.

Ringheim K. Ethical and human rights perspectives on providers' obligation to ensure adolescents' rights to privacy. *Stud Fam Plann* 2007; 38:245–252.

Tylee A, Haller DM, Graham T, *et al.* Youth-friendly primary-care services: how are we doing and what more needs to be done? *Lancet* 2007; 369:1565–1573.



Assurances of Confidentiality

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- Confidentiality for adolescents has important implications for the quality provision of healthcare for this vulnerable population.
- Physician assurances of confidentiality increase adolescents' willingness to disclose sensitive health information.



Best Practice:

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Unconditional Confidentiality

"I want you to understand that when we talk about things that have to do with sex and drugs and your feelings, that it is confidential. This means that what we talk about is just between you and me and that other people, including your parents, will not find out about it unless you want them to know."

Conditional Confidentiality

followed by, "One exception to this is if am concerned someone has abused or hurt you. Another exception is if I am concerned you are planning to commit suicide. In these situations, I would have to talk to other adults, and I would talk to you first so we could figure out the best way to handle it."

Ford CA, Millstein SG, Halpern-Felsher BL, *et al.* Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future healthcare. A randomized controlled trial. *JAMA* 1997; 278:1029–1034.

Ford CA, Thomsen SL, Compton B. Adolescents' interpretations of conditional confidentiality assurances. *J Adolesc Health* 2001; 29:156–159.



Traditional Structural Threats to Confidentiality

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- EOB less pronounced -- more with private insurance
- Labs
- Release of medical records

NEWER CHALLENGES

- Telemedicine
- Open Notes



Legal Framework

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What is the legal and policy framework for confidentiality in adolescent health care?

- How do state laws protect or limit confidentiality for adolescents?
- How do federal laws protect or limit confidentiality for adolescents?
- What are the ongoing and emerging challenges for protecting confidentiality in adolescent health care?



Legal and Policy Framework

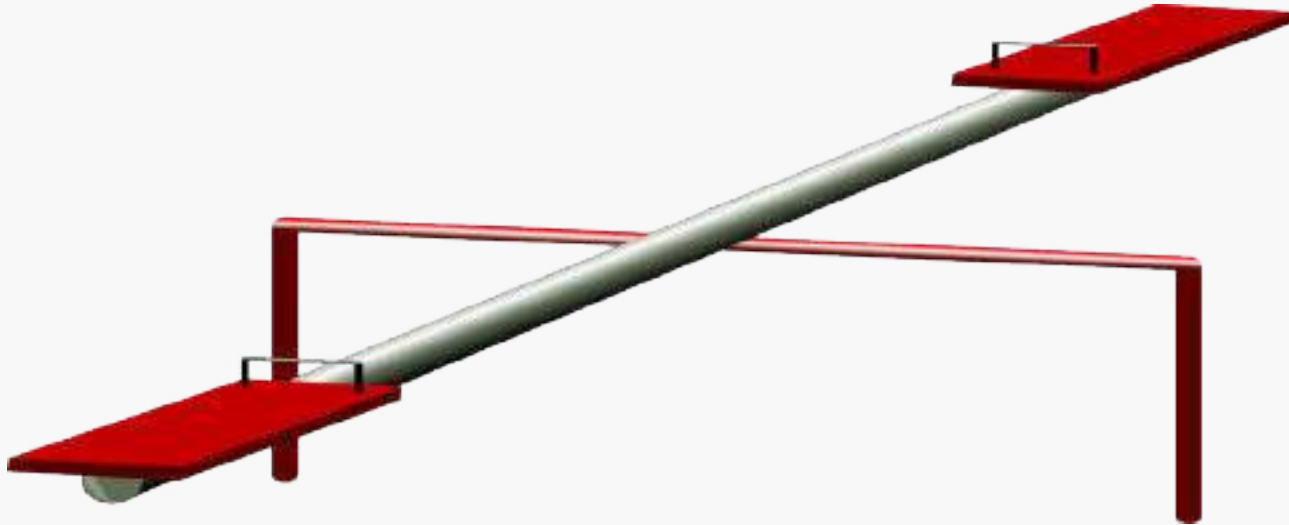
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- “Consent & confidentiality”
- Linkage
 - Clinical practice
 - Ethical guidelines
 - Professional policies
 - State & federal laws
- Confidentiality & disclosure
 - Minor consent laws
 - Medical privacy & records laws
 - Insurance laws
 - EHR & telehealth laws



A Balancing Act

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Abigail English, Adolescent Confidentiality - June 1, 2022



A Critical Confidentiality Challenge

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What is a **critical challenge**?

- finding the right legal and ethical balance ...
- ...between confidentiality and disclosure

Questions to ask . . .

- What **may not** be disclosed?
- What **may** be disclosed?
- What **must** be disclosed?



Required Disclosures

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- Confidentiality is not absolute
- Exceptions to confidentiality
 - Child abuse reporting
 - Physical, sexual, & emotional abuse
 - Human trafficking?
 - Voluntary sexual activity of adolescents??
 - Patient threat of harm to self or others
 - Other disclosures required by law



State Law Protections and Limits

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Important reminder!

- Adolescents < age 18 are legally minors
- “Adolescents” \geq age 18 are legally adults

State minor consent laws

- May prohibit, permit, or require disclosure to parents

State medical privacy laws

- HIV, substance use

Funding program requirements



State Minor Consent Laws Based on Status

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- Emancipated minor
- Married minor
- Minor in the armed services
- Mature minor
- Minor living apart from parents
- High school graduate
- Minor over a certain age
- Pregnant minor
- Incarcerated minor



State Minor Consent Laws Based on Services

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- Pregnancy related care
 - Contraception
 - Abortion
- STD/VD (prevention), diagnosis, & treatment
- Reportable disease (prevention), diagnosis, & treatment
- HIV/AIDS testing & treatment
- Drug or alcohol counseling & treatment
- Outpatient mental health services
- Diagnosis & treatment for sexual assault



Federal Law Protections and Limits

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- HIPAA Privacy & Security Rules
- Title X Family Planning confidentiality regulations
- Substance Use Disorder confidentiality regulations (“Part 2”)
- Family Education Rights & Privacy Act (FERPA)
- Medicaid
- Section 330 FQHCs
- Ryan White HIV/AIDS program



Ongoing and Emerging Challenges

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- Confidentiality in billing and insurance claims process
- Electronic health records & web portals
- Telehealth
- Open Notes & the 21st Century Cures Act



EOBs and Insurance Disclosures

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- Confidentiality breaches in billing & health insurance communications
- Explanations of Benefits (EOBs) are ubiquitous
- Federal & state laws protecting confidentiality
- Federal & state laws requiring disclosures
- Evolving protections in state laws
 - Confidential communications
 - Restrictions on disclosure
 - Minors vs. adults



EHRs and Web Portals

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Who has access?

- Adolescent minor patient < 18 – with or without age limits
- Young adult patient \geq 18
- Parent

Effect of laws?

- HIPAA
- Minor consent laws
- Insurance laws



Telehealth

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Evolving laws and policies

- Will policies put in place during COVID pandemic be extended?

What are some of the specific legal questions?

- Is specific/separate consent required for telehealth visits?
 - Relevance of state minor consent laws
- Application of existing laws to telehealth visits
 - HIPAA Privacy Rule, Part 2 SUD regulations

Considerations related to specific communication platforms



21st Century Cures Act & Information Blocking

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- Office of the National Coordinator for Health Information Technology (ONC)
- "21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program"
- Final Rule - May 1, 2020
 - CMS issued concurrent rule related to patient access to data & interoperability
- **Compliance date for information blocking – April 5, 2021**
 - Impact of COVID-19



Patient Access to EHI

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- **ONC Rule's definition of EHI includes electronic protected health information (ePHI) as defined in HIPAA**
 - Clinical notes included – implementation via Open Notes
 - Exception for psychotherapy notes
- **Rule designed to facilitate access, exchange, and use of EHI**
- **Patients must have access to their EHI**
 - Potential to provide important benefits for patients
 - Risk of harm when others obtain access to a patient's EHI
- **Major challenge: facilitate access & protect confidentiality**



Ban on Information Blocking

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- Information blocking is banned
 - Any practice that is likely to interfere with, prevent, or materially discourage access, exchange, or use of EHI when the entity knows it is likely to do so
- 8 exceptions define activities not considered information blocking
 - Preventing harm
 - Privacy
 - Infeasibility
 - Others: security, Health IT performance, content & manner, fees, & licensing



Information Blocking Exceptions

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- Privacy exception
 - “It will not be information blocking if an actor does not fulfill a request to access, exchange, or use EHI in order to protect an individual’s privacy”
- Preventing harm exception
 - “It will not be information blocking for an actor to engage in practices that are reasonable and necessary to prevent harm to a patient or another person”
- Infeasibility exception
 - “It will not be information blocking if an actor does not fulfill a request to access, exchange, or use EHI due to the infeasibility of the request”



Concerns for Adolescents

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- Importance of information sharing to provide optimal health care
- Risk of harm if adolescents are deterred from seeking health care or disclosing accurate health history
- Special privacy concerns related to
 - IPV
 - Human trafficking
 - Child abuse
- Proxy access by parents
- Need for implementation policies & protocols to protect adolescents
 - Importance of “granular segmentation” to facilitate control



Why might a young person be especially concerned about disclosing private information?

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- Shame, judgement, stigma
- Fear, threats
- Fear of systems, police involvement, ICE
- If a young parent, afraid children can be taken away
- Not knowing what is going to happen with the information
- Lack of awareness of victim status and rights
- Lack of knowledge of U.S. laws and contractual obligations (in cases of labor trafficking)
- Language barriers and limited literacy
- Concerns related to deportation



Challenging the limits of disclosure-driven practice

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Protecting confidentiality and offering options for safety = person centered care



Universal Education

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Provides an opportunity for clients to make the connection between relationships, health problems, and unhealthy behaviors.



**** If you currently have psychosocial screening as part of your health center requirements: we strongly recommend first doing universal education.***



CUES: An Evidence-based Intervention

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Confidentiality
Universal Education
Empowerment
Support



www.IPVHealthPartners.org online toolkit + CUES

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Guidance on:

- ✓ Enhancing patient privacy
- ✓ Disclosing limits of confidentiality
- ✓ Universal education scripts
- ✓ Reaching friends and family
- ✓ Disclosures + supportive messages
- ✓ Warm referrals to local DV programs
- ✓ Safely sharing resources
- ✓ Tech privacy tips



www.ipvhealthpartners.org

Developed by and for
community health centers in
partnership with domestic
violence programs

+ New guidance on COVID-19 and
telehealth support

Safety considerations for telehealth and in person visits

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Disclosing sensitive topics during telehealth or in person visits may put young people at risk for retaliation.

Person who uses violence may:

- Monitor phone call/video chat, texts, emails, impersonate the survivor in texts in order to gain access to PHI, appointment times, review EOB's or other sensitive information
- Many survivors describe having no access to digital privacy.
- Also – may be interfering with efforts to stay healthy and well.



Can we talk privately?

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See patients alone if possible in person or virtually, establish who is in the room

- “Is this still a good time to talk?”
- “Do you have a private space where we can talk”?

Offer suggestions for gaining privacy for the conversation.

- For example, headphones, bathroom, garage and other private places; or reschedule
- **If children present:** Or “do the kids have a headset they can use while we are talking”
- Trust your intuitions about the “right time” to discuss.
- **Embed reminders or prompts in your EHR on privacy**



C: “We always see patients alone”

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Before implementing CUES, establish a clinic-wide policy to see patients alone for part of every visit. Post a sign in waiting rooms and exam rooms that reads:



NEW CLINIC POLICY:

For privacy compliance, every patient will be seen alone for some part of their visit.

Thank you for your help.

C: Disclose Limits of Confidentiality

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“I will not share anything we talk about here outside of the care team unless you tell me that you (or your children) are being hurt or you are going to hurt yourself - that I have to involve others to ensure you are safe”

“While we will do our very best to keep your medical records confidential so that only staff who are helping to care for you have access - I cannot guarantee that no one else will ever see your record so if there is anything you want me to shield let me know.”



UE: Shifting the conversation toward COVID

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“I know with COVID it’s a hard time for all of us.”

“The stress can be overwhelming. We are all worried about how we are going to feed our families, pay bills. Everyone is on top of each other in the house.”

“How has it been for you?” Acknowledge what you hear. “That sounds so hard/complicated.”



UE: Universal Education related to stressors

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“Because of the stress, we are sharing information about resources that are available. For example, we may experience stress in our relationships including increased fighting or harm, and that can affect our health. There is free, confidential help available if you, or someone you know is being hurt in their relationship.”



UE: Universal Education for health-related social needs

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“Many people are also feeling pressure around money and paying rent or bills—sometimes others take advantage of people for work and also for sex—so we’re sharing information about resources that are available if you find yourself in a situation like this. Can I give you unemployment resources, housing and food support, and other things to share if you know someone who needs it?”

E: Empowerment

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The New York Times

The Science of Helping Out

During a crisis, the people who cope best are those who help others.

Universal Education + altruism =
survivor strength



S: What to do with no disclosure

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Embed scripts and offer information via computer or text even if patients says things are fine:

“I am glad to hear that, if anything should change, I will always have the numbers handy if you know someone who needs them.” Offer information for friends and family.

If they say yes they will share the information:

“Thanks so much, and if something like this were ever an issue for you, we can help.”



S: Safety is the First Priority

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- Ask if they can receive a text or email?
- If not, ask them if they can write them down and share with others as needed...
- If conducting visit via computer – entering into chat can be a safe option
- Offering resources in a virtual waiting room



Always ask if texting is ok!

S: Disclosures happen

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Even with universal education patients may disclose abuse.

- Offer supportive messages
- Tell patient they can change the subject if they can no longer talk safely
- Consider partner interference when offering care plan and health promotion strategies

Things to say to people who have experienced harm:

I believe you.	I am so sorry this is happening to you.	Thank you for sharing this.
I don't even know what to say right now, but I am so glad you told me.	You don't deserve this.	Thank you for telling me.
It's not your fault.	You are not alone.	You get to choose what you do next.

Tips for the Patient to Maintain Confidentiality

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Offer patient these tips after a virtual visit:

- ✓ Delete recent phone calls from phone
- ✓ Delete texts from phone
- ✓ Clear browsing data/history from phone or computer
- ✓ Contacts - store hotline or special numbers under a different name— like the name of a grocery store, a typical thing you use.

Managed by the Safety Net Project at the [National Network to End Domestic Violence](#) (NNEDV), [TechSafety](#) discusses technology, privacy, and safety in the context of intimate partner violence, sexual assault, and interpersonal violence.



Trauma Sensitive Care when Documenting

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- Familiarize your care team on how to use confidential and sensitive note functions in your EHR
- Safety of the patient - consider harm from those accessing information in the record
- Respect for patient's autonomy and concerns
- Informed Consent: Inform patients about how the health information will be handled
- Patient participation in deciding how to document (under the limits of relevant laws/policies)
- If you have to report – follow trauma sensitive reporting suggestions



Privacy Principles

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- Individuals should have the right to access, correct, amend, and supplement their own health information; Individuals should receive notice of how health information is used and disclosed, including specific notification of the limits of confidentiality;
- Providers must offer and respect patient's choice of communication preferences and this should be built into electronic health records as mandatory fields;
- Privacy safeguards and consents should follow the data;
- Providers should have broad discretion to withhold information when disclosure could harm the patient; There should be strong and enforceable penalties for violations of privacy and consents both in a clinical setting, and across information exchanges

<http://ipvhealthpartners.org/wp-content/uploads/2018/07/Privacy-Principles-for-Protecting-Victims-of-Domestic-Violence-.pdf>



Important Takeaways

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- Making sure *every* patient has knowledge about where to seek help for violence and other health-related social needs
- Engage the patient in a healing centered care plan
- Make a warm referral to services if needed
- Partner with them on documentation
- Let them know they have your support and understanding
- Your action may save lives



Thank you!

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the chat:

<https://redcap.link/zsxawbjm>

